

THE ROLE OF EXISTENTIAL COPING AND SPIRITUAL COPING IN
ANTICIPATORY GRIEF

by

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ABSTRACT

Anticipatory grief is a universal experience, involving physical, psychological, and spiritual aspects of a person coping with anticipated loss, real or imagined, of health, career, relationship, or life. Different than bereavement grief, anticipatory grief is proactive, and prepares the individuals for the actual loss.

The present study focuses on the existential and spiritual aspects of anticipatory coping for two reasons. First, this topic remains under-researched. Secondly, from clinical observations and existential psychology, the anticipation of death tends to trigger existential and spiritual questions such as “why me?”, “why now?”, “what meaning can there be in the loss?”, “why is God allowing this?” and “where is God?”

This case study design included two meetings one month apart per respondent. Meetings included a semi-structured interview and four questionnaires. The questionnaires were Personal Meaning Profile (Wong, 1993), the Revised Death Anxiety Scale (Thorson & Powell, 1988), the Death Attitude Profile-Revised (Wong, Reker, & Gesser, 1994), and the Coping Schemas Inventory (Wong, Reker, & Peacock, 1993). Content analysis of interview data revealed twenty-two themes. Six themes emerged specifically related to anticipatory grief namely the (a) heightened anxiety and fears related to anticipated death, (b) need to resolve old concerns, (c) recognition of relational changes, (d) need to discover new information leading to a cure, (e) need to focus exclusively on the loved one, and (f) attempting to anticipate the future without the loved one present.

Counselling implications were discussed including: (a) Facilitating the restructuring and management of the meaning of anticipated loss in a transformative

process while integrating the loss into the individual's life story. (b) Encouraging individuals to engage in efforts to resolve issues past, present, and future with loved one. (c) Empowering individuals to open up and discuss with the loved one regarding feelings and preparations for eventual death.

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CHAPTER ONE: INTRODUCTION

Much more than the pain of his death, I think, it was death itself that filled Jesus with fear and agony. For me this is a very important realization, because it undercuts any sentimentalizing or romanticizing of death. We do not want to die, even if we have to face-yes, befriend- our own death with all possible realism. Although we must befriend our death, that is, fully recognize it as a reality that is an intimate part of our humanity, death remains our enemy. Although we can and must prepare ourselves for death, we are never prepared for it. Henri Nouwen (1982, p.72)

Losses are experienced at every stage of life including the loss of possessions, the loss of significant events such as a graduation or a marriage of a child. Losses can also include friendships, marriages, careers, health, safety, status, and hope (Cowles & Rodgers, 1991; Moules, 1998; Pine, 1990; Rosenblatt, 1988) that allow us opportunities to grieve; sometimes the grieving is experienced after the loss while at other times grieving is experienced in anticipation of the loss. These very often difficult opportunities allow us to understand that nothing is static in life; change is ever present. Preparation for death occurs throughout our lives in a myriad of lesser antagonistic ways than death itself.

While we generally do not correlate day-to-day losses with the ultimate loss of life, there is a progressive understanding that can occur as an individual learns how to address the more superficial losses (Kutscher, 1973). Regardless of whether we consciously anticipate our eventual loss of life, we do tend to relegate the thought to a fairly remote priority of consideration. Fear of death itself, not existing, going to an

unknown place, of being alone are reminders of an uncertainty to be avoided at all costs. Culturally, those of us in the West are taught early on to deny the realities of death as though it were an enemy (Wong, 2002). However, what is certain is that we will all eventually die despite our forethought or lack of it.

Some research suggests that how an individual handles the day-to-day losses in life will indicate how that same individual will handle loss of life itself. For many, belief systems and the ability to make meaning in life circumstances enhance the ability to live out the remainder of their lives more fully satisfied (Yalom & Lieberman 1991). Viktor Frankl quotes Nietzsche as saying “He who has a why to live can bear with almost any how” (1984, p.84). This suggests that a sense of meaningfulness in life enables an individual to continue to live in spite of adversity. Dr. Paul Wong (2002a) says “How we live foreshadows how we die”. There is a need for both the one who is diagnosed, as well as their family members, to have opportunity to understand their experience, attempt to make meaning of it, and to normalize it as much as is possible. It is with this proactive approach in mind that the concept of anticipatory grief is singled out for consideration.

The term anticipatory grief was first advanced as early as 1944 when Lindemann introduced the concept of anticipatory grief as one that could allow the grieving process to begin preparatory to the death of the loved one. His was a body of research initiated in observation of individuals not bereaved though having a relationship severed due to the separation of war. He suggested there is a detachment that occurs that can provoke mourning.

Teresa Rando (1986) went on to describe anticipatory grief as a “phenomenon where an individual facing catastrophic loss, such as the death of a loved one, engages in a process of coping with present circumstances while at the same time beginning to

mourn past, present, and future losses” (p. 24). Though Rando (2000) has introduced a change in the terminology of Anticipatory Grief to Anticipatory Mourning, still the basic concept holds. We can see the possibility of this phenomenon in situations where a husband or wife anticipates the worst when their significant other goes off to war or when a parent sees their child engaging in destructive behaviours that “could” lead to their demise. Regardless of the specific circumstances, the universal truth exists that we will all experience anticipatory grief in some capacity throughout life.

While there are some researchers who dispute the validity of anticipatory grief (Lindemann, 1944; Parkes, 1986), still others recognize that there is, for many, a period of time especially after a diagnosis of a terminal illness when individuals enter into similar processes of grief such as are present in bereavement grief. While bereavement grief is vastly different from anticipatory grief in that the death has already occurred, still, there are similarities and differences that are noteworthy. Similarities can include elements of stage theory, identified tasks, and processes (Kubler-Ross, 1969; Westberg, 1971; Worden, 1991). Physiological symptoms such as somatic distress, loss of appetite, sleep disturbance, and tightness in the chest are common difficulties. As well, there is a similar need to ascribe some kind of meaning, spiritual or otherwise, to an event that seems meaningless. There is also death anxiety either before or after the event of death itself.

Differences certainly begin with the post-death perspective of bereavement grief as opposed to the pre-death perspective of anticipatory grief. Post-death grief includes a finality that pre-death grief does not yet know including attendant rituals such as funerals, wakes, and memorials. There is no further hoping for a reprieve from the enemy. Some evidence exists to suggest that bereavement grief includes heightened physiological

symptoms. When there are untimely and traumatic, perhaps stigmatized circumstances leading to the death there is often greater anxiety for the bereaved (Weiss, 1988). There is a definite change in family roles, identities, and emotional resources (Rolland, 1991) that can be crippling until the family system adjusts to the loss while their loved one still lives. From a clinician's perspective, there is an opportunity remaining within the anticipatory grief experience to encourage a terminally ill person and his/her family in "making peace with [his/her] self, family, and their world within the context of the threatened loss" (p.149).

One issue that needs to be addressed for a dying person, and his or her loved ones, is a willingness to share feelings and discuss the potential realities rather than bury or mummify grief. However, there is a *conspiracy of silence* that is pervasive within families as well as within the medical profession. At the time a person is diagnosed terminally ill, the need for support and encouragement from family members is at its zenith. There is a need for some normalcy or balance in spite of the threatened loss. Yet, it is this very time when the self-protective mechanism of distancing begins to evidence itself within many families. The emotional distancing often appears as the terminally ill person physically declines and may be on-going often to the point of real or perceived abandonment of the terminally ill person. Along with the physical decline there is often a decline psychologically particularly in the presence of neurological impairments. Psychological decline may initiate the loss of intimacy within the family unit.

"Premature distancing can occur when family members are torn between their wishes to sustain intimacy and their need to 'let go' emotionally of a member they expect to die" (Rolland, 1990, p.233). Rolland addresses the conspiracy of silence by suggesting an emphasis in medical training that would counter the ambiguity in their communication

with families when death is a possibility. It is evident, then, that there is a need to develop greater emphasis on communication, even including developing opportunities and a language to provide support to individuals and families.

There is a need to be cautious about prognoses and uncertainty, but there is also a need to not leave patients to “wait and see” thereby exacerbating anxieties and confusion. Rolland continues by suggesting that in the presence of openness, there is the opportunity to encourage discussion about such concerns as palliative care, living in the present, planning for practical arrangements, and remaining connected to one another throughout the course of the illness right up until the end of the patient’s life. Clearly, the only way any of this can occur is to lift the taboos associated with speaking, privately and professionally, of death and dying.

Another concern individuals are generally struggling with is the existential/spiritual questions such as why me, why now, and where’s God. Klinger (1998) posits that “the degree and kind of meaning a person finds in life derives from the emotionally compelling qualities of the person’s goal pursuits”(p.146). He cites Joske (1974/1981) who wrote people want to have a purpose, see it as meritorious as well as important, and see it as realizable.

In a Report on Bereavement and Grief Research (Genevro, Marshall, & Miller, 2003), T. Lindstrom expresses that “To be able to think in terms of past, present, and future, to love, and to grieve, is part of the human existential plight and dignity. Grief may add meaning and perspective to one’s life just as shadows give depth to a landscape” (p. 72).

For the person who has embraced faith in God, there may be a sense of purpose beyond the individual worldly experience. For the individual facing the expected death of

a loved one, the recognition of an order in the universe due to an omniscient, omnipotent, and omnipresent God may provide enough of a why for the individual to engage, even embrace, the suffering as acceptable.

It is often the suffering itself that presents a person with the necessity of finding meaning in his or her God and finding solace in knowing his/her experience is not one of being cast adrift but rather safely anchored to a sense of order and purpose (Wong, 1998). While this anchor does not negate the pain, it may ameliorate the suffering inherent in an absence of fulfilling the meaning of life questions. It is the psycho-spiritual transformation that allows for central assumptions and beliefs about life and death to reorganize thought patterns (Marrone, 1999).

For those who do not have faith in a Creator, there is still the need to encourage the finding of meaning. Viktor Frankl (1984) wrote that sometimes what we need to know is “not what we can expect from life but rather what life expects from us” (p.85). This perspective can initiate a change in perspective for an individual as there is a shift in focus from oneself to the broader implications of his or her experience.

When facing the prospect of dying in one’s own or another’s life there is a need to deal with unfinished business such as reconciling of relationships and other problems. Erik Erikson’s (1963) discussion of stage development identifies a period of time in later life as Stage 8 when a person is faced with the tension between Integrity and Despair. This eighth stage of Erikson’s life-span developmental theory is the period of time when the older adult struggles to discover an internal resolution to life crises hopefully resulting in increased wisdom. It is also a time when the accomplishments of the “Generativity stage”, including the care and guidance of future generations, reinforce the older adult’s ability to resolve the crises faced in earlier stages (Hannah & Domino, 1996, p.941). This

time of resolving past difficulties and gaining a greater confidence of one's place within an orderly system produces the wisdom inherently needed to instill in the young an ability to trust. Erikson seems to suggest healthy development would allow a person to more easily adapt to the end stage of development but what happens when a younger person is facing death, a person who has not yet completed all of the prior stages of development and who may miss stages altogether? Whether the anticipated loss occurs in the expected later life or in the unexpected younger years, there is still a need to make amends, reconcile relationships, and help to prepare others.

Another issue that bears consideration is how the person(s) plans to spend the balance of his or her life in a meaningful way. In *Tuesdays with Morrie* (Albom, 1997), Morrie patiently, and with good humour, encourages others around him, including a former student, to prepare to die as Morrie himself prepared for his death. He demonstrated the process of letting go of this life while staying engaged and alive as he was suffering the processes of his own dying. Morrie gave us a glimpse of the meaning he had in his own life and how it allowed him to live the remainder of his life more fully satisfied rather than regretful over past errors, present circumstances, or the loss of an extended future.

For the individual anticipating his or her death there is not only the need to wrestle with the issues, developmental or practical, of impending death, there is also a need to address the terror of death itself. The death anxiety caused by a diagnosis of terminal illness can be in itself debilitating and paralyzing. There is a fear of having to leave before his or her time should have come and how to provide for others in their absence. As well, there is a great deal of grief about the pain and loss inflicted upon the survivors. This is precisely the time to encourage moving from death anxiety to death

acceptance using such means as Wong's (2002c) Meaning Management model. One goal would be to encourage a more adaptive way of anticipating a loss rather than maladaptive as is evidenced when a bereft individual chooses alcohol, drugs, or some other escape mechanism to cope with their losses. Before meaning can truly be attained, however, there must be some measure of acceptance of either the up-coming death or the death itself.

Tomer and Eliason (1996) proposed a model of death anxiety that suggests three distinct causes of death anxiety including, (a) past related regrets (those beliefs of not having completed basic life tasks), (b). future related regret (a recognition of one's inability to complete tasks in the future), and (c) meaningfulness of death (one's ability to ascribe positive or negative meaning to their life). They further suggest that death anxiety is directly connected to what they term 'death salience' that activates an individual's ability to perceived his or her beliefs about the world and oneself as well as be motivated to engage in coping processes.

One problem, however, is the lack of willingness of many to embrace change in life in even the least difficult situations. Often we will strain to maintain the status quo in spite of evidences that might point us toward transformative growth. In the presence of the greatest perceived loss, death itself, we are more likely to deny its reality by not speaking of it. Some people choose not to look at what hasn't happened yet as though they will be better prepared to "handle" it if the inevitability arrives. It would seem that fear and even self-preservation would drive this thought process. A counter argument to this would be that waiting until too late limits the opportunities to make amends with loved ones, be reconciled to others, and to engage in preparations that would help a

process of dying well. Preparations would include physical as well as emotional preparations.

Especially at this time with the “Baby Boomer” generation in middle adulthood, we have greater need to prepare for the overwhelming need that this aging group will require. Children of “Boomers” could be encouraged with tools of communication and understanding to help their aging parents by research done today. As we have more people dying of chronic illness today than of acute illness, we have greater incentive to pursue research.

Of even greater significance, is that we will all have a life trajectory than will eventually end in death. Will we simply have a “good death” experience or will we “die well”? For many a good death would be to die quietly in their sleep without any pain or problem. However within this theme, there is little thought given to the aftermath for the survivors. While this certainly does occur leaving loved ones to struggle in their bereavement with many of the same questions as have been posited here, the reality is, most of us, we will not die quietly in our sleep. We may experience the difficult, chronic nature of terminal illness that allows us to anticipate what is still to come. To die *well*, then, is to participate fully in the opportunity to tie up the loose ends in a life cut short, both developmentally and relationally.

Without doubt, there is need for further research as well as a need for interventions to provide family members with a framework for understanding the process they are involved in and “normalize emotions related to threatened loss [that] can help prevent cycles of blame, shame, and guilt” (Rolland, 1990, p.239). As there is greater understanding, there will hopefully be greater communication enabling individuals an ability to interact in healthier ways, lessening the distancing that often occurs within

families. There is also a need to provide psycho-educational interventions within a clinical framework; which would allow clinicians to support families in a more holistic manner than currently exists.

The anticipatory grief of losing a loved one is often distressing to survivors as it is related to their own mortality. First, the fear of losing a loved one translates into a fear of his or her personal death. Second, the grief of losing a loved one translates into a grief of his or her personal nothingness especially when meaning has not been discovered in the loved one's experience. While current research focuses primarily on the fear of personal death and the grief of a loved one's death, it may occur through anticipatory grief work that grief over personal death is injected into the process as well as a fear of the death of the loved one. Anticipatory grief allows individuals to adapt to the certainty of death. It is a process allowing for adaptation, acceptance, and transformation. As we provide knowledge, insight, and language to encourage people to help him or herself, we leave them less vulnerable.

Though we can never be fully prepared for death, we must engage fully to prepare for the eventuality of it. A potential outcome of interventions may evidence itself by the increased ability of families to deal with the reality of death in a positive sense rather than feeling completely victimized by it.

It is in recognizing the need for research in the area of anticipatory grief that this project has been pursued. In part it was stimulated by the researcher's on-going work with the elderly who were in their later stage of life and were themselves, in many cases, facing or denying their own end of life. However, the primary motivating factor was the anticipation of my husband's death after his terminal diagnosis that prompted what has become a compelling project (See Appendix B).

As I struggled with coping in the presence of my husband's illness, there arose questions about how others make sense or meaning out of impending loss, how people cope, how are individuals sustained by their faith when life does what seems to be an about face? It was necessary to engage individuals personally about the process and experience of their circumstances and losses to uncover any themes which might help others in similar struggles; rather than attempting to find numerical data that could provide inferences about the coping experiences of those anticipating either their own, or a loved one's, death.

While there is a great need to explore this area, there was significant reticence on the part of many to become involved in a project dealing with death and dying. Yet, I had the privilege of working with eight people who were willing to share with me their experience, how they coped, and what has helped them throughout their process. Each invited me to participate in this most intimate time of their lives. It is with the utmost respect and appreciation for their openness and honesty that this material is presented.

This study purposes to explore the lived experiences of each of the eight respondents to determine how they have coped with the expected loss of a loved one from an existential and spiritual perspective. With so little quantitative or qualitative research done in this area and bearing in mind that we anticipate grief far more often in life than experience bereavement grief, it would benefit both clinicians and those suffering to learn whether coping well during anticipatory grief helps individuals cope better during the subsequent bereavement grief. It would also benefit us to know whether this coping helps us to better address our own mortality

CHAPTER TWO: LITERATURE REVIEW

Anticipatory Grief

While a variety of studies have been done, most of them post-death, anticipatory grief remains a debated phenomenon and one that continues to raise more questions than provide definitive answers. When Lindemann (1944) initially introduced the term, he suggested that individuals would experience most of the symptoms associated with conventional, bereavement grief. Because the focal point of the discussion surrounded a wife and her serviceman husband who was away on duty, the symptoms she would experience would include imagining the many ways he could die as well as other more somatic complaints. It was Lindemann's contention that if enough grief and anxiety were experienced prior to the husband's coming back home, the wife would potentially seek another relationship thereby escaping from the pain of expecting her soldier husband to die. What he did not address were the myriad of other ways she might have detached including the relationship having been distressed prior to his leaving for military duty. It certainly begs the question as to just how attached they were to one another. Speculation aside, the discussion of anticipatory grief did not start off on a solid footing.

Regardless of any fallibility in Lindemann's research, the concept of anticipatory grief has emerged as part of a serious discussion within the parameters of loss, death, and dying. It is replete with its own myths as well as the absence of accepted operationalized definitions. At the very least, it is worthy to define the period of time included within this study as the time beginning at diagnosis and ending at the point of death, which is when bereavement grief begins. Kutscher (1973) suggests that the period of time after diagnosis of a terminal illness creates an atmosphere of opportunity to adjust to the potential loss.

He further posits the opportunity for experiencing a catharsis allowing one to face death without the fear of being abandoned or ostracized. Kutscher refers to the need to settle “troubling personal affairs” and stresses the potential of achieving some measure of acceptance about the future death. Weisman (1974) noted that while anticipatory grief does not nullify bereavement grief, however it does begin a process of releasing a loved one and learning how to fill the emptiness. Welch (1982) proposed anticipatory grief to be an opportunity to engage in an emotional rehearsal with the hopes of mitigating the emotionally laden period of bereavement grief.

Therese A. Rando’s (2000) book *Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones, and Their Caregivers* is an excellent compilation of chapters by various authors addressing a topic, Anticipatory Mourning, that up until recently had been termed Anticipatory Grief. This most current writing about Anticipatory Mourning specifies that the conceptual transformations were due, in some measure, to the major changes medically technologically, psychosocially, legally, socio-culturally, and socio-politically (p.2) since an earlier exploration of Anticipatory Grief in the mid-1980’s. There is a further narrowing of the definition of grief as a reaction to the perception of loss thereby relegating it to an initial response as opposed to the set responses and processes proffered by other authors who had defined grief and its attendant “grief work” prior to this most recent publication.

There is a problem with this conceptual transformation or reworking of the terminology encompassing grief in general and more specifically Anticipatory Grief. While grieving and mourning have often been used synonymously, of the two mourning has historically carried the narrower definition. It has included the emotional distress, as has grief but is further evidenced by conventional signs such as wearing black, lamenting,

lowering flags to half-mast as an outward demonstration of sorrow. Each of these outward evidences occurs post-death. Rando's (2000) definition of anticipatory mourning suggests it includes a set of processes including a "grief reaction" prior to an actual death. This suggests that a grief reaction is primarily an emotional response devoid of heretofore-accepted thoughts and actions comprising grief work.

