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The Relationships Among General Coping Style, Hope, and Anticipatory Grief in Family Members of Terminally Ill Individuals with Cancer Receiving Home Care

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February 1995

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements for the degree of Masters of Science.

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Abstract

Family members have been observed to cope with the losses inherent in terminal illness by grieving. Little is known, however, about the factors which influence their grieving before the death of a significant other. This paper describes an exploratory, cross-sectional, correlational study designed to examine the relationships among general coping style, hope, and anticipatory grief in a convenience sample of 61 family members of individuals with terminal cancer. The organizing framework for this study was based on grief theory, Lazarus and Folkman's (1984) theory of stress and coping, and Davies, Reimer, and Martens' (1990) transition framework. Data were collected by a four-part questionnaire comprising the Jalowiec Coping Scale (Jalowiec, 1987), the Herth Hope Index (Herth, 1991), the Non-Death Version of the Grief Experience Inventory (Sanders, Mauger, & Strong, 1985), and a background information sheet developed by the researcher. Findings revealed that family members experienced individual anticipatory grief patterns. Women experienced more despair and anger/hostility than men. Adult children, more highly educated family members, individuals not living with the ill person, and non-primary caregivers expressed more anger/hostility. Multiple regression results showed that emotive coping and hope accounted for significant proportions of the variance in despair, somatization, and loss of control. Emotive coping contributed significant variation in anger/hostility, whereas lack of hope accounted for a significant amount of the variation in social isolation. Neither the general coping styles nor hope significantly predicted death anxiety. Suggestions for research and nursing were indicated.

Sommaire

Nous savons peu de choses a propos des facteurs qui influencant le processus de deuil avant la mort de personnes importantes. Cet article décrit une recherche de coupe transversale, correlationnelle déstinée à examiner une relation entre differents mechanisme de défense, d'espoir et d'anticipation vis-a-vis le deuil dans un échantillon de 61 membres d'une famille ayant un être aimé souffrant d'un cancer en phase terminale. La structure organisationnelle de cette étude est basée sur la théorie du deuil, Lazarus et Folkman's (1984) "Theory of Stress and Coping", et Davies, Reimer, et Marten's (1990) "transition framework". Des données furent recueillies dans un questionnaire ayant quatre sections comprenant "The Jalowiec Coping Scale" (Jalowiec, 1987), "The Herth Hope Index" (Herth, 1991), "The Non-Death Version of the Grief Experience Inventory" (Sanders, Mauger, et Strong, 1985), et un formulaire d'information antérieur developpé par le recherchiste. Les résultats ont révélé que chaque membre de la famille semblait vivre une experience individuelle de deuil anticipatoire répétitive. On a également noté que les femmes vivaient plus de désespoir, de colère et d'hostilité que les hommes. Les enfants, les membres de la famille étant plus scolarisé ainsi que les gens ne vivant pas avec le malade et les personnes qui ne prodiguent pas de soins tout le temps ont démontré plus de colère et d'hostilité. On a pu identifier des différences entre les variables démographiques et les autres dimensions du deuil anticipationnel; détresse somatique, perte de contrôle, isolation sociale et anxiété due à la mort. Les résultats des techniques statistiques régressives ont révélé que le méchanisme de défense émotionnel et l'espoir ont contribué des manière significative dans la variance du désespoir, de somatisation et de perte de contrôle. Le méchanisme de défense émotionnelle fut la seule variable qui a contribué de façon significative à la variation de colère/hostilité alors que l'espoir fut la seule variable qui a contribué de manière significative dans la variance de l'isolement social. Ni le méchanisme de défense ni l'espoir n'ont pu prédire de façon significative l'anxiété due à la mort. Des suggestions pour la recherche et les soins infirmiers on été évoquées.

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Introduction

Dying with cancer usually involves a period of progressive illness and wasting away. Although progress is being made in treating tumors and enhancing the survival of individuals with cancer, people will continue to die of their disease over the next decade (Burge, 1992; MacDonald, 1992; National Cancer Institute of Canada, 1994; Scott, 1992). They and their families will continue to have to cope with the experience of terminal illness.