While an emotional response or "grief reaction" is certainly present upon receipt of the information of some impending loss due to an alteration in health status, career, relationship, and of course, diagnosis of a terminal illness, we would be remiss to assume that this is primarily an emotional reaction as emotion and thought are inextricably intertwined. To suggest that grief is merely an emotional response is an oversimplification. Just as thought is part of the grief response, so are the attendant actions that follow. Throughout the process of anticipatory grieving when terminal illness is diagnosed, there are many of the processes Rando (2000) refers to as: (a) coping & interaction, (b) psychosocial reorganization, (c) planning, (d) balancing conflicting demands, (e) facilitating an appropriate death. These processes have historically been part of the overall "grief-work" process required of individuals either anticipating a loss or when death occurs suddenly leaving a bereavement period.

Kastenbaum & Kastenbaum (1989) define mourning as "the culturally patterned expressions or rituals that accompany loss and allow others to recognize that one has become bereaved" (p. 128). As well, Stroebe, Hansson, Stroebe, and Schut (2002) in their *Handbook of Bereavement Research* define mourning as "the social expressions or acts expressive of grief that are shaped by the practices of a given society or cultural group" (p.6). Further, John Bowlby (1980) suggests mourning begins at the point of loss or bereavement. Grief, on the other hand, has been defined as "a primarily emotional

(affective) reaction to the loss of a loved one through death. It incorporates diverse psychological (cognitive, social-behavioural) and physical (physiological-somatic manifestations) (Stroebe, Hansson, Stroebe, & Schut, 2002, p.6). Each of these incorporated elements is part of the overall coping experience and is not limited to a bereavement time period.

Having briefly addressed the historically accepted definitions of grief and mourning, it is also necessary to provide additional rationale for retaining the previously held definitions. First, a definition of a construct must be consistent within a larger framework including consistency within the empirical findings of psychological processes. Secondly, conventional definitions must not be overlooked or amended as they also provide consistency within the broader construct. Thirdly, definitions of constructs must be logically consistent with how other terms and theories are currently defined.

There is a need here to minimize the ambiguity of the new operational definitions proposed by Rando. It is crucial that those of us who work within the field of loss and grief are fundamentally grounded with reasonably similar understandings of conceptual definitions. For both clinicians and those involved in academic research, this redefining of the terms grief and mourning are cumbersome as well as unnecessary. There appears to be insufficient evidence to suggest that such a conceptual transformation in fact would benefit future discourse.

It is interesting to note that the very person to whom Rando gives credit for his early promulgation of the terminology of the anticipatory mourning concept, suggests that the term mourning used in this context “violates a principle of logic that informs us that a term being defined cannot be used in its own definition as Rando has promulgated

(Fulton, 2003, p.343). He further declares that there is too tenuous a link between definitions of “anticipatory grief” and Rando’s “anticipatory mourning.”

John Rolland (1990) proposed his own terminology change when he defined “Anticipatory Loss” as opposed to Anticipatory Grief. He frames his discussion around the losses that are sustained such as physical losses, psychological loss, relationship loss, and the loss of accustomed roles in family systems. He also suggests that family systems must create a meaning for their experience that enables them to preserve a sense of competency. While Rolland frames his discussion around the term loss, his discussion is in many ways similar to other researchers regarding anticipatory grief.

In addition to suggested terminology alterations, there are misconceptions or myths regarding anticipatory grief within the literature that seem to confuse and mislead some. One myth is that there is only so much grief to be experienced in total; so any grief work done prior to the death will eliminate some of the post-death or bereavement grief work to be done. This researcher merely poses the possibility that anticipatory grief work is a unique phenomenon, though similar in some ways to conventional grief and may better prepare an individual to engage in bereavement grief with less of an overwhelming sense. Another myth is that if an individual or family engages in pre-death grief work they are essentially giving up any hope for his or her loved one’s regaining health. While giving up hope can occur, it is more the intent of this work to demonstrate the need to prepare for the eventuality of their loved one’s death.

An example of such preparation occurred in a study examining the role of Anticipatory Grief in the adjustment of elderly women’s (mean age=66.5 yrs) adjustment to widowhood. Authors Hill, Thompson, and Gallagher (1988) hypothesized that women who had forewarning about the impending death of their loved one would adjust better to

the bereavement stage of grieving than those who had no forewarning (p. 792). Adjustment to widowhood was operationalized as a point at which psychological well being, physical well being, and intensity of grief reaction demonstrate measurable health. The findings in this study indicate that those women who expected their husband's death fared better during bereavement than they would have otherwise.

Another study focused on a theoretical transitions perspective as it attempted to shed new light on the phenomena of Anticipatory Grief (Huber & Gibson, 1990). The authors hypothesized that Anticipatory Grief is a mediating process affecting subsequent bereavement. Results of this study reveal that female caregivers were more positively impacted by pre-death work. As this study does suggest that pre-death grief work benefits those facing a transition in life due to the death of their loved one, it further bolsters the idea that Anticipatory Grief is a mediating influence in bereavement.

Authors Glenda Gilliland and Stephen Fleming (1998) attempted to discover the similarities between anticipated grief and bereavement in a study comparing spousal anticipatory grief with conventional grief. As the authors were interested in the multidimensional nature of the grieving process, three assessment instruments were used once pre-death and once post-death. Perceived stress levels and coping abilities prior to death were found to positively correlate with post-death reactions. However, it was also found that acceptance and preparation for the death of a spouse was associated with greater anger post-death possibly due to greater attachment. While an increased sense of loss of control was noted, there were also fewer atypical grief responses post-death when anticipatory grief work had occurred. Each study addressed the existence of anticipatory grief, though no conclusions have been found nor has any operational definition been clarified at the time.

Another study (Clayton, Halikas, Maurice, & Robins, 1973) attempted to discover whether grief reactions prior to death did, in fact, alter bereavement grief reactions. Their findings suggested that those who experienced grief symptoms prior to the death of a loved one fared no better than those who did not.

Robert Weiss (1988) suggests that the events preceding a spouse's death are not part of an anticipatory grieving process but rather are "arbitrary and misleading" (p.75). He concludes that foreknowledge of an upcoming loss provides for circumstantial planning and preparation for the death, but stops short of indicating that the preparation could allow for coping processes that would mitigate in any way the grief experienced in the subsequent bereavement. He further describes the processes that do occur for recovery to be accomplished. The four processes Weiss refers to are (a) cognitive acceptance, (b) emotional acceptance, (c) identity change, and (d) new social linkages. While he suggests that cognitive acceptance includes a satisfactory explanation of the loss from a bereavement perspective, a pre-bereavement cognitive acceptance could enable finding meaning in the presence of an upcoming loss. Weiss contends that anticipatory grief may be a misleading term as it implies a recovery from a loss that has not yet occurred. However, there is not an attempt in this study to suggest this. Rather, anticipatory grief is distinct from bereavement grief albeit there are specific overlapping functions that may allow for successful anticipatory grief to lessen the impact of bereavement grief. While Weiss argues against the terminology of Anticipatory Grief, the processes he addresses are consistent with Lazarus and Folkman's (1984) viewpoints indicating these processes are what make up coping or managing constantly changing demands.

Levy (1991) engaged a study to determine if engaging in anticipatory grief work could be a risk to subsequent bereavement grief responses. His finding suggested that

anticipatory grief might be reflective of the individual's personal coping abilities and emotional adjustment. Levy also suggested that the concept of anticipatory grief has been stretched by many to a point where it has less scientific merit. Though Levy leaves the impression that he doesn't support the notion of anticipatory grief, his findings did not reflect an obvious risk.

In another study exploring the lived experience of individuals when their spouse was diagnosed terminally ill, Duke (1998) identified four themes that demonstrated a change in their relationship with his or her loved one. The themes include their relationship with the spouse and with others, their role as caregiver, the way they integrated memories, and how they felt throughout the process. The lived experience of the spouse prior to the loved one's death were characterized by the need to be with their spouse, the adoption of the caregiver role, finding themselves in limbo or suspense about the present and the future, and the awareness of the memories being made throughout the lived experience. A significant finding was the role changes the loved ones experienced while their loved ones were dying. Duke suggested the potential for psychological ill-health as a potential problem resulting from the continual role changes required.

Walker and Pomeroy (1996) suggest that when a loved one engages with someone dying within an intermediate time period, there is a greater ability to remain engaged. They also stress the opportunity to deal with "unfinished business" and bring old concerns to some resolution as well as having the opportunity to say good-byes. This is, however, a very difficult undertaking when the significant stressors of anticipating a death are present.

Research findings by Cleiren (1993) in the Leiden Bereavement Study espouse the idea that anticipatory grief incorporates significant elements of traumatic stress. He

suggests that both unnatural deaths and those including long term illness resulting in death elicit similar intensities of reactions and include a similar need to search for meaning in the loss. Generally, traumatic grief is viewed as related to circumstances surrounding a death such as a violent and often sudden death that may result in features of Post Traumatic Stress Disorder. Traumatic death may also include the death of a child and deaths that appear rather unnecessary and arbitrary in nature.

Rando (2000) indicates the necessity to give priority to the work of trauma within the construct of anticipatory grief as elements of trauma can impede the healthy functioning of grief work. She also posits that intimates of terminally ill loved ones incur trauma along with their perceived losses. She suggests the intimates have three areas of loss to focus on: a) the loss of the loved one, b) death of the family unit as it existed in the past, and c) loss of the role within the family system that were rooted in the dying person.

To encourage effective helping, Larson (2000) speaks to professionals and volunteer caregivers to help them recognize their own very real losses when the object of their care is dying. He encourages caregivers to consider carefully how to assist a dying person while simultaneously considering their own attachments to the dying one. Larson describes the losses of the caregiver as “disenfranchised grief” meaning that while the caregivers experience loss, they are trained not to and are expected not to.

Much discussion has been given to the validity of Anticipatory Grief and even to whether it actually exists at all. An example of this debate is the argument Parkes and Weiss (1983) make suggesting that it cannot exist due to the increased attachment experience by couples expecting the death of one or the other. While many researchers do affirm the presence of anticipatory grief within the experience of an individual losing a loved one to a terminal illness, the controversy is persistently present.

To date, it seems the body of research has focused on anticipatory grief as it facilitates the post-death grief experience. Perhaps a focus on the increased ability to cope with the impending loss of a loved one could be explored in an attempt to define the phenomena of anticipatory grief as a unique experience.

Coping Overview.

An aspect of pre-death grieving also meriting consideration is how a person's coping capacity impacts his or her grief experience. Coping has been defined as "constantly changing cognitive or behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, 141-142). This process-oriented method of addressing conditions outside a person's normal sphere of experience can call into play any of several focal considerations. Tunk and Bellissimo (1988) identified three domains that may become focal points. The first domain is an appraisal focus that seeks to find some meaning in a crisis situation. A second domain centers on a problem-focused coping solution that attempts to confront and control the crises. The third domain is emotion-focused. This domain attempts to gain homeostasis by dealing with the feelings associated with the crisis. For the purposes of this study the appraisal focus will consider existential coping as well as spiritual coping in an attempt to find some meaning to the impending loss.

Human beings have a universal aversion to anything that may cause concern, threat, pain, or death and engage in active steps, be they conscious or unconscious, to avoid experiencing the perceived harm. While there is a universal aversion to distressing life circumstances, the methods or steps used are as unique as any given individual.

Individual perceptions, tolerances for discomfort, and expectations for changes are among the uniqueness that individualize an experience.

Appraising a situation or problem and to evaluate resources to deal with that situation in an adaptive manner is what is generally referred to as coping (Lazarus, 1966). Pearling and Schooler (1978) defined coping as “any response to external life-strains that serves to prevent, avoid, or control emotional distress” (p.3). It has also been defined “as on-going cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus, 1993, p.237). The latter definition, arising from a process orientation rather than a style orientation, suggests that coping morphs over time and is directly linked to situational demands. Indeed, there is a suggestion here that coping is unique to the person required to use mechanisms that protect from pain or avoid a challenging threat. However, it is noteworthy to see the need to cope and the outcomes of coping as separate entities. Outcomes can include successfully changing the need to cope by eliminating the crisis, coping well enough to remain independently in control of the meaning of the life-crisis, and as well, maintain control of the stress when it arises out of a life-crisis (Pearlin & Schooler, 1978). It is this last outcome that can demonstrate the interplay between the psychological resources an individual draws from and the circumstances needing to be managed, controlled, avoided, or adapted to.

Another outcome prompting some discussion is whether one is coping well or coping poorly with whatever life challenge is at hand. It would appear there are measures determining successful outcomes, however, assuming that coping is a highly individualized process as to personal psychological resources as well as the specificity of

the life-crisis are there mitigating factors impacting the timing, the skills used, and the goal of coping?

Citing Lazarus and Folkman (1984, p141-142) in their work, researchers Tunks and Bellissimo (1988) reiterate Lazarus' earlier definition of coping as one that is process oriented. Second, the definition of coping has limits as to conditions of psychological stress requiring action but excluding automatic thoughts and behaviours. Third, Lazarus and Folkman limit the definition to coping as an effort to manage the life-stress, regardless of its efficacy. Last, the word "manage" includes minimizing, avoiding and tolerating, accepting stressful conditions including an attempt to "master the environment". Lazarus (1993) presents several meta-theoretical principles he and others have compiled over time: (a) thoughts and actions under stress must be measured separately from outcomes to examine their adaptability or mal-adaptability, (b) there is a need to note the change over time as the threat may itself change, (c) describe, as a professional observer, what a person is thinking or doing as he or she attempts to cope, (d) assess adaptability based on how it improves morale, physical health, and social-functioning, (e) note any relational meaning change evidenced by cognitive re-appraisal toward the threat. It seems reasonable to place these meta-theories into a perspective allowing for an individualized framework.

R.H. Moos (1986) introduced a set of coping skills which he suggested may be effective at certain times while not at others. His position allows for an individualized assessment of adaptability. Moos broke coping skills into three distinct domains: appraisal focused, problem focused, and emotion focused. He states that an appraisal focus engages in finding meaning and gaining understanding. A problem-focus is more analytical while attempting to confront the reality of crisis and created a more desirable

situation. Finally, Moos describes emotion-focused coping as one that attempts to manage emotions in the face of crisis while maintaining effective equilibrium.

While specific coping skills or strategies may demonstrate for the professional observer either adaptability or mal-adaptability, there are still problems in objective assessment and in determining whether they can be successfully taught. By successful, there is a suggestion of positive change within the person/environment for the better, with some mastery in the situation (McHaffie, 1992). As McHaffie points out, some problems are not amenable to mastery. She takes exception to Lazarus and Folkman's definition of coping, indicating coping may not, in fact, be measurable if mastery is indeed part of the criterion (p.69). John Rolland (1987) looks at mastery from a different point of view, as an outcome demonstrating "quality of relations" (p. 501) within family systems dealing with some kind of illness crisis rather than successfully negotiating specific problems.

Another potential problem lies in the goal at stake. If there is an expectation of problems no longer existing due to a given coping behaviour, there will at times be what could be considered a flaw with the coping itself. A prescribed set of expectations does not allow for individual uniqueness and difficulties.

Tunks and Bellissimo (1988) describe technical problems with coping assessment as they highlight the need for reliability and validity checks that would allow for "prescriptive and predictive clinical use" (p. 173). These authors do, in addition, remind us that efforts to study coping have largely implemented self-assessment by way of reporting as opposed to more objective instruments of measurement. While there are, in fact, identifiable technical problems within the concept of coping and its measurement/assessability, there is still a need to discover how people wrestle with life-crises.

At this point let us become more specific while addressing the coping mechanisms that come into play when individuals or family systems are faced with a probable terminal illness of a loved one. For those who receive a terminal diagnosis, particularly those who are younger than the age of senescence, there can be a huge sense of loss and of bitterness over a life cut too short and at an unexpected time. Terminally diagnosed individuals and their families enter into a grieving over what was supposed to be, what should be and some realization of what will never be experienced. They are left with a personal reality of grief. For many of us, as clinicians, there is a tendency to look at grief as its own emotional entity as opposed to a descriptor of a set of coping reactions.

Generally, grief is described by its stages, phases, or tasks to be completed (Bowlby, 1980, Kubler-Ross, 1969, Worden, 1991) or the particularities of normal versus complicated grief. There appears to be an assumption that we clinicians know the distinctions, however the larger body of literature does not readily introduce us to grief as a coping process that is an active rather than passive process.

Thomas Attig (1991) stresses that though terminal illness and its attendant grieving has been considered as something that happens to us, it could rather be approached as something one chooses to engage. The emphasis is certainly on the active nature of grief work. He further distinguishes grief as an opportunity to participate in this complex coping process, to make choices of a transformational nature. While Attig focused his research on the experience of the bereaved, his conclusions are relevant as well to the person anticipating the death of a loved one. Some of those choices are fundamental decisions to either be “paralyzed” by the current grief emotion or to wrestle with finding meaningfulness. Similarly, Attig (2000) emphasizes relearning relationships. He suggests, as does Rando (2000), that before a death occurs there are many losses

incurred. Attig reinforces the need to attend to unfinished business in relationships in order to enjoy and interact with loved ones fully. Engaging in the choice to attend to unfinished business is but one example of a transformational process.

Betty Davies (2000) focused on the transitional process families experienced including redefining life in the present compared to what it had been as well as their experience of living and dying simultaneously. Within each of these transformative choices, there is an assumption that adaptation is occurring evidenced by improved morale and social functioning. Prior to an adaptational, even transformational response, most terminally diagnosed individuals will wrestle with defence mechanisms intended to master the situation or to protect oneself from “conscious or unconscious painful affects” (Heim, Moser, & Adler, 1978). Included within their significant findings are both faith attitudes and stoicism.

The intent of this discussion of coping is to demonstrate the reality that coping is a process one experiences when any significant threat or loss is present. When a probable terminally ill diagnosis occurs, there is a greater need to cope and, in fact, the coping process includes a varying array of individualized responses termed grief. While clinicians do not generally receive, as part of their training instruction on working with such end of life issues as terminal illness, still there is a great need to understand and clarify the semantics of coping and grief. The hope for us as clinicians and other helping professionals is to help the terminally ill and their loved ones to “transform calamities into opportunities for growth” (Tunks & Bellissimo, 1988, p.171).

Existential and Spiritual Coping

When considering the potentiality of “transforming calamities into opportunities for growth” (Tunks & Bellissimo, 1988, p.171), we are drawn into the discussion of what

that transformation entails. The calamity of losing a loved one to death evokes in a person questions such as why me, why now, and where is God? These questions often occur within the early stages of experiencing loss after a diagnosis of terminal illness. Other questions arise as time progresses that are more pragmatic and pro-active in orientation such as how to spend the balance of the loved one's life in a meaningful way and how to manage the meaning of life and of death to bring about greater understanding? Another question evoked is whether life has had meaning up to this point? Kant posed four questions that each of us face during our lifetime: What do I know?, What must I do?, For what can I hope?, and Who am I? (Morgan, 1987). Each of these questions explores the concept of meaning and are focal points within the existential discussion.

Attig (1989) suggests "grieving is primarily a process of finding an appropriate meaning" (, p.366). He cites Edwin Shneidman (1980) as saying the terminally ill are faced with and bewail his or her pending non-existence. Existentialists refer to this as an existential plight or uncertainty about the future as well as eventual death (Thompson & Pitts, 1993).

There are several basic dimensions within the criterion of existential psychology. These dimensions include isolation, death, freedom, and meaning. Each of these dimensions are, according to Existential thinkers, attempts to discover self-identity by an individual throughout life but are often experienced more during mid to late life. Existential thinking has been proposed by various individuals such as Nietzsche who believed a person must develop his or her own unique ego and function out of that uniqueness (Battista & Almond, 1973), Kierkegaard (1944), who theorized that individuals can become aware of their own responsibility to determine how they will choose to decide and act on that decision, and Soll (2001), who postulated that

authenticity included a need to be open to new and unknown experiences including anxiety and changing interpretations while taking full responsibility for those experiences and interpretations. Heidegger (Owen, 1994c) was more concerned with a focus on the “miracle” of human existence rather than the nothingness suggested by other Existential philosophers (Owen, 1994c). Sarte (Morgan, 1988) suggested that we are “condemned to be free” and that we must decide every individual moment “if we will be, what we will be, and whether we will be the kind of person that we know we could be” (p.86).. He further proposed that we each have an innate desire to be.

More recent theorists such as Maddi (1998) suggest there are assumptions that include (a) an individual’s sense of meaning as a major determinant of “mentation and action” (p.3), and (b) personal meaning evolves from the day to day decisions an individual makes allowing one to transcend the limitations of current circumstances providing for more subjective meaning. In the presence of such mentation and action, there is a further assumption that a person’s past, present and future are now directionally motivated toward the future.

Viktor Frankl (1984) understood a human within his or her whole being including all they have been, all that they are, and all they will be. Frankl had been confined to Nazi concentration camps from 1942-1945 in both Auschwitz and Dachau. Though the conditions of his incarceration were horrendous and dehumanizing, Frankl had already come to understand basic premises in human nature. In later writing Frankl (1986) said that “Suffering ceases to be suffering, the moment it takes on meaning” (p. 25). Shantall (1999) writes “suffering calls us to task...suffering challenges us with choice” (p. 111). Frankl posited three basic assumptions within his theory of personality. First, he suggested each individual has the “freedom of will” to choose well and live authentically

regardless of personal circumstances. Second, Frankl emphasized the intrinsic and primary motivation in life to discover meaning or what he referred to as “will to meaning.” Third, Frankl also recognized that each individual has a separate and unique “meaning in life” that can change depending upon current circumstances or situations one finds him or her self confronted with. Further, Frankl believed individuals were comprised of the physical person, the psychological person, and the noetic (uniquely human or spiritual) person in combination rather any one of the parts separated out (Das, 1998; Graber, 2004).

Fabry (1987) describes Frankl’s theory as one suggesting all reality has meaning, that the meaning is unique to each individual across time, and that there are specific tasks one will be demanded to respond to throughout life. He further suggests that there are by-products such as happiness, contentment, peace of mind, and self-actualization as one pursues meaning in his or her life. Regardless of the circumstances surrounding an individual’s life, Frankl (1959) indicates everything can be taken from man but his freedom to choose his attitude regardless of circumstances.

It is with this ability of human choice that we turn now to examining the transcendental nature of grief (Wong, 2002b). Wong suggests that grief “awakens one’s spiritual and existential yearnings to rise above painful experiences of mourning” (p.4). He proposes a model of meaning-management encouraging discovering meaning and purpose, deepening our spirituality, constructing effective psychological and spiritual models of protection against fear and death, motivating us to embrace life, and transforming an individual’s values and beliefs. Within this model, there is the opportunity for a grieving individual to make choices with an emphasis on the transformation of meaning. It is Frankl’s (1963) contention that humans can move beyond

an emphasis on self toward a focus on others, social values, and spiritual values. Reker and Wong (1988) describe the three basic elements of meaning as cognitive, motivational, and affective demonstrating different dimensions of structural components, of sources, of breadth, and of depth.

A study by O'Connor and Chamberlain (1996) investigated sources of meaning that attempted to discover what motivates people to move beyond an emphasis on self. The results provided six categories most identified by the participants including: (a) an appreciation of nature, (b) creativity, (c) personal development, (d) religious/spiritual beliefs, (e) social and political, and (f) relationships with people. These six categories provide a framework to attempt to find constructs of meaning when working with individuals.

Rather than a focus on finding new constructs of meaning and making meaning, Attig (2001) directs our attention to something he calls meaning finding. By this he refers to the less conscious encounters of returning to familiar meanings that have already been established in our lives. He suggests we recognize meaningful continuity in life narratives and who we are within those narratives. Attig further contends that there is a greater appreciation and enriching awareness of what we recognize through the familiar as we enter into the unfamiliar. He also alludes to what he calls "spiritual pain". Attig's definition of spiritual pain describes the core of who we are during a crisis when we are striving to overcome adverse circumstances as well as engaging in a struggle to find meaning and a transcendent awareness.

Marrone (1999) identifies three elements that are part of spiritual awareness for many people. First, a person may have some kind of an experience with an absolute being, a higher power, a religion, or other belief system he or she is committed to.

Second, a person may be aware that the higher power provides order, intelligence, and purpose within their world. Third, there is a greater sense of meaning and purpose as a result of the relationship with the perceived higher power.

Marrone (1999) describes a “psychospiritual transformation” (p. 497), that occurs during loss challenging our assumptions about life, death, love, and God. He further posits that by trusting in whatever religious belief one has about God, there is an ability to recognize a meaningful purpose in life and in death. No longer is death a wall but rather a doorway (Feifel, 1990) that one can pass through toward a transformation of beliefs about what occurs beyond the present circumstances (p. 537). It is an opportunity to discover how the awareness of death can transform and provide meaning in life. Marrone describes psychospiritual transformation as a process that requires an individual to set aside pre-existing needs for order and control for faith in a higher order, structure, and meaning.

Harrison, Koenig, Hays, Eme-Akwari, and Pargament (2001) suggest, “religious coping may be involved in the conservation or transformation of ends” (p.86). It is as an individual engages a trial beyond their own ability to cope and are faced with choices as to how they will deal with the trial, that an individual may begin to discover their own significance within the context of the spiritual (Pargament, 1997). For a person who has a loved one facing terminal illness, there is involved a trial beyond the scope of general understanding that prompts the search for significance Pargament alludes to.

Doka (1993) proposed three essential tasks for those dying that this researcher believes apply as well to those anticipating the loss of a loved one. First, there is a need to recognize an ultimate source of meaning in one’s life. Second, people need to be allowed to accept death within their own construct of ultimate meaning. Third, there is a need to know there is a future for them either in an afterlife or within a legacy left to others.

Oates (1982) would contend these tasks are part of what he refers to as staging operations or preparation for death. He tells us “death confronts us with the end of a life that demands a comprehensive faith-courage” (p.233). Oates quotes Paul Tournier as saying that “we live in a rhythm between finding a place and quitting a place.” For each of us, there is a need to live and die within a context of discovering meaning, experiencing hope, and walking alongside others toward an anticipated future.

The Bible tells about the God of all comfort. Isaiah 61: 2-3 (New International Version, 1984) speaks of God as the One who comforts all those that mourn. He bestows beauty for ashes, the oil of joy for mourning, and a garment of praise instead of a spirit of despair. There is in this description a transformation of a negative condition into a joyful one. The focal point within the Christian Bible is Jesus, who himself was to die. Though He died, He rose again demonstrating yet another transformation...a transformation that fostered life rather than death forever.

Harkening back to Wong’s concept of approach acceptance, there is a satisfaction in anticipating a future or an afterlife where a loved one will be waiting. It does, in fact, remove death of its sting (1 Cor. 15: 54).

CHAPTER THREE: METHODS

Sample

Eligibility to participate in this study was contingent upon meeting specific criterion. Included within the criterion are (a) the need to be at least 25 years old, (b) be in a close, familial relationship with someone who has received a terminally diagnosed medical condition, and (c) the diagnosis must have been made within the past two years at the point of our first contact. In total, eight respondents, five women and three men, met the criteria and were willing to proceed further. The respondents were located either by word of mouth referrals or by invitation of the researcher. Upon acceptance, each potential respondent received and completed a packet that included a written description of the research project together with an informed consent form to be signed and a demographic profile to complete. (Appendix C, D, & E).

The eight respondents who were included in this analysis ranged in age from 29 to 70 years (median age= 57 years). The composite of the relationships included in this sample involves one sister, two husbands, two daughters, and three mothers.

Four of the eight respondents were within a middle class socio-economic level (40-60 thousand per year) while three respondents fell within lower-middle class socio-economic level of 20-40 thousand dollars per year. One respondent reported no income since the time of diagnosis. Of the eight respondents, seven were of Anglo-Saxon descent while the eighth respondent was of Chinese descent. Religious affiliation included a range of three Evangelicals, one Baptist, one Catholic, two Protestants, and one Pentecostal. As well, one respondent had an education at a Graduate level, three carried

Bachelor's degrees, two had an Associate degree, and two had a High School diploma. (Appendix E)

Procedure

Each respondent who agreed to participate and returned the signed "Informed Consent" forms were then scheduled for two meetings. The first meeting was approximately 1 hour with the subsequent meeting, about 1 month later, lasting about ninety minutes. The first meeting included filling out four-pen and paper research instruments. This was followed by a semi-structured and audiotaped interview including four basic questions; yet, there was an opportunity for the respondent to ask questions or debrief with the researcher. There were several respondents who requested the opportunity to fill out the pen and paper research instruments prior to meeting allowing for us to meet for a shorter length of time. The first meeting also allowed for the researcher to ascertain background information about the diagnosis and the progression of events leading up to the terminal diagnosis in some cases. The second meeting included the same four research instruments (Appendices, H, I, J, & K) as well as the same four questions (Appendix G) with the corresponding sub-questions. There were an additional four questions asked to allow the respondents to comment on participation in the study as well as providing an opportunity for the respondent to debrief. While there was the use of quantitative pen and paper research instruments, the emphasis of the research was the qualitative experience of the eight respondents.

The meetings with the respondents were conducted either in their homes, in the researcher's office, or in his or her personal office per their request. Of the eight respondents who started the research project, all eight completed it.

At the conclusion of the final meeting, the respondent was left with a research evaluation form (Appendix L), a thank you note, and a \$30 token of appreciation for their participation in the study.

Semi-Structured Interview

The semi-structured interview included a list of questions for the respondents to address. The questions were left open-ended allowing for respondents to have greater freedom in answering them. There were initially four main questions including clarifying corresponding sub-questions. The questions were as follows:

1. How did you initially react to the diagnosis of your loved one's illness?
 - *Who else was present?
 - *What was the setting?
 - *What did you do immediately upon hearing the news?
2. How are you feeling now?
 - *How concerned are you now about losing your loved one?
3. How are you coping with the prospect of losing your loved one due to this illness?
 - *How are you emotionally?
 - *What has been helpful for you since your loved one's diagnosis?
4. What has been the impact of your loved one's diagnosis on your relationship?
 - *Are you closer now?
 - *Has it caused you to resolve old concerns/problems?
 - *How do you feel toward your loved one with this diagnosis?
 - *Has your relationship changed at all?

At the time of the last interview, four additional questions were asked allowing for a time of debriefing as well as determining the perceived merit of the discussion for the respondent. The questions included:

1. How were you after our last interview?
2. Do you believe talking about this topic has helped you or hindered you?
3. Have you openly talked about death?
4. What has prevented it?

Instruments

Four psychometric research instruments were included within this study. Because the study addresses death and how people cope from both an existential perspective and a spiritual point of view, there were instruments focusing on each area. The Death Attitude Profile-Revised (DAP-R) (Wong, Reker, & Gesser, 1994) is a 32 item, Likert style instrument that measures a wide variety of death attitudes including Fear of Death, Death Avoidance, Neutral Acceptance, Approach Acceptance, and Escape Acceptance. (Appendix H)

The Revised Death Anxiety Scale (RDAS) (Thorson & Powell, 1988) is a 25 item Likert response format instrument that measures on a scale of 1 to 100 a person's death anxiety. This scale appears to be age-sensitive and has acceptable levels of reliability. (Appendix I)

The third instrument is the Personal Meaning Profile (PMP) (Wong, 1993) with a 57-item Likert format. The PMP indicates a person's sense of personal meaning including a sense of purpose and an awareness of personal significance. It allows for the researcher to determine the domains that most impact meaning in a person's life. The range of domains includes: (a) Relationship, (b) Fair Treatment, (c) Fulfillment, (d) Achievement,

(e) Intimacy, (f) Self-acceptance, (g) Self-transcendence, and (h) Religion in order of significance with respect to the total PMP criterion measures. As well, the PMP has good test-retest reliability ($r=.85$). While there are other instruments similar to the PMP such as the Purpose in Life instrument and the Life Regard Index (LRI), the focus of the instruments suggest some differences. The Purpose in Life (PIL) instrument provides a more generalized statement about purpose but doesn't address meaning. The Life Regard Index measures purpose and meaning but is more an attempt to determine what resources a person has to achieve that meaning. The PMP, like the PIL, measures an overall score for meaning but the PMP takes the process another step forward to measure specific sources of meaning. (Appendix J)

Finally, this study includes use of the Coping Schemas Inventory (CSI) (Wong, Reker, & Peacock, 1993; Wong, 2005). The CSI is a 76 item inventory that evaluates a wide range of coping strategies including: (a) Religious, (b) Passive Emotional, (c) Active Emotional, (d) Situational, (e) Self-restructuring, (f) Social Support, (g) Meaning, (h) Tension Reduction, and (i) Acceptance in order of significance using the Cronbach's alphas. The Coping Schemas Inventory was chosen particularly as it is the only coping scale that provides existential and religious coping measures within the same scale. (Appendix K)

CHAPTER 4: RESULTS

Sample

As this research project was designed with a qualitative case study approach, the responses generated by the respondents were significant as they provided a range of themes that were commonly significant to this sample. As well, the quantitative data provided further support of the respondent's methods of coping. However, it is also important to present a portrait of each of the respondents as they participated in the research process. This portrait is based on:

1. What the researcher knows about the respondent,
2. Clinical observations during each session,
3. What was said before and after each interview?

It is essential to capture a bit of each respondent's thought process and struggle. Though each theme contributes to the overall knowledge of a respondent's experience, a portrait provides a greater appreciation of their experience. While the themes described do present a general picture, there is still a need to have a fuller understanding of how an individual copes with the death of a loved one that themes cannot adequately represent. Following is an introduction to the eight respondents and their relationship to dying loved ones. Greater detail can be found in Appendix A.

Respondents

Respondent 1. Susan is a 51-year-old Caucasian female. Susan's dying loved one is her 82-year-old mother-in-law that is dying of Emphysema. Her mother-in-law was diagnosed terminally ill approximately 6 months ago. Susan sees her mother-in-law infrequently though she maintains a close relationship with her. Emotionally, Susan was non-emotive during the first interview but was more emotive during the second interview.

Respondent 2. Fred is a 55-year-old male Caucasian who is married to Susan. His mother was diagnosed approximately 6 months prior with terminal Emphysema. Both Fred and Susan live approximately 300 miles from their dying loved one. Fred calls his mother regularly and visits her frequently. He is also very involved in providing for her practical needs. Fred's primary emotion was anger toward the tobacco companies for peddling legalized drugs.

Respondent 3. Lily is a 52-year-old Chinese female whose husband is dying of a form of brain cancer. Lily has three adult children who have been very supportive of her and have participated in gathering information and supporting their mother in practical ways. Lily was measured in her responses to questions and even provided her own audio equipment to record our conversation. Lily was generally non-emotive especially during our first interview. She was also very hopeful for a cure or at least a stay from the terminal diagnosis.

Respondent 4. Norm is a 57-year-old male Caucasian whose daughter is dying of brain cancer. His daughter was diagnosed terminally ill approximately 18 months prior. Norm appeared emotionally restrained though at times he was emotive. He uses work, exercise, and participating in research projects as forms of normalizing his distressful life circumstances. Norm had a need to accept his daughter's dying within a context of discovering meaning attached to it. His faith figured prominently in our discussions.

Respondent 5. Becky is Norm's 56-year-old Caucasian wife and mother to her daughter dying of brain cancer. Becky had a difficult time remaining focused and appeared in an almost trance-like state as she spoke. She communicated a trust in God and believed she accepted the condition of her daughter though she was actively seeking

to accomplish healing for her daughter through praying with others over her daughter. Becky had a great need of outside support but felt quite isolated.

Respondent 6. Jan is a 70-year-old Caucasian woman whose husband is dying of a form of Lymphoma (cancer of the blood). Jan's husband also has Parkinson's disease and has suffered for most of his life with a Bi-polar condition. She was completely non-emotive during the interviews and tends towards a "matter of fact" disposition. Jan's only focus is to minimize the discomfort of her husband though she has significant medical concerns for herself.

Respondent 7. Terry is a 32-year-old male Caucasian who is a son to Norm and Becky. Terry's sister is dying of brain cancer and Terry lives with her family to provide help and care for her. Terry has coped with his sister's dying often by escaping through the use of drugs and alcohol. He has actively engaged in trying to trust God for direction and comfort as he struggles with the expected loss.

Respondent 8. Patricia is a 42-year-old female Caucasian whose mother was dying of Chronic Pulmonary Obstructive Disease. The terminal diagnosis was given approximately one year prior to our discussion. Patricia struggled in her role to function as the primary caregiver for her mother even though the family was fairly large. She was isolated and needed support from both family and external sources. As a nurse, her own needs were overlooked. Throughout the course of the interviews, Patricia attempted to maintain a cool detachment emotionally.

Themes

After having gained a glimpse of how each respondent presented to the researcher, we can better understand the themes that were provided during each interview. In all, the Content Analysis of the semi-structured interview yielded in total 704 meaning-units. Mini-units are statements made by the respondents that contain a complete idea relevant to the study. After identifying and defining more specific themes, the researcher was able to consolidate the 704 meaning-units into 22 themes.

To determine validity for the representative themes, the researcher asked two of the respondents to participate in a validity check to determine if 10 percent of their responses were reasonable representations of what the researcher had represented. As well, they also participated in a cross-validity check to determine if they would identify 10 percent of other respondent statements similarly to the researcher. In the validity check there was a .94 percent accuracy rate while the cross-validity check yielded .87 percent accuracy.

A further cross-validity check occurred through the repetition of consistency from one respondent to another. Rather than examining data, thematic and quantitative, from a single case study, there were eight case studies providing for greater validity.

To establish reliability, the researcher engaged a professional counsellor who works with individuals struggling with bereavement or are expecting lose to someone to death to identify at least 10 percent of respondents meaning-unit statements into representative themes. The reliability was established as .85 percent accuracy with the researchers.

Definition of Themes

Acceptance: Recognition and agreement with the fact that the loved one's prognosis will conclude with death. Relatively at ease with mortality.

Anticipating the Future: Wondering what the loved one's death will be like including rituals and customs. May also include a period of time after death.

Denial/Escape: Lack of willingness to accept the diagnosis/prognosis. Avoidant behaviour may also be included such as self-medicating.

Emotionally Detached: Lack of emotion when discussing death. Distancing self from his/her loved one or the event of the death itself.

Emotional Responses: Includes emotional reactions such as anger, sadness, anxiety, fear, concern, confusion, a sense of being overwhelmed, crying, tearful, empathic, upset, sorrow, despair, frightened, fluctuation of feeling and vacillating emotions.

Fear of Future: Anxiety of living life without the loved one. May include the fear of being alone or otherwise ill equipped to cope with daily tasks previously performed by the love one.

Focus on Loved One: Becoming absorbed in the needs of the dying loved one in an attempt to provide support, comfort, and help.

Initial Response/Recollection: The first reaction to the diagnosis of a life-threatening disease for a love one. May include emotional reactions such as numbing, shock or an absence of memory.

Meaning Making: Experiencing a sense of purpose or direction in life regardless of circumstances.

Needs Family Support: Emotional or physical support from immediate and extended family members to attend to the difficulties presented by the dying of a loved one.

Needs Outside Support: A need for others beyond the family network to inquire or emotionally/physically provide help for the person who has a loved one who is dying. May include reaching out for social opportunities.

Negative Medical Intervention: Immediate medical care that doesn't provide satisfactory results. May include perceived insensitivity by physicians or their staff, lack of timeliness in medical care, or an unacceptable outcome.

Normalizing Behaviours: Behaviours an individual may engage in that appears to stabilize a seemingly chaotic experience such as using routine to cope with life and a focus on exercise or other patterns of activity that serve minimize the daily stressors of a loved one's dying.

Participation in Study: Responses that pertain to an individual's opinion of their experience of engaging in this research study.

Positive Thoughts: The ability to think positively about some general or specific aspect of the dying loved one or the circumstances surrounding the dying experience.

Practical Needs: The need to attend to the more mundane details of care giving. May also include the care of other family members who are impacted by the present and future losses.

Recognition of Problem: The initial dawning of awareness of physical and emotional changes that suggest a problem exists. There is some noticeable difference in the loved one's person. May include gathering information as a response to unusual symptoms or medical diagnosis.

Relational Changes: Alterations in relationships that are noticeable. Examples may include closer relationships, more distant relationships, and role changes such as in parent-child relationships (Who will care for who depending on who is dying?).