The literature suggests that a diagnosis of terminal cancer strikes all members in the family simultaneously and confronts each member with an overwhelming number of actual and impending losses, such as the dying person's physical and mental abilities. It has been reported consistently that family members cope with terminal illness in individual ways (Cooper, 1984; Kubler-Ross, 1969; Lewandowski & Jones, 1988; Woods, Lewis, & Ellison, 1989). Clinical observations and recent research findings have shown the difficulty that some family members have watching the person who is dying of cancer "wither away to nothing" (Davies, Reimer, & Martens, 1990; Lev, 1991). This becomes even more relevant because family and friends are assuming the major responsibility for the dying person's care and support since "more people requiring palliative care are exercising their choice to receive care in their home, rather than be admitted to a cure-oriented hospital." (Rol, 1992, p. 28).

Grief is an individual response to loss. It is manifested as a progression of emotional, social, spiritual, physical, cognitive and behavioral changes through which an individual attempts to reorganize and resolve, or adjust to, the loss. While it is normally associated with death, it does occur with other losses. Purtilo (1976) referred to the losses associated with an impending death as "little deaths". He proposed that persons respond to these losses in a similar way as to the death. Unfortunately, it is difficult to separate the grieving for losses due to illness from the grieving for the anticipated loss to death, since the losses occur simultaneously.

Grief occurring before death has generally been described as anticipatory grief. During the period between the diagnosis of irreversibility and death, that period seen as encompassing the time of anticipatory grief, it is common to see people grieving for present, past, and future losses (Brown & Powell-Cope, 1993; Rando, 1988). In contrast, during a chronic illness wherein death is not expected within a given time frame, anticipatory grief may not be as prevalent (Vachon, Freedman, Formo, Rogers, Lyall, & Freeman, 1977). There are some researchers who question whether anticipatory grief exists (Gerber, Rusalem, Hannon, Battin, & Arkin, 1975; Rando, 1983; Parkes & Weiss, 1983; Steele, 1990; Vachon, Sheldon, Lancee, Lyall, Rogers, & Freeman, 1982). Some, such as Gerber and associates, Rando (1988) and Steele (1990) hypothesize that if death is sudden there is no time for anticipatory grief.

Since many researchers believe that anticipatory grief is a universal phenomenon among terminally ill individuals with cancer and their families, it is important for nurses to be knowledgeable about it in order to provide appropriate and timely support both before and after the death (Worden, 1991). Family-centered nursing care will be enhanced if nurses gain an understanding of how family members respond to the losses involved in terminal illness and what influences these responses (Howell, 1986; Lev, 1991; Vachon et al., 1977).

The purpose of this study was to explore and describe the relationships among general coping style, hope, and anticipatory grief in family members of individuals with terminal cancer receiving home care and to examine how these variables are related to specific demographic variables.

Literature Review

The review of the literature addresses the major works about the study of grief, anticipatory grief, coping, and hope.

Grief

Freud (1957), who wrote about grief as early as 1917, described it as a process of withdrawal of the energy that exists between the survivor and the deceased, characterized by both somatic and psychologic depressive symptoms. Much later, Eliot (1930) suggested that individuals experiencing a loss feel a sense of abandonment, shock, denial, anger/hostility, and longing for the deceased. Building on Eliot's work, Fulconer (1942) showed that the grief process occurs in phases, starting with shock and ending with an integration of a new and stable life.

Lindemann (1944) did pioneering work on the conceptualization of grief. Based on extensive interviews with recently bereaved widows and widowers, Lindemann concluded that grief is a normal response to loss that consists of somatic distress, longing for the deceased, anger/hostility, guilt, and loss of patterns of thoughts and behaviors. He offered a picture of the multidimensionality of grief that has not been offered by many researchers.