Relational Difficulties: Challenges to interpersonal dynamics between members of the dying loved one's intimate circle, including family and friends, which strain the relationships. May include self-blame, feeling isolated in care-giving, and physical strain of care-giving.

Resolution of Concerns: Old issues or concerns between the respondent and the dying loved one are addressed in a positive or negative way. Often there is some measurable difference when positive change has occurred. May include no change at all or a lack of awareness of any problems.

Self-Transcendence: May notice other individuals (not associated with own personal loss) discussions or personal experiences of death, dying, and loss.

Trusting God: Actively choosing to believe God will help the respondent cope, provide solace, provides direction, and cares for the dying of the loved one and other family members. Actively pursues direction from God, attempts to see an eternal perspective, believes there is some purpose for the death of the loved one, and is seeking some demonstration of His presence.

The following table provides frequencies of the identified 22 themes along with the number of respondents who mentioned within their mini-units similar thoughts. There is also the total number of times a statement was made by the group of the eight respondents. Note that the Table 1 is in order of participating rates first and then by frequency of statements rather than alphabetical order.

Table 1: Participating rates and frequencies of themes

<i>Themes</i>	<i>Participating Rates</i>	<i>Frequency</i>
Emotional Responses	8/8	128
Resolution of Concerns	8/8	30
Initial Response/Recollection	8/8	37
Relational Changes	7/8	57
Relational Difficulties	7/8	45
Trusting God	7/8	43
Emotionally Detached/Avoidant	6/8	31
Positive Thoughts	6/8	27
Practical Needs	6/8	23
Needs Outside Support	6/8	24
Denial/Escape	6/8	16
Participation in Study	6/8	13
Fear of Future	5/8	23
Recognition of Problem/	5/8	19
Gathering information		
Acceptance	5/8	15
Needs Family Support	4/8	9
Anticipating the future	3/8	18
Focus on Loved One	2/8	13
Negative Medical Intervention	2/8	12
Normalizing Behaviours	2/8	8
Meaning Making	2/8	5
Self-Transcendence	2/8	5

It is important at this juncture to establish which of the themes represented here have any basis in past research either through empirical work, clinical observation, or theoretical research formulations. The preponderance of grief literature, be it empirical or theoretical, alludes first of all to the presence of emotional responses. It is safe to say that most individuals faced with the death of a loved one will experience some emotional response; unless, however, an individual is disconnected emotionally due to shock, denial, or some other complication of grief. Certainly the majority of responses represented this theme.

Within empirical research, there are evidences of higher intensities of emotional responses such as anger, loss of emotional control, as well as atypical grief (Gilliland & Fleming, 1998). As well, there is evidence of lesser amounts of death anxiety among an older population as opposed to the younger adults.

Similar to the larger body of grief literature (Aldrich, 1974; Bourke, 1984; Pine, 1974, 1986; Rando, 1988; Reed, 1974; Weisman, 1974), this research demonstrates that anticipatory grief and conventional bereavement grief have similarities emotionally, physically, and socially. Another study suggested subjects reported a more factual attitude about accepting the loved one's death when certainty was inevitable (Hinton, 1999). The same study reported subjects focused on a future reunion due to spiritual beliefs enabled greater acceptance of the death.

In a bereavement study, Yalom and Lieberman (1991) found that those who had a heightened awareness of their meaning and purpose in life demonstrated greater evidence of personal growth, which may provide a link between anticipatory grief and conventional grief. Each of these studies was represented within the themes presented in this research project.

The researcher's clinical observations do support the presence of emotional responses, a need to resolve old problems or concerns, relational changes in the relationship with the dying loved one, and the presence of difficulties relating as the dying loved grows more and more ill. There is also evidence, from a clinical point of view, that a person generally attempts to make some meaning out of the loved one's dying and is often drawn into an awareness of a God or have their own relationship with God deepen. There is, as well, a general anxiety of what life will be like without the loved one. This fear of the future may impact the individual cognitively, socially, emotionally, physically, and spiritually. It is also not unusual for an individual to respond to the dying of their loved one with blame directed often at medical practitioners, suppliers of products such as cigarettes and alcohol, and family members seen as unsupportive.

For each of the eight respondents there were significant emotional responses, both verbal and affective, revealing something of their internal stressors. Fred was one, in particular, that expressed pent up anger that he aimed at the tobacco companies who he held partly responsible for his mother's emphysema. Becky also expressed anger that she hadn't known what was happening to her daughter's body many years before the diagnosis though the cancer had not yet metastasized to the point of revealing recognizable physical manifestations. Becky focused much of that anger on those around her who had let her down, specifically family members who were more tentative about talking with her.

Each respondent was very concerned about resolving old conflicts. They also experienced difficult relational changes as well as relational difficulties. Often when a respondent would speak of some change or difficulty, there would be an emotional

response attached to it. Patricia was the one respondent whose unresolved past concerns with her mother had impacted her entire adult life; but she was unable and unwilling to deal with the potential ramifications that attempting resolution could incur. It appeared that fear of her mother and her desire to protect her mother from further distress worked in tandem to prevent any attempt at resolution. There was, however, one respondent who did not see that any old concerns existed. Lily was so intent upon being everything to her husband, providing for his every need and never discouraging him by word or deed, that she appeared to have distanced herself from any difficulties between them.

All of the respondents reported a great need for support, both within the family network and outside social connections, to provide emotional, physical, and spiritual support. What became clear to the researcher was the need of each respondent to express verbally his or her pain, frustrations, needs, and experiences. Susan, Fred, and Becky all commented on their need to have someone simply ask how their loved one was faring and how each respondent was doing in response. They each mentioned feeling like it was socially unacceptable to mention a dying condition. According to the respondents, it was as though the people around them, often family members and close friends, were afraid to say anything. The result for Susan, Fred, and Becky was to harbour resentment and become more isolated in their grieving experience.

Each respondent commented on the benefit of participating in this study because of the opportunity to speak aloud his or her internal machinations. It was as though they needed permission, albeit under the guise of a research study, to explore how they were personally affected and coping as there was no other opportunity within the context of their own family or social structures. It was interesting to note at the beginning of the first interview there was tentativeness about speaking of their sorrows that morphed into a

more comfortable conversational exchange. By the time of the second interview it appeared each respondent was more quickly ready to engage. Certainly a part of the readiness could have been that they were more familiar with what to expect of the interview process, however, it appeared to this researcher that the respondents were simply less reticent due to the opportunity to give voice to their concerns.

While coping styles differed from respondent to respondent, the common denominator appeared to be their trust in God to make meaning out of the dying of their loved one. Each had a need to talk to someone who could understand the suffering they were experiencing.

Part of the process of sharing their lived experiences and how they are coping with the dying of their loved provided an opportunity for them to enter a process of transformation rather than adaptation or reaction. It is hoped that the grieving individual moves beyond the reactive or adaptive processes to engage in a transformative process. Wong (2002b) suggests that transformative grieving is essential in moving through the recovery process. He posits that transformative grieving allows one to build the loss into his or her future in a constructive and redefining way. He further discusses the new meanings attached to an individual's life experience and the opportunity to re-author one's life story. At its zenith, the transformative process encourages one to engage and appreciate a greater understanding of what his or her place is in the world and not be limited by the experience of another's death.

Quantitative Data

Due to the small sample of respondents, the quantitative findings within this study were intended to provide another perspective on the experience of each respondent and to support, or not, the themes presented. The data was an additional source of information,

rather than the focus of this research. One hope was to establish how this sample's data related to the norms of other studies where these particular research instruments had been used. How age, gender, and backgrounds may influence similarities or differences in respondent's experiences were to be examined. The researcher looked at the total of the "all respondents" mean from Time 1 to Time 2 to determine if there was significant difference amongst individual data.

The Personal Meaning Profile (PMP). Comparing the rank order of the mean ratings for PMP norms that are rated Relationship, Fulfillment, Achievement, Self-Transcendence, Fair Treatment, Self-Acceptance, and Religion in order of significance to the mean results of the total respondents for this project, we can see that the norms do not necessarily represent this sample. For instance, where the norm rankings suggest Religion falls in the last ranked position, this study placed Religion at the first ranked position. In a study engaged in by Wong (1998a) for the purposes of building the PMP, age factored highly in whether individuals had "different implicit theories of meaning". It was found that only the elderly (age 60 +) rated Religion as high as opposed to the Young Adult group (age 18-29) or the Middle Age group (age 30-59). Additionally, there was a significant gender effect with women giving Religion a higher ranking than men. Additionally, females also ranked relationships higher than men.

Another study that Wong used to build the PMP (Wong, 1998a), provided profiles of personal meaning among laypeople and determined whether higher self ratings would translate similarly to criterion measures and other well-being measures. It was also approached as a tool to determine whether ranking would occur in a manner close to that of the aforementioned study. In fact, Religion again ranked lowest on the profile while Relationship ranked highest.

Wong suggests the Religion factor is believed by laypeople to be part of a meaningful life (Wong, 1998a). Perhaps it is also viewed as part of a meaningful dying experience.

Pertaining to this research project, Self-Acceptance and Relationship factored similarly by rank, number 2 and 3 after Religion. In contrast, the norms suggest Relationship would factor first with Self-Acceptance ranking near the end of the sub-categories. Self-Acceptance suggests an individual has an appropriate attitude toward oneself while Relationship is described as the ability to work together with others toward a common goal. Within this study, it becomes apparent that Religion and Self-Acceptance factor highly toward each respondents ability to assign meaning to their experience of losing a loved one to death. (See appendix M)

Death Attitude Profile-Revised. Consistent with the lack of change between Time 1 and Time 2 represented by the PMP, the Death Attitude Profile-Revised remained essentially unchanged over time. This measure intends to demonstrate three types of death acceptance; neutral acceptance, approach acceptance, and escape acceptance.

The most notable change occurring in this study was demonstrated in the area of Approach Acceptance with mean scores of 6.2 and 6.26 respectively to Time 1 and Time 2. These mean scores were significantly higher than the normative group (Wong, Reker, & Gesser, 1994) in a sampling generated for the purposes of constructing the DAP-R demonstrating scores of 4.7 for 30-59 year olds and 5.38 for 60-90 year olds. As well, Approach Acceptance as a function of gender had normative mean scores of 4.66 for men and 5.23 for women. The normative mean scores as a function of age and of gender were the two main effects of the data.

Approach acceptance suggests the desire of a person to be with a loved one in heaven. According to Klenow and Bolin (1989), greater religious involvement is the only discriminating factor in believing in an afterlife. According to the data included within this study, there was a significant belief in life after death and awareness that, indeed, the respondent will join the loved one in heaven at a later date.

Escape Acceptance was also higher by approximately a point as both a function of gender and of age. This suggests there was a welcome sense of relief from suffering for the loved one. This further establishes death as a good alternative when coping has become quite difficult and it seems there is no other way out. That Approach Acceptance and Escape Acceptance are double the scores of Fear of Death and Death Avoidance within this population suggests they are learning to accept their own mortality and the mortality of their loved ones. (See Appendix M)

Revised Death Anxiety Scale (RDAS). The purpose of the RDAS is to measure with reasonable ease, the anxiety level of a person who is expecting death. This is a scale measuring from 1-100 an individual's level of death anxiety. While the normative mean is sensitive to a respondent's age, it is not apparently sensitive to a respondent's gender. Mean scores based on one sample of 325 participants (Thorson & Powell, 1990a) demonstrated mean scores greater than 49 represented (a) a fear of not being, (b) a fear of pain and helplessness, (c) fear of life after death and decomposition, and (d) a fear of loss of control, pain, and unresolved afterlife issues. Mean scores less than 39 represented (a) uncertainty, (b) afterlife concerns, (c) helplessness and bodily integrity, and (d) a fear of pain. According to Thorson and Powell, the mean score for 18-20 year olds was 51.85, for 21-36 year olds the mean was 48, for 37-67 year olds the mean was 39.79, and for 66-88 year olds the mean was 41.22. The data accumulated from the respondents in the

current study demonstrated a mean score for all respondents of less than 39 suggesting a relatively low level of death anxiety. It was noteworthy that while the mean for all respondents was less than 39, certain of the eight respondents had markedly higher personal mean scores indicating higher death anxiety (see Appendix M).

Coping Schemas Inventory (CSI). The Coping Schemas Inventory identified the Religious and Meaning coping strategies as the two most significant within this study. The all respondents mean score in Religious coping strategies was 4.4 on a scale of 0-5 and the mean of the Meaning coping strategy was 3.8 on a scale of 0-5. There was consistency for the Religious coping strategy as ranking first in the normative studies along with the results of this study. The Meaning coping strategy ranked seventh in normative studies as opposed to this study's rank of second.

It is noteworthy that the scores represented by the overall respondents scores were nearly double the normative scores within the Religious sub-category and markedly higher for the Meaning sub-category compared to the normative scores. Existential and Religious coping would appear to be more relevant to those expecting the death of a loved one (see appendix M).

Conclusion

There was the hope that the collected themes of the qualitative aspect of this study together with the results of the quantitative data would provide triangulation with the experience of the respondents. It was significant that the "all respondents" mean scores of quantitative data coincides with the thematic observations. As well, there was marked consistency from a clinical point of view.

The results appear to be consistent within the literature specifically relating to the Revised Death Anxiety Scale and the Coping Schemas Inventory. The Death Attitude

Profile-Revised also provided consistent results in keeping with the mean scores, some significant themes of the content analysis, and the lived experience of the respondents.

However, there was some contradiction between the data examined in the Personal Meaning Profile and the results of this study. While Religion was ranked last within the PMP, it was ranked highest within this research. However, there was a need on the part of each of the respondents to experience a sense of purpose in life regardless of the circumstances but most especially in the face of having a loved one die.

While the individual results are not necessarily new, what was new was the value of having data from a variety of sources to create a portrait of the lived experience of an individual who has a loved one that is dying. Beyond that there was a need to help people who grieve, such as the respondents in this study, to express their sorrow, concerns, and fears as well as help them learn in greater ways how to make meaning out of extraordinary pain.

CHAPTER FIVE: DISCUSSION

Sample

Each of the five women and three male respondents were located either by word of mouth referrals or by invitation of the researcher to participate in this study. Attempts were made to include a wide variety of individuals with different faith backgrounds or those who had no faith persuasion in order to provide as broad a palette of understanding as possible within this type of research. However, reaching this particular population was extremely difficult.

The first attempts included reaching out to local hospice organizations and hospitals. After providing the written proposal and meeting with the representatives from the various organizations to answer any questions, I received a generally warm reception

but I did not, over several months, hear anything more from them. I was told that for purposes of liability there could be no endorsement from the organizations in question, rather, I could leave a hand-out with them to be provided upon request. Of course, few individuals in crisis due to a diagnosis of terminal illness would be inclined or even cognizant of asking about participation in a research program.

After many fruitless months of attempting this avenue, the researcher attempted to pursue pastors within local churches. While many could see the relevance of such work, there was a general wariness to ask their parishioners to participate in this study.

Another avenue pursued was to speak with individual doctors who might be able to make a referral or steer the researcher in a more productive direction. This was also a fruitless endeavour. It is possible that physicians were concerned with liability issues related to such a referral.

Only after these attempts generally failed did the researcher decide to invite specific individuals within her sphere of influence to participate. The researcher first sent out a general information letter regarding this research to her clients on her counselling client roster (See Appendix F). While there were several individuals who were interested in the work in general, there were only two of about fifty individuals who wished to participate and met the inclusion criteria.

Another respondent was gained by sending a letter to a church where the researcher's thesis professor, Dr. Wong attends. The letter was directed toward the pastor who determined whether there was a possibility within his congregation. In fact, there was one who was interested and met the inclusion criteria.

Next, the researcher asked members of the local Parkinson's disease support group of which the researcher is involved within a community service capacity. There

was one volunteer from within that population who stepped forward and met the inclusion criteria.

Two of the sample of respondents were referred by a client/respondent of the researcher's and are of the same family as the client/respondent. The two referrals are parents of the client/respondent and parent of the dying young woman.

Finally, the researcher drew from her personal circle of friends as they were experiencing a loss within their own family. This was a husband and wife who were expecting his mother to die.

In all, there were nearly one hundred individuals approached about participation in this study with only eight individuals meeting the inclusion criteria. There was also the difficulty present that all of the individuals involved represent the Judeo-Christian faith persuasion which may have created a bias in this study. While the researcher attempted not to have any representative bias toward those individuals she knows personally or professionally, there was still the possibility that bias existed. It is worth mentioning, in spite of the obvious, that the sample would tend to lean heavily toward a spiritual coping experience with so similar a faith background. This tendency certainly bears on the results in that the results do not necessarily represent all peoples but rather a particular segment of the population. As well, most of the respondents were of Caucasian descent with only one respondent representing another ethnic background. This was another example of potential bias in the results. While the results do suggest particular ways of coping in the midst of losing a loved one to death, they are not necessarily generalizable within the broader population.

The respondents within this study were different from one another in their walks of life, gender, and range of age. However, they were homogeneous in that they were all

from a Judeo-Christian faith background. While they did all have this faith background, there was a broad difference in how they allowed their faith to provide for them in the midst of the enormous changes they were experiencing. This was most evident for those, such as Lily and Becky, who were quite fearful of the future. Some individuals who experienced an inordinate fear of the future tended to be somewhat challenged in their faith at the times of the interviews.

Observations of Individual Data

Lily was one who demonstrated marked fear of her husband dying and leaving her alone. Her DAP-R mean score provided fear of death data (5.286) three standard deviations above the standard norm (3.10) suggesting significant fear of his dying while the sub-category of Religion on The Personal Meaning Profile suggested a mean score of 4.667 (2 standard deviations below the norm) compared to the norm of 5.667. Lily's score was a full two standard deviations below the norm. This could be interpreted as indicating that as Lily was trusting God less, her anxiety increased.

Becky's mean scores reflected differently. She spoke often about trusting God with her daughter who was dying but exhibited symptoms of visible confusion and anxiety during the both interviews. In fact, her scores on the Death Anxiety Profile-Revised and the Revised Death Anxiety Scale were higher than most others in this cohort group. This was interesting in that her mean score (6.667) in the sub-category of Religion on the PMP was two standard deviations above the norm (5.667). This suggested that even in the presence of high strain and anxiety, Becky was able to measurably trust God.

Similarities to Previous Findings

The findings in this research project are similar to those presented in the Rando (2000) discussion about the six dimensions of Anticipatory Grief. Rando addressed one

of the dimensions recognizing the time foci of the losses including past recognized losses, present and unfolding losses, or future and expected losses. This sample was quite cognizant of their losses. This was demonstrated with Lily as she observed her husband's diminishing capabilities both physically and psychologically. She had, in the process of recognizing her husband was seriously ill, begun to note the losses already of normal interaction and participation in significant family events such as one daughter's graduation and another daughter's upcoming wedding. Lily would worry about what the future would be like without him to support their daughters as well as her self from emotional, physical, and financial perspectives.

Rando's five other dimensions of anticipatory grief include (a) the perspective or viewpoint of the one expecting the loss, (b) influencing factors, (c) major sources of adaptational demands, (d) generic operations including coping, psychosocial reorganization, and balancing conflicting demands, etc., and (e) contextual levels. Within this population of this study, the dimension of perspective/viewpoint was similar in that each respondent was losing a specific intimate relationship. Each family experienced a few elements of the psychological factors and social factors Rando discusses within Influencing factors. For instance, each respondent copes differently depending upon his or her unique relationship with the dying family member. This was particularly obvious when interviewing the two representative families. Within each family unit, individuals responded differently depending upon the relationship they had with their loved one as well as upon the social structure present within the family. Consistent with Rando's Generic Operations dimension, this research certainly found respondents recognizing their loss, reacting to the potential separation, loosening their hold upon old assumptions

of what life would be like without their loved one present, and attempting to adapt to the circumstances.

Thomas Attig (2000) reinforced the need to attend to unfinished business within relationships where a death is expected. For each of this sample, there was an awareness of the need to resolve old concerns and to mend their relationships. Of the eight respondents, only Patricia and Lily did not attempt resolution with their dying loved ones. As Attig mentions in his work, there is a need to recognize the choices at hand, the partial losses of presence, and how to engage in healthy leave-taking. With the exception of Lily, the other respondents had actively desired to see their loved ones die with no regrets in the relationship and so engaged actively in dealing with and clearing away of any problems, real or perceived. Lily chose to distance herself from any possibility of relational concerns remaining between herself and her husband. In fact, Lily would not talk of anything with her husband that would either distress him or herself.

In addition to Attig's discussion regarding resolving old concerns or problems, Adrian Tomer and Grafton Eliason (2000) present a model of death anxiety including three determinants, namely past-related regrets, future-related regrets, and meaningfulness of death. Their description of past-related regret refers to an awareness of unfulfilled aspirations that would include unresolved issues with loved ones. Tomer and Eliason further define future-related regret as an awareness of the "inability to fulfill basic goals in the future" (p.5). A future-related regret, then, suggests there is no more opportunity to make decisions in one's life that would effect change. Their descriptions are consistent with the findings in this study. For seven of the eight respondents there were identifiable past-related regrets propelling them toward resolving those concerns.

While there was future-related regret evidenced for each respondent as it pertained to perceived future losses, there was also a need to make the most of the remaining time each had with his or her loved one. Terry exemplified this as he engaged his sister repeatedly over the months he interacted with and cared for her as she died from brain cancer. He facilitated his sister's need to plan what time she had left on behalf of her young daughter and husband. This was also true of Jan as she considered planning the future both while her husband remained alive and beyond his ultimate death.

Another finding in this study was the need to seek social support both within the family framework and outside the family. This was consistent with the Seeking Social Support coping factor explored by Jacobs, Kasl, Schaefer, and Ostfeld (1994). Seeking Social Support is defined as a conscious emotion-focused and problem-focused coping mechanism (Folkman & Lazarus, 1984) for those who are either bereaved or expecting a significant loss of a loved one. While the bereaved score a bit higher than the non-bereaved, it was found for both that a problem-focused plan in seeking social support minimized psychological distress at follow-up.

For each of the eight respondents who participated in this study, there were statements made addressing the need for help practically, emotionally, and psychologically. Some, like Fred and Becky, were very agitated and disappointed that most people, both close to them and acquainted, did not even inquire about losing their loved one. Norm, on the other hand, was very engaged with others as he attempted to normalize his life and was out-going enough to elicit the much needed social support. As Norm was also willing to look at what needed to be done and follow through, he was engaging another problem-focused coping mechanism that had been found to reduce separation anxiety and the potential for depression at follow-up (Jacobs, et. al, 1994).

Results Contradicting Prior Research

While there certainly were many similarities among the individual respondents lived experiences: they were losing a loved one to what seemed an untimely death. It became apparent as the interviews progressed that to suggest their suffering followed a linear progression would be inaccurate. Stage theorists such as Kubler-Ross (1969) have promulgated a theory that human beings follow a prescribed pattern of behaviour when experiencing grief. It has been suggested (Corr, 1993) that there are considerations beyond the five-stage model Kubler-Ross postulated. Those considerations are that those who are dying and those who are struggling with the anticipated death of a loved one must be recognized as vulnerable yet resilient, finite yet adaptable, mortal yet lovable. Corr indicates a need to include both the universality of a person's grief experience as well as the individual experience.

Without the opportunity to speak of their personal experience and how they were coping, the respondents each had the potential to remain in the grief that had surrounded them. With the opportunity to speak and be heard, there is, as well, an opportunity to be transformed within the experience.

New Findings

Up to this point little has been done to include both qualitative information and quantitative data in one research project to discover more about the lived experience of individuals expecting the death of a loved one due to terminal illnesses. There has, as well, not been a study including the qualitative and quantitative elements that provides data from two separate interviews. This is a new form of study within a subject area needing greater exploration. It is due to the unusual nature of this research that the findings are unique. Though not each of the specific findings is new to the body of

research available, there is a more in-depth look at the specific themes as they pertain to this sample's lived experience.

Of the twenty-two themes generated within this study, only six are specific to anticipatory grief while the rest are at least shared with conventional or bereavement grief, if not exclusive to conventional grief. First, all respondents experienced emotional responses unique to their expected loss as opposed to the responses after a death. There was significant anxiety for some as they faced a future without their loved one. Second, most of the respondents demonstrated a need to resolve old problems/concerns/issues in the time their loved one remained alive. Though all respondents did comment in some way about the resolving of past concerns, seventy-five percent actually were working for resolution. Third, most of the respondents recognized the relational changes evidenced as their loved one physically and psychologically declined. Generally those same respondents alluded to the change in roles and recognized some fear attached to the changes. Fourth, more than half of the respondents found it necessary upon diagnosis of their loved one to generate information in an effort to find some information pertinent to bringing about cure or improved health for their loved one. In some cases there was an expectation of stumbling upon new and overlooked medical miracles. Fifth, there was a need to focus exclusively on the loved one for the remainder of the loved one's life. In twenty-five percent of the cases there appeared to be an extraordinary need to capture every nuance of the loved one's being. Last, nearly half of the respondents anticipated how life would be without their loved one present.

While trusting God and existential understanding are not necessarily specific only in anticipatory grief, it was never the less noteworthy that all respondents leaned heavily upon their faith to sustain them and attempted to find some meaning or purpose for the

loss in their lives. In conjunction with the quantitative data and the thematic evidence, most respondents presented clinically with a questing to discover how their loss could be interpreted in a positive light by finding something beneficial or reasonable in it.

Contribution

It is, in my estimation, an asset to the body of literature to have produced a research project that includes a body of information from three sources (a) Content Analysis, (b) Quantitative Data, and (c) Clinical Observation. In the researchers exploration of the present literature, there was little available that provides such a rich source of understanding. This descriptive research, within a larger context, has the potential to advance our understanding and expertise in the area of grief counselling.

As we understand the lived experience of the grieving, the need for using theoretical constructs that allow for the greatest benefit to the griever becomes apparent. This is best served through meeting their need for making meaning during a time that is an emotional mine field. It is not only for the sake of understanding that the author would propose an emphasis on a Meaning-Management model. It enables an individual to enter into a transformative process that motivates individuals to embrace their life, as well as the lives of others, in a manner that is conducive to greater growth and a fuller appreciation of their personal values, beliefs, and system of understanding.

Limitations

One primary limitation to this research project is the small sample that was involved. While the content analysis and quantitative data do provide continuity along with the respondent's lived experience, a larger sample would provide more conclusive information. In addition, a longitudinal study would have enriched the findings a great deal and would have, perhaps, demonstrated greater shifts in coping strategies.

Another limitation to this study includes the limited cultural representation. While this study was too small to well describe the cultural differences in struggling and coping with the anticipatory grief of having a loved one die, a larger sample including a broader cultural representation would have allowed the researcher insight into the similarities and differences among a greater population of peoples. This particular study had too much of a Western representation to be applicable across other populations.

In the early stages of this project, it had been a goal to explore more specifically the coping strategies implemented when a middle-aged spouse loses a husband or wife to an untimely death. There is a great deal of research discussing the challenges for parents when they have a young child die and, of course, a large body of research has been accomplished regarding the dying of the aged; but little exists that addresses specifically the loss of a husband or wife during the years of mid-life, roughly 35-55 years of age. While this study does include some younger respondents, often the loved one who is dying would naturally be expected to be in ill health and perhaps dying, especially when older. There is a hope that further exploration of this combination of qualitative and quantitative information would yield even more useful information.

Implications for Counselling

The implications for counsellors, as well as other helping professionals, are broad. I believe counsellors, pastors, and other helping professionals must become equipped to help people grieve in healthier ways. As the researcher prepared to embark upon this project, it became abundantly clear that there were few resources for talking openly about dying pre-bereavement. We have systems in place to help the bereaved, those mourning post-death, but few systems exist to help someone anticipating the death of a loved one. It would be very useful for there to be written resources available to allow counsellors,

pastors, physicians, and laypersons to learn about the dynamics of an anticipated loss. It would also be very useful for there to be programs within training institutions to educate those in helping professions to reach out, to listen, and to enable the often isolated and distraught individuals they come in contact with.

We, as professionals, also have the responsibility to leave the rigidity of super-imposed systems of understanding to allow our clients to experience their losses in the unique manner in which they find themselves. It is important that we do not add an additional burden upon them by expecting them to fit within the identifiable patterns currently held. We will offer each individual we work with the opportunity to gain a vision for their future in a positive manner, one that promotes a transformation in their thinking and experience.

In light of the findings, the researcher has proposed a set of guidelines for helping professionals to further attend to the unique needs of the person who is anticipating the death of a loved one.

1. Due to the heightened emotional responses, counsellors need to facilitate the sorting out of different emotions so that they can better cope with the complex and often overwhelming emotional reactions.
2. This research demonstrates most respondents struggled with past concerns and issues that were yet unresolved. Therefore one need of professional counsellors is to facilitate discussion toward resolution of issues. If this work is done during the period of anticipatory grieving, individuals are less likely to be as troubled when death finally claims the life of their loved one.
3. There is a need to encourage discussion about role changes both intra-family and external to the family. These role changes may include unique familial relationships

- (husband-wife, mother-daughter, father-son, etc.) as well as support roles and financial roles. There may as well be a need to encourage an exploration of the family system's concepts of roles, rules, and boundaries.
4. Professional counsellors have a task to encourage balanced hope for a miracle with preparedness to accept the inevitable to help individuals avoid bitterness. There is a delicate balance to be weighed in authentic helping with promoting hope yet assuming responsibility for encouraging individuals to look beyond the hoped for miracle to meet the relational and practical needs still present.
 5. Professional counsellors must attempt to help the loved one to learn how to cope in the absence of the dying family member. As well, there is a need to broaden the scope of individuals who demonstrate a lack of self-care for themselves as well as care for other family members while they focus exclusively on the needs of the dying loved one.
 6. Professional counsellors can encourage individuals to engage in a process of making meaning, such as Wong's Meaning-management model to learn how to (a) Mourn the loss, (b) Accept the loss, (c) Adjust to the loss, and (d) Be transformed by the loss as the individual begins to "re-author one's life story".

Summary

Anticipatory grief is a universally common process that engages an individual physically, psychologically, and spiritually in a potentially adaptive process over time. This research project sought to explore the lived experiences of eight respondents anticipating the death of a loved one to terminal illness. There was also an opportunity for respondents to explore existential questions such as "why me?" and "why now?" as well as spiritual questions such as "where is God in the midst of their expected loss?"

The Content Analysis of the interview data provided twenty-two themes with only six of them primarily addressing anticipatory grief. These themes included (a) experienced anxiety and fears related to anticipated death, (b) a need to resolve old concerns, (c) a recognition of relational changes over time, (d) a need to discover new information that might lead to finding a cure, (e) a need to focus exclusively on the loved one for the remainder of his or her life, and (f) attempting to anticipate what the future would be like practically without the loved one present. Proposed implications for counselling are:

1. Counsellors need to facilitate the sorting out of different emotions so that they can better cope with the complex and often overwhelming emotional reactions.
2. Counsellors need to facilitate discussion toward resolution of issues, past, present, and future.
3. Professionals need to encourage discussion about role changes both intra-family and extra-familial.
4. Counsellors have a task to encourage balanced hope for a miracle with preparedness to accept the inevitable to help individuals avoid bitterness over disappointments.
5. Counsellors must attempt to help the loved one learn to cope with life after the death of the loved one.
6. Counsellors can facilitate the restructuring and management of personal meaning so that the loss can be transformed and integrated into their life story.

While the individual results are not necessarily new, what is new is the value of having data from a variety of sources to create a portrait of the lived experience of an individual who has a loved one that is dying. Beyond that there is a need to help people who grieve, such as the respondents in this study, to express their sorrow, concerns, and

fears as well as help them learn in greater ways how to make meaning out of extraordinary pain.

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APPENDIX A: Clinical Impressions

Respondent 1, whom I will call Susan, is a 51-year-old Caucasian female that I have had a friendship with for over 20 years. Susan was invited to participate in this study when her mother-in-law became critically ill. Susan's mother-in-law (age 82) had been diagnosed with the early stages of emphysema several years ago. Approximately 6 months prior to Susan's participation in this study, her mother-in-law was told by her physician that her condition had become terminal.

Susan and I met in her home for the first meeting and in my office for the second meeting. She was her typically warm self when I arrived for the first interview, however it was immediately evident that she was prepared to provide facts but was not particularly emotionally engaged when speaking of her mother-in-law. What made this most noticeable to me was that though our relationship is a safe one for her to be vulnerable and her relationship with her mother-in-law is a very close one of over 20 years, Susan was speaking as though in the third person about a situation quite removed from her.

Throughout the interview, Susan continued to remain somewhat separate from her emotions. She spoke highly of her relationship with her mother-in-law and was seemingly open about her concerns for her husband as he was losing his mother. Not until after the formal part of the interview, when the audiotape was off, did Susan begin to emote at all.

Our second meeting was conducted in my office. Susan was markedly different from the first interview. Her emotions were more evident from the start and she was more talkative. Susan was still detail oriented with the facts surrounding the dying of her mother-in-law but was visibly moved. At the end of our second meeting when we debriefed, Susan commented that she had few opportunities to talk about how she is

feeling and coping with the upcoming death of her mother-in-law. She also commented on her appreciation of an opportunity to talk.

One area that was noteworthy to me was that Susan did not mention her faith in God even once during either interview though the quantitative data does suggest her reliance upon Him. What makes this specifically noteworthy was that generally her conversation is peppered with references to God.

Respondent 2 is a 55-year-old male Caucasian (I'll call him Fred) who is married to Susan. Fred's mother was diagnosed with emphysema after more than 50 years of smoking heavily. Not until about 7 months ago was his mother diagnosed as terminally ill, and it appeared imminent.

As with Susan, we met in his home for the first interview. Fred was very attentive in conveying accurate information; however he was also very angry. Fred repeatedly berated the cigarette companies for faulty advertising and creating addictions for people like his mother.

Fred and Susan live about 350 miles from his mother so he travels back and forth frequently to tend to her growing needs for care. Of course, his mother desires to stay in her own home; however her declining health causes her to move back and forth between the hospital and a convalescent care facility. This circumstance, coupled with his mother's suffocation from the emphysema, raises Fred's tension level and increases his anger toward the cigarette companies. Throughout the first interview Fred agitatedly made reference to the criminal behaviour of the tobacco companies.

Fred's primary emotion was simmering anger. He softened a bit as he spoke about how a person actually suffocates as he or she dies of emphysema. Relating the specifics of the dying process served to further agitate him.

Fred commented at length about the support of his very large family as they rally together to encourage one another and provide practical support for their dying mother. He was disappointed, however, by the absence of support from friends. Fred seemed to understand that the friends were not equipped or were perhaps afraid to ask questions about his mother and his family from a cognitive perspective, but he experienced pain and the friends' reticence to reach out. In fact, this lack seemed to perplex him as we continued our interview.

The second interview was conducted in my office. The tenor of Fred's responses included the same simmering anger at the tobacco companies as well as the same sense of perplexity that others did not ask much about his mother or about himself. However, this interview included a more primary emotion as he spoke of his mother's difficult early years and her long suffering throughout life. Fred demonstrated admiration for his dying mother and was willing to be more emotionally exposed.

During both the first and second interview Fred continually made reference to his trust and faith in God to care for his mother. As we finished our second interview, Fred did comment that talking about his mother and how he was coping with her dying had served to engage his emotions more fully.

Respondent 3, whom I will refer to as Lily, is a 52-year old Chinese female whose husband was dying of brain cancer. Her involvement in this study occurred through her pastor's referral to me. What was initially of interest was Lily's desire to audio tape our interview that I was already audiotaping for research purposes. As we continued on, it became clear that Lily depends a great deal on others' interpretations on events and attention to detail to help her.

Lily and I began the first interview in her home, at her request, which allowed her to stay close by her husband in case he had a need of any kind. Lily's home was remarkably quiet, most unusually quiet. We sat across from one another at her dining room table. It was as though the table allowed for safety. Lily was very composed as she answered each of the questions quietly and with emotional reservation.

Lily had little recollection of details; regarding the events leading up to the diagnosis as well as after, she referenced often her need for her children to be present in discussions with doctors and other professionals, hence the audio tape.

What became evident throughout our time together was Lily's fear of her husband dying and of her being left alone. She was tenacious in hanging on to any possible hope of his survival. For instance, she had heard of one other person with the same form of brain cancer who had survived far beyond the odds. This possibility became Lily's lifeline.

From an emotional standpoint, Lily was non-emotive, though it was clear by the pain etched on her face that she was suffering. Not until our second interview one month later did she express more open emotion. During the interview Lily needed moments to recover her composure. If her husband were to come into the room, Lily would quickly contain herself so as not to distress him. When the interview was formally over, Lily was interested to know more of my own personal experiences with death. As I related to her my experience with my husband (Appendix B), she was a bit more open. She described not having anyone to talk to openly about her husband's dying. In fact, she and her husband do not speak of the seriousness of his illness at all, let alone the progression of his terminal illness. Her sole focus was to spend as much time as possible with him while

there was an opportunity. The second interview concluded with Lily thanking me for allowing her to talk and for sharing some of my experience.

Respondent 4, whom I will call Norm, is a 56-year-old male Caucasian whose 30-year-old daughter was dying of brain cancer. His married daughter had been diagnosed as terminal 6 months prior to our discussion. Her ordeal with brain cancer began about 2 years before but the cancerous tumours had been operable at that time providing an expectation of a cure. By the time Norm's daughter was finally diagnosed as terminal, she had physically deteriorated to a point where Norm was not surprised by the prognosis; upset, but not surprised. His immediate reaction to the event was to gather all pertinent information about what to expect and to provide support for his immediate family, including his wife, two sons, son-in-law, and granddaughter.

Norm found support from others who would inquire about how he is doing and he attempted to maintain some normalcy in his life by continuing to work and engaging in regular physical exercise. Norm also sought out research projects to participate in, such as this one, to help researchers learn how to help others. His son, Terry, referred Norm to this study.

As Norm and I met during the first interview at his workplace, he was very cordial and wanted to pursue conversation not necessarily relevant to the study. It appeared he needed to prepare himself for speaking about his daughter's dying. During the greater part of the interview, Norm was factual and very composed. He resisted discussing his feelings, preferring to stay with topics where he could remain more objective. Those times when he did address his feelings, there were emotions surfacing that he struggled to contain.

While Norm generally accepted his daughter's dying as reality, he seemed somewhat disconnected from the relational aspect between he and his daughter. For instance, he didn't believe his relationship was any different with her than before her illness, other than in practical ways. Therefore, there weren't really any issues to resolve. Unlike his son Terry who was with his sister round the clock, Norm was with her at prescribed times. It didn't appear there was much relating between father and daughter.

The second interview one month later was again in Norm's office. He seemed a little more eager to start the interview right away and did not particularly want to linger over a debrief time. During this interview Norm mentioned that his estranged marriage was reunited after the terminal diagnosis of daughter as they sought to endure this pain and stand together in helping their suffering child.

Norm also made it clear that he wanted to accept his daughter's dying with some meaning attached to it. A vociferous reader, he mentioned several times L. Stroebel's *A Case for Faith* as he tried to trust God for the why of her death.

He commented he is generally more aware of pain and dying around him. Norm has also appreciated the opportunity to talk more openly about his daughter's dying.

Respondent 5, Becky, is a 56-year-old Caucasian female who is wife to Norm (respondent 4) and mother of Terry (respondent 7). Becky was also mother of her 32-year-old daughter who is dying of brain cancer.

When Becky and I met the first time, Becky presented as fairly intense yet confused. Her confusion and difficulty focusing required me to read aloud from the pen and paper research instruments each question, as she could not understand when she attempted to read them. Even when I read them aloud, they sometimes needed to be read one or two times more.

While Norm was more factual and somewhat distanced from his emotions, his wife Becky was not. She seemed to be at once slogging through thick mud to concentrate and steeling her emotions so as not to fall completely apart. There was weariness about her, a resignation.

Becky also spoke as though she was accepting of her daughter's dying but would then speak of God healing her through a prayer session. It appeared that Becky was clinging tenaciously to her faith in God in whatever He would allow but also clung to her belief in her daughter's healing.

Becky expressed a similar concern to her son Terry as she related the difficulty of resolving some family issues around the early childhood molestation of her daughter by another son. She was also struggling in her role as caregiver to her daughter when challenges arose with her son-in-law. Her responses indicated some difficulty in interpersonal relationships.