Parkes (1970, 1972) developed a theory of grief based on comprehensive clinical work with 22 widows. He described grief as a psychological transition commencing with a phase of shock and numbness (characterized by strong denial and expressions of feeling dazed and stunned), continuing through the phases of separation anxiety and intense searching (characterized by behaviors such as crying, pining, yearning, hallucinating and feelings such as anger and fear) and apathy and despair (associated with aimlessness, disorganization, physical symptoms and yearning) and ending with a phase of reorganization and adaptation (Parkes, 1971). This view of grief identified it as a complex process that "may follow a 'healthy' course ... or may become blocked or distorted in some way" (Parkes, 1971, p. 106). Despite limitations, such as research design and operationalization of grief, Parkes' (1970) conceptualization of grief was convincing because of its clarity and its consistency with observations of grief made by others (Freud, 1957; Glick, Weiss, & Parkes, 1974; Jacobs & Douglas, 1979; Lev, 1991; Lindemann, 1944; Vargas, Loya, & Hodde-Vargas, 1989).

More recently, Cowles and Rodgers (1991) analyzed data on grief obtained from a systematic review of the literature published in nursing and medicine during the years 1985 through 1988. They found that grief was not time limited; it occurred in stages that were variable; it consisted of any number of symptoms; it was a process not a state of being; and it was normative because there are limits to it, beyond which it became inappropriate. There was no agreement on the amount of time involved in the grief process.

For further theoretical clarification, Attig (1991) attempted to distinguish grief as an emotion from grief as a coping strategy. He asserted that the emotion grief renders an individual helpless and passive whereas the coping strategy grief challenges the individual and requires that choices be made. Grief as a coping strategy promotes health by enhancing feelings of strength and security, increasing feelings of self-esteem and mastery, and promoting development by motivating the individual to invest energy into making changes (Attig, 1991).

The primary antecedent of grief was loss (Bowlby, 1961, 1980; Lindemann, 1944; Parkes, 1972; Switzer, 1970). Although any type of loss was believed to stimulate the grief response, most research focused on the experience of grief resulting from the death of a significant other.

Rodgers and Cowles (1991) found that creating a new reality and developing a new personal identity were outcomes of grief. Herth (1990a) discussed grief resolution as another positive outcome of grief. In contrast, other investigators found an increase in mortality rates of widows and widowers following bereavement (Cox & Ford, 1964; Parkes, Benjamin, & Fitzgerald, 1969). Outcomes were sometimes confounded with the process.

Operationalization of grief. Many researchers measured grief reactions by using indicators such as mortality and rates of physical and mental illness. Measures have been developed which operationalized grief as depression, despair, guilt, anger/ hostility, pining, yearning, death anxiety, and difficulty accepting the loss (Clayton & Darvish, 1979; Zisook, Devaul, & Click, 1982; Zisook & Shuchter, 1985). Going beyond other instruments, the Grief Experience Inventory (GEI) (Sanders, Mauger & Strong, 1979) consisted of nine bereavement subscales (despair, anger/hostility, somatization, loss of control, social isolation, death anxiety, rumination, depersonalization, guilt), three validity scales (denial, social desirability, atypical responses) and six research scales (sleep disturbance, appetite, vigor, physical symptoms, optimism versus despair, dependency). The scales, derived through research, reflected the multi-dimensionality of grief responses. Since it was assumed that one's attitude toward the questionnaire would influence his/her score on the bereavement scale, the validity scales were incorporated to identify if the "grief profile" could be interpreted. The research scales still required further study because they were not yet fully developed. Despite its limitations (length and a low inter-item consistency of some subscales), the GEI remains one of the most reliable measures of grief. Further refinement of the GEI led to a shortened non-death version (Sanders, Mauger, & Strong, 1985). The non-death version was useful in measuring grief responses in situations such as divorce and separation, placement of an elderly parent in a nursing home, and living with a mentally challenged child.

Grief and other variables. It was found that widows experience more feelings of grief (such as death anxiety, difficulty with somatic problems, loss of vigor, sadness, guilt, anger, and yearning) than widowers, who were more likely to suppress their expressions of grief (Broverman, Vogol, & Broverman, 1972; Glick et al., 1974; Jacobs, Kasl, Ostfeld, Berkman, & Charpentier, 1986; Kirschling & McBride, 1989; Lundin, 1984a, 1984b; Sanders, 1979-80). In contrast to findings from other studies (Kirschling & McBride, 1989; Sanders et al., 1979), Jacobs and his associates (1986) asserted that widows express their avoidance, denial, and defence against feelings of grief more than widowers. Widowers may exhibit these same behaviors but they may not be as prevalent or obvious since widowers, in contrast to widows, suppress their expressions of grief.

Characteristically, the younger the terminally ill individual, the more intense and longer-lasting the grief reaction is in bereaved persons (Rando, 1988). Young widows (18-46 years of age) experienced a stronger grief reaction (characterized by more restlessness) than middle- (47-59 years of age) or old-aged widows (60-75 years of age) (Ball, 1976-77). However, several studies revealed that widowers over the age of 60 thought more about the deceased, displayed less numbness and disbelief, experienced an increase in emotional distress associated with loss as they aged, and felt more separation anxiety than middle-aged and younger widowers (Jacobs et al., 1986; Sanders, 1979-80).

Pfost, Stevens, and Wessels (1989) found a negative relationship ($p < .05$) between purpose in life and anger as measured by the GEI (Sanders et al., 1979) in a retrospective, correlational study of 40 undergraduates who had suffered a loss. The authors suggested that emotion-focused coping strategies might be related to anger, a dimension of grief, or meaninglessness.

Some researchers found home care to enhance grief outcomes in the form of less anxiety, depression, withdrawal and so on (Lauer, Mulhern, Wallskig, & Camitta, 1983). Others found that families receiving home care experienced more conflict than families receiving hospital care (Birenbaum & Robinson, 1991). Conflicting results might be attributed to the difference in populations under study: parents of terminally ill young children (Birenbaum & Robinson, 1991) versus terminally ill adults (Lauer et al., 1983).

Clinical observation and qualitative research showed that there was wide variation in cultural beliefs regarding grief (Rosenbaum, 1991; York & Stichler, 1985). It was also observed that family members' relationship to the ill person influenced their response to loss (Fulton, 1982-83; Sanders, 1979-80; Steele, 1992). Research findings have shown consistently that the death of a child evoked the most intense grief reaction. This was followed by the death of a spouse.

Summary. Grief has been described as a response to loss that occurs in phases through which individuals progress at their own pace. A universal definition of grief was not found. Most of the instruments, like most of the studies on grief, focused on individuals, predominantly widows, who lost a loved one due to death. Various researchers found age, gender, home care, culture, and relationship to the ill individual to influence grief responses. Due to the existing gaps in the literature on grief, many questions remain unanswered.

Anticipatory Grief

Anticipatory grief has been described as grief occurring prior to a loss, containing most of the elements of normal (that is, post-death) grief (Aldrich, 1974; Kubler-Ross, 1969; Lindemann, 1944; Parkes, 1971). Most researchers argued that anticipatory grief was not simply grief started in advance; it differed from post-death grief in both form and duration. Anticipatory grief neither required complete separation from the dying person nor was it infinitely prolonged since there was always the endpoint of death. It was expected to accelerate as death approached. It was only after actual loss that the intensity of separation anxiety diminished and the individual was able to experience a conscious relinquishing of the deceased, acceptance of the loss, and recovery (Parkes & Weiss, 1983).

Early researchers identified anticipatory grief as a coping strategy associated with actual or impending loss, a view of anticipatory grief that has remained stable over the years. Lindemann (1944), one of the first individuals to use the term "anticipatory grief", identified five characteristics of grief: guilt, somatic distress, anger, loss of patterns of conduct, and fixation with the image of the dying person.

Although Kubler-Ross's (1969) work was dominated by discussions of the dying person, she offered additional insight on family members' anticipatory grief. Her clinical observations of family members revealed that the anticipated loss of a loved one evoked common behaviors, such as denial, reassurance-seeking, secrecy about the diagnosis among family members, anger, guilt, and sharing of the situation, as part of the grief reaction before death. She further observed that each family member varied uniquely in his/her grief expression throughout the course of the dying person's illness. More recently, these observations were supported by findings from Lev's (1991) qualitative study of the concerns of 34 cancer patients and family members facing loss. The validity of Lev's findings were enhanced not only by using a longitudinal design but also by using triangulation, a research strategy using different techniques to enhance the precision of measuring a phenomenon (Woods & Catanzaro, 1988).