Another concern for Becky was those people in her social network who were reticent to ask about her daughter's condition or how she was really doing. As a result, Becky was becoming more and more isolated in her daily life. (Some feedback her son mentioned was that mom was extremely emotional after the first visit due to her looking with more clarity at the prospect of her daughter dying.)

When we met a month later to continue on, Becky still required my help with the research instruments. She appeared somewhat more present than the first meeting.

During this meeting she made reference to a family member who believed she had a word from God about healing Becky's daughter. Because the family member hadn't communicated this information when it first arrived, Becky expressed anger that there was a lost opportunity. She also had ambivalent feelings toward those she knew who

remained reluctant to speak openly with her. According to Becky as we concluded, it had helped to talk even though it brought her face to face with the reality of her daughter's dying.

Respondent 6 is Jan, a 70-year-old Caucasian woman whose husband is dying of a form of Lymphoma (cancer of the blood). We originally met through a Parkinson's disease support group meeting that she attends, as her husband also wrestles with that condition. Those maladies, notwithstanding, he also had been afflicted his entire life with a bi-polar condition. While he has struggled for many years, it was just less than two years ago that he was diagnosed as terminal due to his lymphoma.

Jan and I met both times in her home, at her request, to make it easier for her to attend to her husband. Jan's entire focus was to keep her husband comfortable and minister to his needs. She was not willing to leave him in the care of others for any reason, so she was more and more isolated as time goes on. For her, our times to meet were as much an opportunity for her to have company as to be involved in this project.

Jan has a family who provides some support but Jan and her husband are left to themselves a good deal. Due to Jan's own medical problems, the isolation is difficult from both an emotional and physical perspective.

While Jan did make note of a belief in God generally, she did state that she was unable to understand why these things were happening. Jan gave the impression of one who is used to taking care of herself, a "pull-yourself-up-by-your-bootstraps" kind of woman. She appreciated the pastor from the church she doesn't currently attend dropping by to check on her and her husband.

Jan's emotional nature seemed overly well contained. She was completely non-emotive and rather matter-of-fact about her life. She did express some concern about the financial ramifications of the assorted medical expenses and how to plan for the future.

The second interview, one month later, was very similar to the first. While Jan was hospitable, she was markedly disconnected from her emotions. At most, she presented as a very overwhelmed and tired woman.

Respondent 7, whom I will refer to as Terry, is a 32-year-old Caucasian male. Terry is a client of the researcher and had asked to participate in this study after having come to see me about how to cope with his grief over the dying of his younger sister. His sister had been diagnosed with terminal brain cancer after an approximately 2-year struggle with operable cancerous brain tumours. Only just within the past six months had the cancer metastasized to an inoperable status.

As his sister's condition worsened, Terry was aware that his coping mechanism of seeking escape and relief through drugs and alcohol was ineffective. He sensed he needed to seek God's help instead. It was at this point Terry came to see me.

Terry was fairly accepting of his sister's dying and wanted to be as helpful and present for her as possible. He had left his employment in order to be as available as possible.

Terry was emotionally connected through both interviews, which were conducted in my office. The most difficulty he seemed to have pertained to problematic family dynamics with an older brother who had molested the sister who was dying when she was a young girl. That was only made known by the sister after she learned she was dying. This information was, as yet, unacknowledged by the offending brother. For Terry, there was a great need for his brother to resolve this issue as well as others Terry perceived

might yet exist between him and his sister. It was his impression, however, that the relationships among other family members and him had improved as they all supported one another in this time of crisis.

It seemed to the researcher that Terry was reasonably able to articulate his feelings as he understood more of why they existed and where they came from. The sessions we had been in prior to his interest in this study provided him some insights that seemed to promote a greater sense of purpose in his experience with his sister.

As Terry and I concluded our time together, he asked if his parents could also participate in this research. He also commented on the usefulness of being encouraged to speak openly of his experience.

Respondent 8 is Patricia, a 42-year old Caucasian female whose mother was dying of Chronic Pulmonary Obstructive Disease (CPOD). Her mother was diagnosed with CPOD some six years ago but was diagnosed as terminal approximately one year ago. Patricia's mother smoked for most of her life and was in poor health to begin with, so the original diagnosis was no surprise. When the terminal status was given, Patricia immediately fell into a care-giving role, as that was both her natural inclination and her professional role as well.

Patricia asked to participate in this study after she heard about it through our counselling work together. Because Patricia was a nurse in cancer care, she was routinely exposed to death and dying. As a result, she initially presented as emotionally disconnected from her own expected and present losses.

As Patricia and I talked during the first interview, she gradually began to engage emotionally. She mentioned the lack of emotional support from her husband and other family members. Rather, she was expected to be the emotional and physical support for

the rest of the family as well as provide those essentials to her dying mother and bereft father.

Patricia had experienced a sense of isolation in her care-giving role and recognized the significance of her reaching out to others, allowing her an opportunity to talk to others. She mentioned after our first interview that she appreciated the opportunity to be heard and to know it was acceptable to feel.

Throughout the first and second interviews Patricia referenced her faith innumerable times as a help to her as she was losing her mom. While she did not expect her mom to be healed, she did hope for more time with her.

One area that caused angst for Patricia during both interviews was the unresolved issues with her mother over decisions made when Patricia was a much younger woman. There had been harboured anger and resentment by Patricia and her mother that Patricia had decided to leave unresolved, as she believed there was nothing to be gained by bringing them up. Any unpleasantness by her mother Patricia had chosen to overlook, but for the most part there appeared to be an unspoken truce.

The second interview was more emotional for Patricia. Her mother had been recently hospitalized; at which time it appeared her mother would not survive. As was typical for her family, she assumed the primary care role as well as trying to maintain her immediate family and work her job. Patricia was stretching herself very thin and the toll it was taking on her was noticeable. Her emotions were right on the surface, yet she still struggled with maintaining a calm detachment while she answered the interview questions. It was as though Patricia needed permission and opportunity to feel her hurt.

APPENDIX B: Personal Story of Coping

My own experience of coping with grief began approximately nine years ago when my husband was diagnosed with the virus Hepatitis C that was supposed to be terminal within 2-7 years. The prognosis was not good specifically due to the small remission rate amongst those who participated in the traditional pharmacological regimen. With the treatment the remission rate was set at between 10% and 18%, low enough to be considered a death sentence while no treatment was, at that time, a likely death sentence. In either case there was little hope of a reprieve. For a man who works as a contractor in home building and is very active within his own personal life in activities such as building our own home, chopping firewood, maintaining twenty acres of property and hunting, this was a huge blow. He is also a man who has a very sensitive, creative side that is manifested in writing poetry and art. The blow was both psychological in nature and physical. What I recall of the first days was a shocked man, even numb at times, who demonstrated awareness that life was irrevocably changed. I was also aware that my husband's response and my own were significantly different.

Observations of my husband were that his attempt at coping with such devastating news included adopting a fatalistic outlook on life in general. As well, he seemed to give up on looking forward to meaningful relationships and began to absorb himself in his hunting pursuits. I interpreted this absorption at the time as a distraction from the rigors of thinking. However, in retrospect I am seeing this behaviour a bit differently. Hunting for my husband has always been a significant part of his life. He was raised within a family of hunters dating back generations. He hunted large game animals and upland game birds with regularity for as long as I had known him with a similar pattern of

interest from year to year. It was and still is a common denominator of communication between himself and many of his male friends. There was always a passion for hunting but when he received his diagnosis of Hepatitis C the passion turned into something more akin to a compulsion. It was as though he became fixated on this activity in the detailed planning he engaged in as well as the trips he participated in. More and more the books he read were hunting tales, what poetry he wrote occurred within the context of a hunting trip, his conversations were peppered with hunting experiences or the next anticipated hunt, and less were his interests in pursuing relationships or experiences outside this passion.

Today I am more aware of other possible reasons for the increase of his interest in hunting other than using it as a distraction. It is possible that the hunting did something for his psychological well being such as providing moments of reassurance that he was still engaged in life in a vital way. In fact he was still very vital physically. He may also have felt he was still powerful as a man. As the word of his illness spread amongst our friends and some family, there was a great deal of emphasis on what could be a future reality (i.e. prolonged sickness, death). His own need to see himself as strong and manly may have been somewhat undermined by well intentioned others. It is reasonable to conclude that for him the hunting became a tool for emotional survival. Though my husband is creative and physically active in his personal and professional life, his background didn't actually prepare him to cope with such a loss strictly intellectually. Rather, he was better prepared to address this adversity by becoming more aggressive physically.

This was also a time of watching my husband emotionally deteriorate. From my perspective he lost his motivation to stay connected interpersonally and was often lost

within his own thoughts. Relationships with family could be strained beyond the norm and there was awareness that the man who had always been husband and father was now quite distant. Cognitively he seemed to experience a swing between depressive symptoms and agitation. Emotionally, he seemed to be fearful at times while at others he was nonchalant about life in general. His thoughts and emotions could be erratic and generally difficult to predict.

While my husband appeared emotionally disconnected from others unless focused on his hunting, I was different altogether. When I heard the news of his terminal condition it was as though a bell had gone off in a boxing ring with me coming out swinging. I moved into high gear immediately. There was, for me as well as my husband, the shock of the moment when we learned that life was to be different than we'd planned, however we were dramatically disparate in our reactions.

High gear, for me, included engaging in on-going research into a virus that appeared ultimately deadly. I wanted to know about any other treatment options including the traditional Western approach as well as the non-traditional approaches. I read anything I could find, talked to anyone who knew more than I did, and believed that he did not have to die just because one doctor had said it was to be so.

Also, over the next one and one-half years I started a support group for those with Hepatitis C and their significant others (my husband did not participate). This group has since grown and become a vital source of information and support to many in the local community especially as Hepatitis C has become better known. It also provides a link of one person to another in a situation that lends itself to the isolation of individuals. Initiating the inception of a support group required contacting existing state and national organizations that had already begun to discuss Hepatitis C in some capacity. It also

required finding the location, advertising, and setting protocols for how to reach out to those who were hurting from an absence of information. It further required that my own skills in relating interpersonally must be honed. I was fortunate at that time to work within an organization that was willing to provide what resources they could, both financially and logistically, to promote an environment where frightened individuals with this virus could receive support.

Within that period of time I also created two separate conferences to bring together both allopathic and naturopathic medical practitioners to educate other practitioners as well as laypersons about current research trends and treatments. Because I wanted the most current and up to date information and cutting edge procedures more available, I assumed others did as well. Also, I had observed in my research that there seemed no discussion between practitioners of different points of view regarding this deadly virus. There was only one treatment regimen available and it made its consumers so ill that the cure was too often more difficult than the viral progression itself. With such a low remission rate, it did not appear to be a very viable option though it appeared the only one. One of the most difficult issues for the consumer was that information seemed only available to physicians.

With those considerations at hand, I began the process of talking to pharmaceutical companies about sponsoring a conference event, speaking with allopathic and naturopathic medical practitioners to line up speakers, arranged the location, and did all the assembling of advertising. I also compiled packets of information from a variety of sources that included current trends of treatment, dietary considerations, and resources. In addition to creating these conferences, I also had the opportunity to gather the various practitioners and a variety of supporters to a dinner event prior to the conference itself in

the hopes of encouraging less rigid discussion of the virus as well as building healthy working relationships between them. This also included seeking funding, providing special invitations, and negotiating with the appropriate restaurant for this formal event. During this time I not only gained more knowledge of the virus but I gained a great deal of experience and confidence. My own coping mechanism was to engage in a primarily intellectual avenue. My mind was engaged, I was learning a great deal, and my hope for an alternative grew as I pursued this direction.

It was interesting to note how my husband's family reacted to his illness. They were, of course, very upset but other than asking how he was feeling at any given time, they did not seem to want any information. Part of my own work of putting together the conferences was to videotape the programs and gather information for conference packets. These resources were of little interest to his family though they were proffered to them numbers of times. It was as though if nothing were looked at there would be no negative outcome. They were actively engaged in what has been called a "conspiracy of silence". This was unfortunate as conversation during that difficult time with his family could have helped him to grieve and cope with his own losses in a more healthy way.

Throughout this time I was tending to my husband's now markedly changed dietary needs and providing for the emotional/physical needs of our three young children. His dietary changes involved providing a diet high in produce, fewer highly cooked foods, fresh raw juices, and a variety of supplements. For us this was a marked change in our routine. Much thought and energy was required to shop differently, cook differently, and enjoy food differently.

Looking back now I can recognize that I actually took greater ownership of his illness than he did in some ways. It was as though I lived in a highly energized and

motivated state with few needs for respite. At that time our three daughters were 13, 14, and 15 years old. Their needs for reassurance and learning how to cope with what seemed to be the loss of their dad required a great deal of energy and thought. Each of them struggled uniquely with anger, tears, and acting out in ways that required discipline through this time. Though they didn't know how to understand the changes in their lives, they were each wrestling with an uncertain future with their dad not in the picture. They looked to us to establish the norms of how to cope.

In our own ways neither my husband nor I were fully willing to accept what appeared to be the inevitable. He chose the physical route of coping and I chose to fight back intellectually. For both of us, I believe, survival required action even though of different sorts.

Since that time of diagnosis, we have consulted with a myriad of specialists and my husband has had a more favourable long-term prognosis. Now doctors are suggesting he may live much longer than originally expected, as his disease process is slow to manifest. It is interesting that with the life sentence he has now, his coping mechanisms are still in evidence. In some ways the more favourable news did little to abate the fatalism learned at the time of original diagnosis. While our coping styles are essentially the same as when in crisis, we have both been more relaxed up until three years ago.

At that time a series of five deaths either within or extremely close to our family were occurring which heightened the need to escape via distraction for my husband. For him, these losses were devastating as these were individuals close to him and he was connected with most of them in their passing from life to death. The first death was that of his best friend who was struggling with terminal liver cancer due to Hepatitis C. His friend has been diagnosed after my husband had but the viral process was much swifter.

After his own treatment regimen failed, his liver became cancerous and within a year he died. My husband was faithful to stay close to his friend supporting him emotionally and physically whenever there was need. They had both hunted together so my husband took his friend for his last hunt just months before he died. His sensitivity toward his friend was very evident and when the friend died my husband did seem to grieve in healthier ways than when he had himself been diagnosed.

The second death was that of his father. His father's own diagnosis with brain cancer was made just after my husband arrived at the family home out of state to embark on another hunting journey. His father had experienced a series of minor car accidents and would fall for no seeming reason requiring a decision to be made to have his dad checked out before leaving for their two-week trip. The diagnosis was made within a day that my father-in-law had metastatic brain cancer though there was never any discussion amongst family or physicians that this cancer could be terminal. The cancer grew quickly and was not at all halted by the radiation he had begun to receive. My husband remained with his dad until his dad died 6 weeks later. My husband was present when his father took his last breath on Thanksgiving Day, 2001. The day dad died was very surreal. As it was Thanksgiving Day, there was a desire by some of the family to let it be one that honoured dad by engaging as best we could in the traditional experience including cooking the traditional family feast and putting out the best china, silver, and so on. However, we were all in shock and overall not able to do much more than go through the motions. It is interesting to me that even in the critical period of time over those 6 weeks no one was seemingly willing to discuss death as a possibility besides my husband and myself.

Less than 6 months later another death occurred very close to the family. This was an older friend of my father-in-law who my husband was attached to. His diagnosis of liver cancer was only two weeks old when he died. My husband was also with this man as he struggled with his last days but still no conversation was made about the possibility of death. This man's children were not connected to their father relationally and were not involved at all with him in his last days. When death came quickly, there was no preparation.

Just another 6 months after the death of the family friend, my husband again went with family and friends out of state to hunt big game. After having been gone just days he called me late one evening to tell me another close friend, only 50 years old, had died suddenly of a heart attack after a long day of hunting. My husband had attempted to resuscitate (unsuccessfully) this man over a period of 40 minutes with no response. My husband was dazed by the experience. Not only had he attempted resuscitation but the authorities were involved creating a greater drama over the next few hours. The days after that included coming home, planning a funeral, and attempting to answer questions the family had. My husband was more withdrawn than ever at that point.

The trauma of these experiences coupled with my husband's own awareness of personal mortality have greatly increased his anxiety. He lives more in the moment and generally stays away from considering the future. Just recently a diagnosis was made that he may be struggling with Post Traumatic Stress Disorder. The last death was not as close to him as to me. My stepmother died suddenly on a visit to the hospital for other reasons. While that death did not impact my husband personally, still it was for him just another example of how death strikes at any time and appears fickle in who it chooses.

For me, these losses are probably most significant in how they impacted and have changed my husband. I am learning how I now need to function to encourage, help, and minister to a man who has been so altered by life circumstances. This can be very difficult at times as I have also experienced these losses though certainly in different way. I'm not sure that I have really had the opportunity to process my own losses as I have been so absorbed in helping those around me. While my husband's experiences have been devastating to him, in some ways they have also been devastating to me. I lost the same people he did, though differently, but I also lost the person I knew as husband when he withdrew into his fatalistic world. What has been my own lifeline is the awareness that my faith is richer and I have greater reliance on God to help me through the struggle. It seems that I experience less death anxiety, as I am dependent on my Creator. It has, in fact, helped me to recognize how diverse are individual coping styles and how important it is to have a measure beyond ourselves to help make meaning of something that seems so senseless.

APPENDIX C: Informed Consent

Informed Consent Form for Effects of Coping on Anticipatory Grief

PURPOSE: The purpose of this research is to explore the roles of existential and spiritual coping on the experience of anticipatory grief.

PROCEDURE(S): You have been invited to participate in this research study as a volunteer with the goal of better understanding the role of coping on anticipatory grief. At no time are you obliged to complete the research project. By agreeing to participate you consent to the following: 1) to participate in two audio-taped semi-structured interviews, 2) complete four questionnaires on two separate occasions including the “Ways of Coping” questionnaire, the “Death Attitude Profile-Revised”, the “Revised Death Anxiety Scale” as well as the “Personal Meaning Profile”, and 3) complete an evaluation form following the project. You agree to meet on two occasions lasting approximately one and a half hours in length to complete both interviews and questionnaires. All participants in the study will receive the same interviews and evaluation forms. A random one-half of participants will receive the questionnaires.

RISKS/BENEFITS: Though there are always potential risks in any research, great care and professional standards will be implemented throughout this research to minimize any difficulty. It is, however, expected that you may gain: 1) an ability to cope more effectively with your current experience, 2) experience therapeutic benefits such as a more relaxed and calm peace of mind, and 3) an opportunity to provide information that may help others dealing with similar circumstances in the future. It is also understood that no monetary exchange will occur for either harmful effects or remunerative purposes.

CONFIDENTIALITY: Any and all information discussed during the interview process and obtained from psychological assessments are strictly confidential. Only Debra Ivancovich and Dr. Wong will have access to this privileged data. Any data will be kept under secure conditions for five years at which time the data will be destroyed to ensure confidentiality.

AUTHORIZATION: The above information has been thoroughly explained to me and any questions responded to adequately. I am aware that by signing this form I am under no obligation to complete the research project nor am I releasing any of my legal rights.

_____ Respondent _____ Date

RESEARCHER’S DECLARATION:

I have fully described the nature and purpose of this research project to the above name respondent. I declare that I have received and answered all questions put forth by the respondent to address the purpose and risk/benefits of this study. I also declare that the greatest care and professional conduct will be used throughout this duration of this study and beyond. Furthermore, I assume that the respondent has signed with a legally valid signature.

_____ Researcher _____ Date

APPENDIX D: Initial Letter

First Formal Contact after Respondent Interest

Dear Respondent,

Thank you for your interest in participating in this research project concerning coping with the anticipated grief that accompanies your loved one's diagnosis of terminal illness. The study of bereavement grief (grief that follows death) has been studied at length and has provided much information. This information has helped many individuals, both professionals and those suffering, to better understand the experience and processes of grief.

The understanding of grief in the presence of an anticipated death is less understood leaving many unanswered questions for those facing such a loss as well as the myriad of professionals seeking to provide help and resources. Because this is painfully difficult for the grieving individual, the study of anticipated grief has been undertaken less often.