Researchers described the behavioral aspects of anticipatory grief as moderate depression, denial and excessive emotion, shock, somatic symptoms, apathy, weakness, sighing, increased motor activity, a tendency to talk about the dying person and a detached feeling (Friedman, Chodoff, Mason, & Hamburg, 1983; Switzer, 1972). These features had a striking similarity to the grief reactions outlined by Parkes (1970, 1972).

Operationalization of anticipatory grief. Welch (1982) was one of few researchers who attempted to use quantitative measures to describe the anticipatory grief experience in family members of adult dying patients. She administered the Texas Inventory of Grief (TIG) (Zisook, DeVaul, & Click, 1982) to 41 relatives of cancer patients. Findings suggested that family members experienced anticipatory grief as a normal and expected aspect of coping with the impending death of their loved one. Higher scores on the TIG

(Zisook et al., 1982) were found in family members who cried about the diagnosis and in those with a patient being treated in an oncology unit compared to those being cared for at home. Lower scores were associated with families whose dying member was elderly and those who had experience with loss.

Only one instrument was specifically designed to measure anticipatory grief, the Anticipatory Grief Inventory (AGI) (Levy, 1991). Levy identified 21 items comprising anticipatory grief from retrospective data from spouses of cancer patients. The seven items, which comprised one of three factors identified through factor analysis, captured feelings of loneliness, anxiety, rumination, anger, and grief (weeping and pining); the other factors measured stress and coping. The AGI offered a broad picture of grief, albeit restrictive, since none of the items measured despair, a feeling consistently identified in the grief literature as the most pervasive grief experience. The validity and reliability of the AGI have yet to be well established.

Another instrument with the potential of measuring anticipatory grief is the Non-Death Version of the Grief Experience Inventory (NDGEI) (Sanders, Mauger, & Strong, 1985). Although not designed to measure anticipatory grief, the NDGEI measures the grief response to losses other than death. One population with whom it has been tested was adult children who had placed a parent in a Nursing Home. A common belief is that placement in a Nursing Home is often associated with anticipated death since the individual is expected to remain there until death. In essence, this may evoke anticipatory grief associated with dying. The NDGEI is discussed in more detail later.

Anticipatory grief and other variables. Researchers have focused on identifying the link(s) between anticipatory grief and bereavement outcomes. The benefits of anticipatory grief have been questioned by some researchers (Clayton, Halikas, & Maurice, 1972; Gerber et al., 1975; Maddison & Walker, 1967). In a randomly selected sample of widows and widowers (mean age was 62 with a range from 20-90 years), Clayton and his associates found that those who experienced anticipatory grief, measured retrospectively as self-reported depression, felt worse at one month post-death and were no better or worse at one year. Thus, they concluded that anticipatory grief did not make mourning either less intense or shorter. Similarly, Gerber and his colleagues (1975) found that those persons who had experienced a prolonged, chronic illness of a family member (greater than six months duration) were more likely to experience poorer medical adjustment. However, the cross-sectional design of the study restricted them from identifying the actual length of poor medical adjustment.

Not all researchers agreed that anticipatory grief was detrimental. Some researchers provided evidence that anticipatory grief enhanced one's adjustment during bereavement leading to improved health (Brock, 1984; Glick et al., 1974; Lundin, 1984a; Parkes, 1975; Parkes & Weiss, 1983; Vachon, 1976).

Inconsistent findings among studies might be due to weak research designs in which results were based on untested assumptions (for example, the belief that everyone experienced anticipatory grief). As well, conflicting results might be accounted for by the lack of consistency in the operationalization of anticipatory grief such as depression or length of illness. This was especially problematic when it was defined as "length of illness" since there was no consensus in the literature on what constituted "length of illness". In fact, recent research did not support the theory that a relationship existed between anticipatory grief and length of illness (Levy, 1991).

Unlike many other researchers studying anticipatory grief, Steele (1990) examined factors (enrolment in a hospice care, place of death, length of time in a hospice program, length of illness) influencing the process during terminal illness and post-death grief, rather than the impact of anticipatory grief on bereavement. When Steele operationalized grief with the Grief Experience Inventory (Sanders et al., 1979) in a retrospective, comparative study of 60 randomly selected widows and widowers who had been primary caregivers, she found that those individuals whose spouse had been ill for less than six months experienced more irritation, guilt, and feelings of unfairness over the death. Yet, they felt more control over the situation. Despite the strengths in her research, the study should be replicated using a larger sample size and prospective data collection. It would be of interest to know if these same results would be found in family members who were not primary caregivers.