However, such research has the potential to benefit the participants in several ways. The first benefit in studying anticipatory grief is that it may allow individuals to cope better with their impending loss. As well, professionals seeking to provide more appropriate care for the terminally ill person and his or her loved one will be more aware of the needs of those in their care.

The second benefit to those participating in this study is the potential for some relief from anxiety. For the person suffering in the presence of anticipatory grief, there is often an acute and unsettling mental anguish. Relief may be experienced as a relaxing or calming of the participant's mental state.

The third benefit of participating in this study is the potential for the results to help others suffering in a similar way. Because there are patterns to the way people experience impending loss, it is important for professionals to understand those patterns in order to gain greater insights so they might serve others more compassionately.

In participating in this research you can expect to: 1) engage in two audio-taped semi-structured interviews with the researcher (Deb Ivancovich), 2) complete 4 questionnaires on two separate occasions, and 3) complete an evaluation form at the end of the study.

This study is undertaken as part of a Master's Thesis project under the supervision of Dr. Paul T.P. Wong, director of the Counselling Psychology program, at Trinity Western University. With over 20 years experience working with older adult individuals in individual counselling settings, group settings, and in hospice related circumstances, my goal as a researcher is to ensure, as far as is possible, that respondents are not harmed by their participation.

There is, however, the potential that participation in this study may trigger a strong emotional reaction such as death anxiety and/or an exacerbated fear of the upcoming loss of the loved one. This potential reaction may be the result of answering questions about death.

To counteract the potential risk, the researcher will spell out explicitly that participants will be asked to fill out two death-related questionnaires, the "Death Attitude Profile-Revised" (Wong, Reker, & Gesser, 1994) and the "Death Anxiety Scale" (Thorson & Powell, 1984). As well, a coping questionnaire, "Coping Schemas Inventory" (Wong, 1993) and a meaning questionnaire, the "Personal Meaning Profile" (Wong & Fry, 1998), will be presented to the participant to complete the questionnaire component of the research. Another approach to counteract the potential risk will include a preliminary discussion with the participant to discover his/her attitudes toward death. As well, the researcher will attempt to determine if the participant finds any meaning in the current life situation he/she is in.

To further provide protection for the participants in this study, the researcher will specifically discuss with the prospective participants that they are under absolutely no obligation to complete the study. If a participant does not feel comfortable with taking part in a death-related study, he/she should not participate. If the person agrees to participate in the study but becomes distressed in answering the questionnaires, he or she need not participate any further. If further clarification is needed in order to fill out the questionnaires, the participant may request such clarification from either the researcher or Dr. Wong (Thesis supervisor). If, after completion of the questionnaires, the participant finds him or herself distressed in any way, additional support will be provided by either the researcher or Dr. Wong.

Another protection for the participant in this study is the absolute confidentiality of the individual's identity and the results of the data. This confidentiality will be protected by 1) deleting or disguising any references to names, places, or clues, 2) focusing on the collective themes rather than individual data, and 3) using a coding system to represent each participant. Anonymity is assured as the researcher (Deb Ivancovich) will be the only one to know who the actual respondents are and the researcher is bound by the ethical standards of confidentiality. Files will be held for five years in a locked cabinet at which time they will be shredded to ensure confidentiality. As well, the audiotape and transcribed materials will be destroyed after a period of five years to ensure anonymity.

It is with great appreciation and respect for the individuals impacted by the anticipated loss through death of a loved one that this research is begun. Should you choose to participate you can be assured that the greatest care will be exercised to ensure your comfort and safety. If you have any further questions regarding this research project, please contact Dr. Wong (Thesis supervisor) or myself at Trinity Western University, Graduate Department of Counselling Psychology at (604) 888-7511.

Thank you in advance for your time, energy, and effort.

APPENDIX E: Demographics

Initial Assessment Information

The following information is confidential and anonymous. The purpose of collecting this information is to provide additional demographic data for the research. All information obtained will be used in a summary format only.

Age: _____

Gender:

Male _____

Female _____

Religious Affiliation:

Protestant _____

Catholic _____

Evangelical _____

Lutheran _____

Episcopalian _____

Buddhist _____

Muslim _____

Atheist _____

Jewish _____

Hindu _____

Ethnicity:

Hispanic _____

Caucasian _____

Black _____

Native American _____

Asian _____

Other _____

Education:

High School _____

2-year college _____

4-year college _____

Graduate school _____

Income:

Below \$20,000 _____

\$20,000-\$40,000 _____

\$40,000-\$60,000 _____

\$60,000-\$80,000 _____

Over \$80,000 _____

APPENDIX F: Letter to Clients

July 22, 2003

Greetings to all of my clients,

I hope this letter finds you all well and enjoying this wonderful weather. I am writing you this letter to extend an invitation to each of you to participate in a study I am working on. As most of you know, I completed my coursework for my Master's degree in Counselling Psychology several years ago and have been working on my thesis project to complete my degree during this past two and one half years. My area of study deals with grief and loss which is, of course, something that all of us are touched by in some capacity during our life span. This particular study I have had on hold for much of the past two and one half years as we, in my own family, had five losses within a two year span that required my living with grief and loss instead of studying it. In just the past few months I have endeavoured to pick it up again though the healing in my family continues.

The goal of my study is to discover how people cope with the anticipated loss of a loved one and how such expectations affect their own death attitudes and well-being. The criteria for participation in this study includes 1) being a loved one of an adult who has been diagnosed with an incurable disease that may be life threatening, 2) be over 30 years of age, and 3) the diagnosis should have occurred during the past two years. Participation in the study will involve completing four questionnaires plus an interview at two separate times approximately 3-4 weeks apart. Each meeting will take no more than 90 minutes.

One benefit to the participants of the study is the opportunity to share with an experienced mental health counsellor (myself) about the concerns and challenges of anticipating such a loss. Another more general benefit is the vital contribution to the general body of knowledge regarding coping with anticipatory grief so that counsellors and pastors might be better equipped in helping grieving individuals.

This research project is the final part of my Master's thesis of a degree in Counselling Psychology at Trinity Western University under the supervision of Dr. Paul T. Wong. Dr. Wong is a professor in the Counselling Psychology program at TWU and is also internationally known for his research in death attitudes and grieving.

To show my appreciation to individuals who complete both sessions of the study, I will give a token gift of \$30. I appreciate your willingness to consider this request as well as any opportunities to work with you or someone you know. Please also know that there is no expectation on my part and I completely understand if this is not something you could or want to participate in. Should you have any further questions, please feel free to contact me. Inquiries or responses can be made on my voice mail at the office at 734-8475. I will call you back.

APPENDIX G: Semi-structured Interview Questions

1. How did you initially react to the diagnosis of your _____ illness?
 - *Who else was present?
 - *What was the setting?
 - *What did you do immediately upon hearing the news?
2. How are you feeling now?
 - *How concerned are you now about losing _____?
3. How are you coping with the prospect of losing _____ due to this illness?
 - *How are you emotionally?
 - *What has been helpful for you since _____ diagnosis?
4. What has been the impact of _____ diagnosis on your relationship?
 - *Are you closer now?
 - *Has it caused you to resolve old concerns/problems?
 - *How do you feel toward _____ with this diagnosis?
 - *Has your relationship changed at all?

At the time of the last interview, four additional questions were asked allowing for a time of debriefing as well as determining the perceived merit of the discussion for the respondent. The questions included:

1. How were you after our last interview?
2. Do you believe talking about this topic has helped you or hindered you?
3. Have you openly talked about death?
4. What has prevented it?

APPENDIX H: Death Attitude Profile-Revised

Wong, Reker, & Gesser, 1994

Age: _____ Sex: M _____ F _____

This questionnaire contains a number of statements related to different attitudes toward death. Read each statement carefully, and then indicate the extent to which you agree or disagree. For example, an item might read: "Death is a friend." Indicate how well you agree or disagree by circling one of the following; SA= strongly agree; A= agree; MA= moderately agree; U= undecided; MD= moderately disagree; D= disagree; and SD= strongly disagree. Note that scales run both from strongly agree to strongly disagree and from strongly disagree to strongly agree.

If you strongly agreed with the statement, you would circle SA. If you strongly disagreed you would circle SD. If you are undecided, circle U. However, try to use the Undecided category sparingly.

It is important that you work through the statements and answer each one. Many of the statements will seem alike, but all are necessary to show slight differences in attitudes.

- | | | | | | | | | |
|--|----|----|----|----|----|----|----|------|
| 1. Death is no doubt a grim experience. | SD | D | MD | U | MA | A | SA | |
| 2. The prospect of my own death arouses anxiety in me. | | | SA | A | MA | U | MD | D SD |
| 3. I avoid death thoughts at all costs. | SA | A | MA | U | MD | D | SD | |
| 4. I believe that I will be in heaven after I die. | | SD | D | MD | U | MA | A | SA |
| 5. Death will bring an end to all my troubles. | | | SD | D | MD | U | MA | A |
| | SA | | | | | | | |
| 6. Death should be viewed as a natural, undeniable, and unavoidable event. | SA | A | MA | U | MD | D | SD | |
| 7. I am disturbed by the finality of death. | SA | A | MA | U | MD | D | SD | |
| 8. Death is an entrance to a place of ultimate satisfaction. | SD | D | MD | U | MA | A | SA | |
| 9. Death provides an escape from this terrible world. | SA | A | MA | U | MD | D | SD | |

Existential and Spiritual Coping in Anticipatory Grief -109

10. Whenever the thought of death enters my mind, I try to push it away.		SD	D	MD	U	MA	A	SA
11. Death is deliverance from pain and suffering.		SD	D	MD	U	MA	A	SA
12. I always try not to think about death.	SA	A	MA	U	MD	D	SD	
13. I believe that heaven will be a much better place than this world.		SA	A	MA	U	MD	D	SD
14. Death is a natural aspect of life.	SA	A	MA	U	MD	D	SD	
15. Death is a union with God and eternal bliss.		SD	D	MD	U	MA	A	SA
16. Death brings a promise of a new and glorious life.		SA	A	MA	U	MD	D	SD
17. I would neither fear death nor welcome it.		SA	A	MA	U	MD	D	SD
18. I have an intense fear of death.	SD	D	MD	U	MA	A	SA	
19. I avoid thinking about death altogether.	SD	D	MD	U	MA	A	SA	
20. The subject of life after death troubles me greatly.		SA	A	MA	U	MD	D	SD
21. The fact that death will mean the end of everything as I know it frightens me.		SA	A	MA	U	MD	D	SD
22. I look forward to a reunion with my loved ones after I die.		SD	D	MD	U	MA	A	SA
23. I view death as a relief from earthly suffering.		SA	A	MA	U	MD	D	SD
24. Death is simply a part of the process of life.		SA	A	MA	U	MD	D	SD
25. I see death as a passage to an eternal and blessed place.		SA	A	MA	U	MD	D	SD
26. I try to have nothing to do with the								

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subject of death.		SD	D	MD	U	MA	A	SA
27. Death offers a wonderful release of								
the soul.		SD	D	MD	U	MA	A	SA
28. One thing that gives me comfort in								
facing death is my belief in the								
afterlife.			SD	D	MD	U	MA	A
SA								
29. I see death as a relief from the burden								
of this life.		SD	D	MD	U	MA	MA	SA
30. Death is neither good nor bad.	SA	A	MA	U	MD	D	SD	
31. I look forward to life after death.	SA	A	MA	U	MD	D	SD	
32. The uncertainty of not knowing								
what happens after death worries me.		SD	D	MD	U	MA	A	SA

Death Attitude Profile- Revised: Scoring Guide

Dimension	Items
Fear of Death (7 items)	1, 2, 7, 18, 20, 21, 32
Death Avoidance (5 items)	3, 10, 12, 19, 26
Neutral Acceptance (5 items)	6, 14, 17, 24, 30
Approach Acceptance (10 items)	4, 8, 13, 15, 16, 22, 25, 27, 28, 31
Escape Acceptance (5 items)	5, 9, 11, 23, 29

Scores for all items are from 1-7 in the direction of strongly disagree (1) to strongly agree (7). For each dimension, a mean scale score can be computed by dividing the total scale score by the number of items forming each scale.

APPENDIX I: Revised Death Anxiety Scale

Thorson & Powell, 1994

	Least			Greatest	
1. I fear dying a painful death.	1	2	3	4	5
2. Not knowing what the next world is like troubles me.	1	2	3	4	5
3. The idea of never thinking again after I die frightens me.	1	2	3	4	5
4. I am not at all anxious about what happens to the body after burial.	1	2	3	4	5
5. Coffins make me anxious.	1	2	3	4	5
6. I hate to think about losing control over my affairs after I am gone.	1	2	3	4	5
7. Being totally immobile after death bothers me.	1	2	3	4	5
8. I dread to think about having an operation.	1	2	3	4	5
9. The subject of life after death troubles me greatly.	1	2	3	4	5
10. I am not afraid of a long, slow dying.	1	2	3	4	5
11. I do not mind the idea of being shut into a coffin when I die.	1	2	3	4	5
12. I hate the idea that I will be helpless after I die.	1	2	3	4	5
13. I am not at all concerned over whether or not there is an afterlife.	1	2	3	4	5
14. Never feeling anything again after I die upsets me.	1	2	3	4	5
15. The pain involved in dying frightens me.	1	2	3	4	5
16. I am looking forward to new life after I die	1	2	3	4	5
17. I am not worried about being helpless.	1	2	3	4	5
18. I am troubled by the thought that my body will decompose in the grave.	1	2	3	4	5

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19. The feeling that I will be missing out on so much after I die disturbs me.	1	2	3	4	5
20. I am worried about what happens to us after we die.	1	2	3	4	5
21. I am not at all concerned with being in control of things.	1	2	3	4	5
22. The total isolation of death is frightening to me.	1	2	3	4	5
23. I am not particularly afraid of getting cancer.	1	2	3	4	5
24. I will leave careful instructions about how things should be done after I am gone.	1	2	3	4	5
25. What happens to my body after I die does not bother me.	1	2	3	4	5

Revised Death Anxiety Scale: Scoring Guide

The RDAS is a scale with 25 statements, 17 phrased positively and eight negatively. Respondents are asked to agree or disagree with the statements on a five-point Likert format: items are scored with the value 0 given for least anxiety and 4 for highest death anxiety; responses to negatively phrased items are reversed in the scoring process. Thus, the possible range of an individual respondent's total score is from 0 (lowest) to 100 (highest possible score). Note that some earlier articles using these items had a true-false format; we now recommend using the Likert response format with the RDAS.

Simply score the following values for the responses indicated on the positively phrased agree= 4; agree= 3; neutral= 2; disagree= 1; strongly disagree= 0. And, items (Numbers 1, 2, 3, 5, 6, 7, 8, 9, 12, 14, 15, 16, 18, 19, 20, 22, and 24): strongly score the following values for the items that are phrased negatively (Numbers 4, 10, 11, 13, 17, 21, 23, and 25): strongly agree= 0; agree= 1; neutral= 2; disagree= 3; strongly disagree= 4. Count any items left blank as neutrals (score= 2). Then, just add up the assigned item scores to get a respondent's total score.

APPENDIX J: Personal Meaning Profile

Paul T. P. Wong, 1993

This questionnaire measures people's perception of personal meaning in their lives. Generally, a meaningful life involves a sense of purpose and personal worthiness. However, people often differ in what endows their lives with meaning.

The following statements describe potential sources of personal meaning. Please read each statement carefully and indicate to what extent it characterizes a source of meaning in you own life. You may respond by circling the appropriate number according to the following scale:

1	2	3	4	5	6	7
Not at all			Moderately			A great deal

For example, if going to parties does not contribute to your sense of personal meaning, you may circle 1 or 2. If taking part in volunteer work contributes quite a bit to the meaning in your life, you may circle 5 or 6.

It is important that you answer honestly on the basis of your own experience and beliefs.

- | | | |
|----|---|---------------|
| 1. | I have a good family life | 1 2 3 4 5 6 7 |
| 2. | I believe I can make a difference in the world..... | 1 2 3 4 5 6 7 |
| 3. | I am a peace with God..... | 1 2 3 4 5 6 7 |
| 4. | I have learned that setbacks disappointments are an
inevitable part of life..... | 1 2 3 4 5 6 7 |
| 5. | I believe in an ultimate purpose in life..... | 1 2 3 4 5 6 7 |
| 6. | I engage in creative work..... | 1 2 3 4 5 6 7 |
| 7. | I am successful in achieving my aspirations..... | 1 2 3 4 5 6 7 |

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8. I pursue worthwhile objectives..... 1 2 3 4 5 6 7
9. I strive to achieve my life goals..... 1 2 3 4 5 6 7
10. I care about other people..... 1 2 3 4 5 6 7
11. I have someone to share intimate feelings with..... 1 2 3 4 5 6 7
12. I believe in the value of my pursuits..... 1 2 3 4 5 6 7
13. I seek to actualize my potentials..... 1 2 3 4 5 6 7
14. I have found that there is rough justice in this world..... 1 2 3 4 5 6 7
15. I strive to make this world a better place..... 1 2 3 4 5 6 7
16. I am at peace with myself..... 1 2 3 4 5 6 7
17. I have confidants to give me emotional support..... 1 2 3 4 5 6 7
18. I relate well to others..... 1 2 3 4 5 6 7
19. I have a sense of mission or calling..... 1 2 3 4 5 6 7
20. I seek to do God's will..... 1 2 3 4 5 6 7
21. I like challenges..... 1 2 3 4 5 6 7
22. I believe that human life is governed by moral laws..... 1 2 3 4 5 6 7
23. It is important to dedicate my life to a cause..... 1 2 3 4 5 6 7
24. I take initiative..... 1 2 3 4 5 6 7
25. I am able to make full use of my abilities..... 1 2 3 4 5 6 7
26. I strive to do my best in whatever I am doing..... 1 2 3 4 5 6 7
27. I have a number of good friends..... 1 2 3 4 5 6 7
28. I am trusted by others..... 1 2 3 4 5 6 7
29. I am committed to my work..... 1 2 3 4 5 6 7
30. I have a purpose and direction in life..... 1 2 3 4 5 6 7
31. I seek higher values-values that transcend
self-interests..... 1 2 3 4 5 6 7
32. I am highly regarded by others..... 1 2 3 4 5 6 7
33. I seek to glorify God..... 1 2 3 4 5 6 7
34. I am enthusiastic about what I do..... 1 2 3 4 5 6 7
35. Life has treated me fairly..... 1 2 3 4 5 6 7

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- 36. I accept my limitations..... 1 2 3 4 5 6 7
- 37. I have a mutually satisfying loving relationship..... 1 2 3 4 5 6 7
- 38. I am at peace with my past..... 1 2 3 4 5 6 7
- 39. I believe that there is coherence and continuity in my life..... 1 2 3 4 5 6 7
- 40. I do not give up when I encounter setbacks or obstacles..... 1 2 3 4 5 6 7
- 41. I am altruistic and helpful..... 1 2 3 4 5 6 7
- 42. I am liked by others..... 1 2 3 4 5 6 7
- 43. I have found someone I love deeply..... 1 2 3 4 5 6 7
- 44. I strive toward personal growth..... 1 2 3 4 5 6 7
- 45. I bring happiness to others..... 1 2 3 4 5 6 7
- 46. I accept what cannot be changed..... 1 2 3 4 5 6 7
- 47. I am persistent and resourceful in attaining my goals..... 1 2 3 4 5 6 7
- 48. I value my work..... 1 2 3 4 5 6 7
- 49. I make a significant contribution to society..... 1 2 3 4 5 6 7
- 50. I contribute to the well-being of others..... 1 2 3 4 5 6 7
- 51. I believe in afterlife..... 1 2 3 4 5 6 7
- 52. I believe that one can have a personal relationship with God..... 1 2 3 4 5 6 7
- 53. I attempt to leave behind a good and lasting legacy..... 1 2 3 4 5 6 7
- 54. I believe that there is order and purpose in the universe..... 1 2 3 4 5 6 7
- 55. I am treated fairly by others..... 1 2 3 4 5 6 7
- 56. I have received my fair share of opportunities and rewards..... 1 2 3 4 5 6 7
- 57. I have learned to live with suffering and make the best of it..... 1 2 3 4 5 6 7

Personal Meaning Profile: Scoring Key

- | | |
|----------------------------------|--|
| 1. Achievement (16 items): | 6, 7, 8, 9, 12, 13, 21, 24, 25, 26, 29, 34, 40, 44, 47, 48 |
| 2. Relationship (9 items): | 10, 18, 27, 28, 32, 41, 42, 45, 50 |
| 3. Religion (9 items): | 3, 5, 19, 20, 22, 33, 51, 52, 54 |
| 4. Self-Transcendence (8 items): | 2, 15, 23, 30, 31, 39, 49, 53 |
| 5. Self-Acceptance (6 items): | 4, 16, 36, 37, 46, 57 |
| 6. Intimacy (5 items): | 1, 11, 17, 38, 43 |
| 7. Fair Treatment (4 items): | 14, 35, 55, 56 |

APPENDIX K: Coping Schemas Inventory

P.T.P. Wong, G.T. Reker, & E.J. Peacock, 1993

To what extent do you usually use each of the following strategies to cope with difficult or stressful events in your life?