Summary. Early research focused on the description of anticipatory grief as a coping strategy. More recently, the focus has been on the relationship between anticipatory grief and bereavement outcomes. While these studies provided valuable information about anticipatory grief, there are still many unanswered questions. Retrospective studies have examined the relationships between anticipatory grief and other variables prior to death, but overall, very little is known about grief, either as an emotion or as a coping strategy, during terminal illness.

Coping

A diagnosis of terminal cancer is associated with multiple losses that stimulate the grief process. Simultaneously, this diagnosis is a stressor that stimulates coping.

Although many researchers had examined the concept of coping, there was still confusion in the 1970s concerning its essence (Haan, 1977; Lipowski, 1970; Weisman, 1979). Lazarus and Folkman (1984) conceptualized coping as, "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the person" (p. 141). This definition highlighted the dynamic quality of coping and the focus on psychological stress which demanded the use of thoughts and behaviors that were not automatized. It also addressed coping as efforts to manage a situation, despite whether they were beneficial or not.

In some early literature, coping was conceptualized as a stable personality-based behavioral and emotional way of responding to stressful situations (Weisman & Worden, 1976-77). Other researchers observed the multidimensional quality of coping (Lazarus & Folkman, 1984; Mechanic, 1962; Murphy, 1974; Pearlin & Schooler, 1978). Lazarus and Folkman (1984) viewed coping as primarily situation-specific but they still believed that a coping style transcending a specific situation existed. They criticized a "trait-style approach" not because it was "inappropriate, unimportant, or unnecessary to locate stable patterns of coping", but because earlier efforts to operationalize coping did not foretell how individuals coped with the threat as it happened (Lazarus & Folkman, 1984, p. 178). They suggested that defining coping as a situation-specific process made it difficult to describe the individual's style over events (Lazarus & Folkman, 1984). Yet they asserted that observations of behavior indicated that individuals have a characteristic way of appraising and coping that transcends specific situations.

Antonovsky (1985) asserted that, "there is some basis for thinking that, given our individual cultural, historical, structural, and personal-historical backgrounds, we each tend to work a typical coping strategy" (p. 112). He believed that a general coping style was consistent with Lazarus and Folkman's (1984) transactional model of coping. Folkman, Lazarus, Gruen, and DeLongis (1986) found that although individuals coped differently from one encounter to the next, over time the variability of coping had decreased. They argued that if their sample had consisted of more than five encounters the stability of coping would have been more evident (Folkman et al., 1986).

Lazarus and Folkman (1984) suggested that coping styles can be defined in terms of the functions coping strategies serve: regulating emotional distress (emotion-focused coping) and "doing something to relieve the problem" (problem-focused coping) (Lazarus & Folkman, 1984, p. 44; Folkman, Lazarus, Gruen, & DeLongis, 1986; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Lazarus & Launier, 1978; Roskies &

Lazarus, 1980). Other researchers also recognized these functions of coping (Mechanic, 1962; Murphy, 1974; Murphy & Moriarty, 1976; Pearlin & Schooler, 1978). Originally, Jalowiec (1979) identified two styles of coping: affective-oriented and problem-oriented, which parallel emotion- and problem-focused coping (Jalowiec, Murphy, & Powers, 1984), but further research indicated three coping styles (emotive, palliative, and confrontive) (Jalowiec, 1987).

Findings from several studies revealed that individuals used both problem-focused and emotion-focused coping in almost every situation (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984). More recent research by Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986) showed that although problem-focused and emotion-focused coping could occur simultaneously in a specific situation one style of coping tended to be predominant.

In general, people who felt that they could do something about the situation used more problem-focused coping than people who appraised it as beyond their control (Billings & Moos, 1981; Folkman et al., 1986; Gass, 1987). In relation to health matters, emotion-focused coping was generally used to deal with "unsolvable" health conditions, such as terminal cancer, whereas problem-focused coping was generally used to manage work concerns.