In making your rating, use the following scale: _____

_____ 1 _____	_____ 2 _____	_____ 3 _____	_____ 4 _____	_____ 5 _____
Not at all (Never) <u>always</u>	A little bit (Rarely)	A moderate Amount (Occasionally)	A considerable Amount (Often)	A great deal (Almost)

Please circle the appropriate number for each coping strategy.

1. Rely on others to do what I cannot do myself..... 1 2 3 4 5
2. Do something about the situation..... 1 2 3 4 5
3. Wish that I could undo the past..... 1 2 3 4 5
4. Express my feelings and thoughts..... 1 2 3 4 5
5. Confront the problem by taking appropriate actions..... 1 2 3 4 5
6. Do what is necessary to maintain a personal relationship w/ God..... 1 2 3 4 5
7. Believe that I can communicate with God..... 1 2 3 4 5
8. Run away from the problem or situation..... 1 2 3 4 5
9. Do what is necessary to fulfill the requirements of the situation..... 1 2 3 4 5
10. Accept what has happened because eventually things will work
out as well as can be expected..... 1 2 3 4 5
11. Talk to myself to reduce tension..... 1 2 3 4 5
12. Break down the problem into smaller steps and work on one

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at a time.....	1 2 3 4 5
13. Learn to live with the problem, because nothing much can be done about it.....	1 2 3 4 5
14. Confront and understand my own feelings.....	1 2 3 4 5
15. Accept/tolerate life as it is and make the best of it.....	1 2 3 4 5
16. Learn to accept the negative realities of life.....	1 2 3 4 5
17. Suppress or avoid facing my own emotions.....	1 2 3 4 5
18. Air my complaints and frustrations.....	1 2 3 4 5
19. Feel guilty for what has happened.....	1 2 3 4 5
20. Practice controlled breathing techniques.....	1 2 3 4 5
21. Change my negative attitude toward this problem into a positive one.....	1 2 3 4 5
22. Change my pace to suit the situation.....	1 2 3 4 5
23. Rely on people who have successfully coped with the problem.....	1 2 3 4 5
24. Take the problem into my own hands by fighting back.....	1 2 3 4 5
25. Look at unavoidable life events as part of my lot in life.....	1 2 3 4 5
26. Engage in mental exercise (such as imagery) to reduce tension.....	1 2 3 4 5
27. Share my feelings with a confidant.....	1 2 3 4 5
28. Try to reduce my anxious thoughts.....	1 2 3 4 5
29. Seek help and direction from God.....	1 2 3 4 5
30. Actively seek out information on my own.....	1 2 3 4 5
31. Wish that I were a different person.....	1 2 3 4 5
32. Feel ashamed for my inadequacies.....	1 2 3 4 5
33. Put off doing something about the problem.....	1 2 3 4 5
34. Accept the present situation because no matter how bad things are they could always be worse.....	1 2 3 4 5
35. Wish that a miracle or something fantastic would happen.....	1 2 3 4 5
36. Believe that God will answer prayers.....	1 2 3 4 5
37. Try to develop a positive self concept or self image so that I can better face future uncertainties.....	1 2 3 4 5

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- 38. Believe that there must be a purpose in the suffering I experience..... 1 2 3 4 5
- 39. Make a plan of action and follow it..... 1 2 3 4 5
- 40. Look to others for moral support..... 1 2 3 4 5
- 41. Ignore the problem and pretend that it doesn't exist..... 1 2 3 4 5
- 42. Avoid thinking about the problem or things that are upsetting..... 1 2 3 4 5
- 43. Wish that the situation were different..... 1 2 3 4 5
- 44. Believe that God watches over me..... 1 2 3 4 5
- 45. Mentally transform the situation into something less threatening..... 1 2 3 4 5
- 46. Rely on available connections to solve the problem..... 1 2 3 4 5
- 47. Follow religious principles..... 1 2 3 4 5
- 48. Try not to focus on likely negative outcomes..... 1 2 3 4 5
- 49. Practice muscle relaxation techniques..... 1 2 3 4 5
- 50. Change my attitude in view of this problem..... 1 2 3 4 5
- 51. Feel sorry for what I have done..... 1 2 3 4 5
- 52. Be determined and persistent in attacking the problem..... 1 2 3 4 5
- 53. Seek emotional support from others..... 1 2 3 4 5
- 54. Receive practical help from friends..... 1 2 3 4 5
- 55. Restructure my actions in light of the problem..... 1 2 3 4 5
- 56. Pray to God..... 1 2 3 4 5

- 57. Depend on the experts and follow their advice..... 1 2 3 4 5
- 58. Try to maintain a sense of contentment or fulfillment in life..... 1 2 3 4 5
- 59. Try to look at the problem from a new perspective..... 1 2 3 4 5
- 60. Rearrange my activities to accommodate the situation..... 1 2 3 4 5
- 61. Know my limits so that I will not get into difficulties later on..... 1 2 3 4 5
- 62. Believe that there is meaning and purpose to the things that
happen to me..... 1 2 3 4 5
- 63. Release my pent-up emotions..... 1 2 3 4 5
- 64. Double my effort to change the situation..... 1 2 3 4 5
- 65. Don't worry about he past or the future. Accept each day

as it comes.....	1 2 3 4 5
66. Develop better time management skills so that I will be more efficient in the future.....	1 2 3 4 5
67. Blame myself for what has happened.....	1 2 3 4 5
68. Believe in an almighty God.....	1 2 3 4 5
69. Believe that valuable lessons can be learned from undesirable experiences.....	1 2 3 4 5
70. Depend on friends for emotional/moral support.....	1 2 3 4 5
71. Believe that God will execute final justice.....	1 2 3 4 5
72. Derive meaning from my past.....	1 2 3 4 5
73. Rehearse the planned action in my mind.....	1 2 3 4 5
74. Remind myself that worrying will not accomplish anything.....	1 2 3 4 5
75. Practice meditation techniques to reduce tension.....	1 2 3 4 5
76. Depend on opinions of people who have experienced similar problems.....	1 2 3 4 5

Coping Schemas Inventory (CSI)

Schema Scoring Guide

<u>Coping Schema</u>	<u>Item Number</u>	<u>Total</u>
Situational	2, 5, 12, 24, 30, 39, 52, 64	8
Self-Restructuring	9, 21, 22, 37, 50, 55, 59, 60 61, 66, 73	11
Active Emotional	4, 14, 18, 27, 40, 53, 63, 70	8
Passive Emotional	3, 8, 17, 19, 31, 32, 33, 35, 41, 42, 43, 51, 67	13
Meaning	38, 62, 69, 72	4
Acceptance	10, 13, 15, 16, 25, 34, 58, 65	8
Religious	6, 7, 29, 36, 44, 47, 56, 68 71	9
Relaxation	11, 20, 26, 28, 45, 48, 49, 74 75	9
Practical Social Support	1, 23, 46, 54, 57, 76 <u>6</u>	
	76	

Scoring

Sum the individual item ratings for each coping schema and divide by the number of items. The score for each subject is then expressed as a Mean Rating that varies from 1.00 to 5.00. A high score reflects a great deal of use of that particular coping schema.

APPENDIX L: Research Evaluation

Thank you for choosing to participate in this research project. I would appreciate your taking the time to evaluate your experience.

Please circle any of the following that apply:

Questionnaires used were:

Relevant

Irrelevant

Appropriate in length

Overly long

Other comments: _____

Interview questions were:

Relevant

Irrelevant

Appropriate to topic

Inappropriate to topic

Other comments: _____

Researcher was:

Compassionate

Uncompassionate

Responsive

Unresponsive

Professional

Unprofessional

Other comments: _____

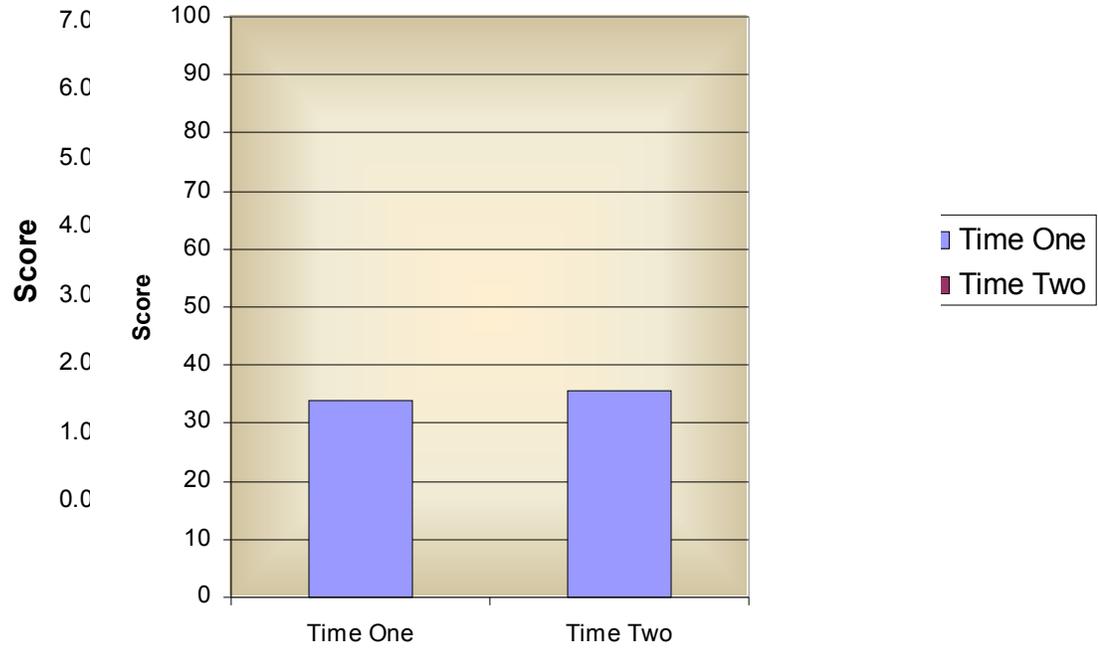
Please mail to:

USA

Deb Ivancovich

Chart of Means						
	Score	All Respondents				
		Time One	stdev	Time Two	stdev	
PMP						
Achievement		4.6	0.8	4.9	0.7	One Two
Relationship		5.0	0.9	5.2	1.0	
Religion		5.7	0.9	5.6	0.8	
Self-Transcendence		4.7	0.8	4.9	0.8	
Self-Acceptance		5.2	0.8	5.1	0.8	
Intimacy		5.0	0.5	5.0	0.5	
Fair Treatment		4.8	0.9	5.0	0.9	
DAP						
Fear of Death		2.7	1.1	2.6	1.1	
Death Avoidance		2.4	1.1	2.3	1.0	
Neutral Acceptance		5.5	0.6	5.4	0.6	
Approach Acceptance		6.2	0.7	6.3	0.7	
Escape Acceptance		5.6	0.9	5.8	0.9	
RDA						
Positive		17		18		
Negative		18		17		
Totals		34		36		
CSI						
Situational		3.2	0.4	3.5	0.3	
Self-Restructuring		3.3	0.5	3.5	0.4	
Active Emotional		3.3	0.6	3.5	0.6	
Passive Emotional		2.5	0.7	2.6	0.6	
Meaning		3.8	0.8	3.8	0.9	
Acceptance		3.4	0.6	3.5	0.6	
Religious		4.4	0.4	4.4	0.4	
Relaxation		2.3	0.6	2.6	0.6	
Practical Social Support		3.0	0.6	3.4	0.6	

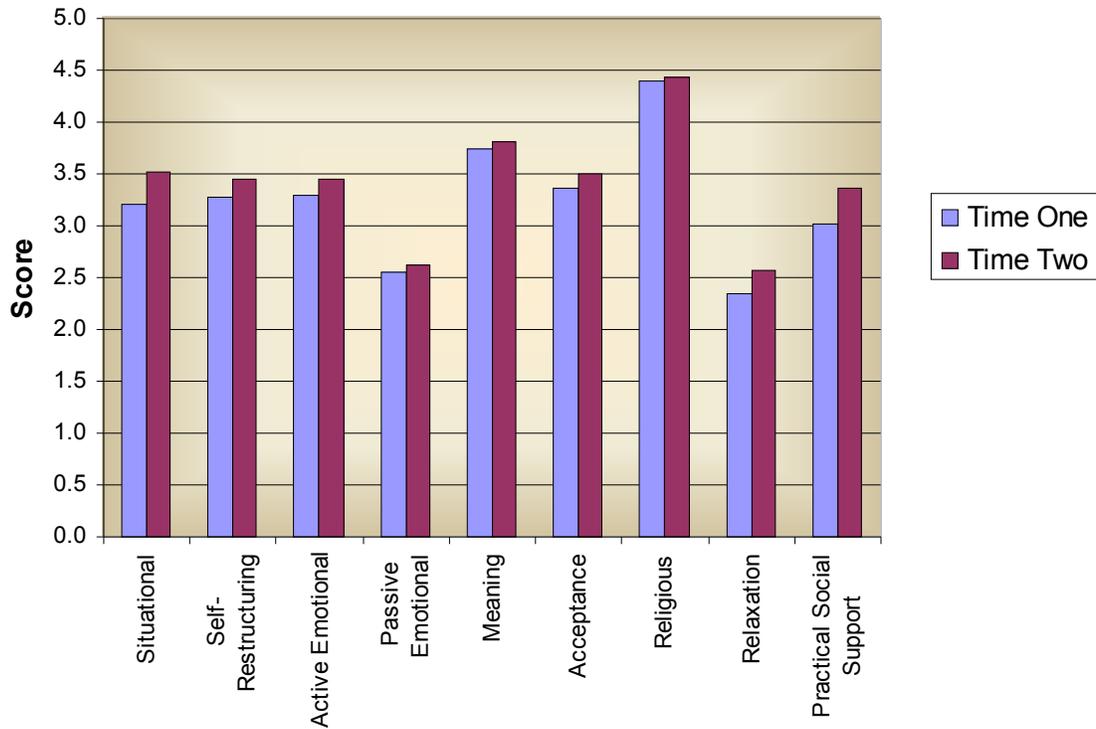
ALL RESPONDANTS REVISED DEATH ANXIETY



Existential and Spiritual Coping in Anticipatory Grief -127

	Respondent #4		Respondent #5		Respondent #6	
	time one means	time two means	time one means	time two means	time one means	time two means
PMP						
Achievement	5.9	5.6	5.9	5.7	4.7	4.9
Relationship	5.7	5.7	5.1	4.9	4.2	3.9
Religion	6.0	5.8	6.7	6.6	4.6	3.9
Self-Transcendence	5.4	5.0	6.3	6.1	3.9	4.0
Self-Acceptance	6.5	5.8	4.2	4.2	5.2	4.7
Intimacy	5.4	5.2	4.4	4.8	4.6	4.8
Fair Treatment	6.3	5.8	4.5	4.5	5.5	5.3
DAP						
Fear of Death	2.9	2.3	2.1	2.7	2.6	2.1
Death Avoidance	2.0	1.8	2.4	2.4	2.4	2.4
Neutral Acceptance	5.8	5.2	4.8	5.0	4.8	5.4
Approach Acceptance	6.3	5.7	6.9	6.9	4.8	5.2
Escape Acceptance	5.4	5.2	6.6	6.2	4.0	5.0
<i>Not Answered</i>						
RDA						
Positive	15.0	18.0	22.0	22.0	7.0	15.0
Negative	8.0	14.0	12.0	16.0	23.0	21.0
CSI						
Situational	3.4	3.9	3.8	3.6	2.9	3.4
Self-Restructuring	3.5	3.5	3.4	3.7	2.9	2.8
Active Emotional	3.4	3.6	3.9	3.5	2.6	2.5
Passive Emotional	2.5	2.2	3.2	3.3	1.8	1.7
Meaning	4.5	3.5	4.3	4.5	2.8	3.0
Acceptance	4.1	3.6	2.4	2.8	3.0	3.9
Religious	4.6	4.1	4.8	4.9	3.7	3.9
Relaxation	2.8	2.8	2.9	2.5	2.2	2.8
Practical Social Support	3.2	3.7	2.8	3.2	1.8	2.3

ALL RESPONDENTS COPING SCHEMAS INVENTORY



APPENDIX N: Individual Respondent Charts

	Respondent #1		Respondent #2		Respondent #3	
	time one	time two	time one	time two	time one	time two
PMP	means	means	means	means	means	means
Achievement	3.6	4.7	4.2	4.1	4.1	4.5
Relationship	4.7	6.2	4.9	4.7	3.6	3.8
Religion	6.9	6.6	5.8	5.8	4.3	4.7
Self-Transcendence	4.3	5.6	4.3	4.5	3.6	4
Self-Acceptance	5.8	5.5	4	4.8	5.5	5.3
Intimacy	5	6	4.6	4.6	5.2	4.6
Fair Treatment	3.5	6.3	4.3	4.3	4	3.8
DAP						
Fear of Death	3	2.4	1.6	1.9	5	5.3
Death Avoidance	1.6	1	1.8	1.2	4.6	4.8
Neutral Acceptance	4.8	5	5.4	5.2	6.6	6.2

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Approach						
Acceptance	6.7	7	6.7	6.9	6	5.6
Escape Acceptance	7	7	6.6	6.2	4.6	4.6
<i>Not Answered</i>						
RDA						
Positive	8	9	13	11	33	45
Negative	23	19	20	20	15	13
CSI						
Situational	2.5	3.6	3.6	3.5	3.4	3.8
Self-Restructuring	2.1	3.9	3.6	2.8	3.8	4.1
Active Emotional	3.5	4.5	3.3	2.8	2.6	3.3
Passive Emotional	1.4	2.6	2.6	2.8	3.5	3.5
Meaning	3.5	5	3	2.5	4	4.3
Acceptance	3	4.4	3.3	3.1	4	4
Religious	4.6	4.9	4.8	4.3	4.1	4.4
Relaxation	1.3	2.6	1.8	1.9	3.6	3.7
Practical Social Support	3.5	4.2	3.2	3	3.2	3.7

Existential and Spiritual Coping in Anticipatory Grief -131

	Respondent #7		Respondent #8	
	time one means	time two means	time one means	time two means
PMP				
Achievement	3.7	4.8	5.2	5.0
Relationship	6.0	6.4	6.1	5.8
Religion	5.3	5.8	5.8	5.7
Self-Transcendence	4.5	5.0	5.4	5.1
Self-Acceptance	6.0	6.2	4.5	4.3
Intimacy	5.8	5.4	4.8	4.6
Fair Treatment	6.3	5.5	4.5	4.5
DAP				
Fear of Death	2.1	2.0	2.1	2.0
Death Avoidance	2.2	2.4	2.0	2.0
Neutral Acceptance	5.2	5.2	6.4	6.0
Approach Acceptance	5.6	6.6	6.6	6.2
Escape Acceptance	4.8	6.0	5.6	6.0
<i>Not Answered</i>				
RDA				
Positive	17.0	14.0	17.0	12.0
Negative	15.0	15.0	24.0	20.0
CSI				
Situational	2.6	3.0	3.5	3.5
Self-Restructuring	3.7	3.5	3.2	3.2
Active Emotional	4.0	3.9	3.1	3.6
Passive Emotional	3.1	2.2	2.4	2.6
Meaning	5.0	4.8	3.0	3.0
Acceptance	4.0	3.5	3.1	2.8
Religious	4.3	4.8	4.4	4.1
Relaxation	1.9	2.0	2.3	2.3
Practical Social Support	3.5	3.7	3.0	3.2