Operationalization of coping. The early instruments designed to measure coping depicted it as a state or trait (Byrne, 1961; Gleser & Ihilevich, 1969; Goldstein, 1959, 1973; Krohne & Rogner, 1982) or in terms of "ego processes" (Vaillant, 1977). Unfortunately, the instruments underestimated the complexity and variability of coping. Coping has also been operationalized both in terms of the unique demands of specific situations (Lazarus & Folkman, 1984; Mechanic, 1962; Weisman & Worden, 1976-77) and as a measure of general patterns (Jalowiec, 1987). Operationalizing coping as situation specific allowed for a more comprehensive view of coping, but limited generalizability of results.

Coping and grief. No study was found that examined the relationship between coping and grief. Levy (1991) indicated that an individual's typical way of coping with stress may be dependent on anticipatory grief. Herth (1990a) examined the relationship between coping, operationalized with the Jalowiec Coping Scale (1987), and grief resolution, operationalized with the Grief Resolution Index (1987). She found that the use of confrontive and of palliative coping styles were positively related to the level of grief resolution. An inverse relationship was found between the use of emotive coping styles and grief resolution. Although Herth studied grief resolution not anticipatory grief, her findings provide rationale for a possible relationship between coping styles and anticipatory grief.

Bereavement, coping, resources, and health dysfunction were studied in a cross-sectional, correlational study of 159 elderly widows and widowers (Gass & Chang, 1989). Findings revealed that coping was significantly influenced by appraisal, offering clear support for Lazarus and Folkman's (1984) observation that appraisal is important in influencing coping. A positive relationship was identified between threat appraisal (that is, evaluating a situation in terms of harm[s] or loss[es] yet to occur), which was high among widows and widowers, and the use of mixed coping. Furthermore, the more an individual used emotion-focused coping, the more he/she experienced psychosocial health dysfunction ($p < .001$).

Coping and other variables. Findings from a variety of studies revealed that characteristics of the stressor influence choice of coping strategies (Billings & Moos, 1981; Coyne, Aldwin, & Lazarus, 1981; Diamond, 1981; Gass, 1987; McCrae, 1984; Miller, Denner, & Richardson, 1976). McCrae found that individuals facing a positive stressor used rational action, humor and positive thinking. In contrast, those individuals facing a threat used wishful thinking, faith and fatalism. Miller and his associates found that cancer patients used mainly cognitive processes (withdrawal, denial, compensation, rationalization, and suppression) to cope with the stress of their diagnosis.

Coyne and his associates (1981) found that depressed individuals used a combination of coping styles. Individuals in their study coped more by wishful thinking (form of emotion-focused coping) and seeking affirmational and informational support (form of problem-focused coping). In contrast, Billings and Moos (1981) found a positive relationship between problem-focused coping and depression ($\underline{p}<.05$). Differences between the samples, research designs (longitudinal versus cross-sectional), and measures might have accounted for the inconsistent findings.

Several researchers have found that women used more emotion-focused coping and men used more problem-focused coping (Billings & Moos, 1981; Folkman & Lazarus, 1980). Others found that individuals with a higher level of education used more problem-focused coping (Gass & Chang, 1989; Lazarus & Folkman, 1984). Although some researchers had not found a relationship between age and coping (Folkman & Lazarus, 1980), Gass and Chang found an inverse relationship between age and emotion-focused coping. A significant correlation was not found between age and problem-focused coping. As noted earlier, differences may be attributable to research designs or variability, such as age range.

Two studies were found that addressed coping in family members of terminally ill individuals (Davies et al., 1990; Hull, 1992). Hull conducted a longitudinal, exploratory study in order to better understand how family caregivers in hospice home care cope with the care of a loved one. Using semi-structured interviews and observations, data were collected from 14 individuals from ten different families. Coping strategies were identified through the technique of comparative analysis. Overall, family caregivers used more emotion-focused coping strategies to cope with the stresses inherent in the caregiving experience. Davies and her colleagues (1990) found similar results.

Summary. Coping has been viewed as both a trait and a process. Researchers who described coping as a situation-specific process did not negate the existence of a general style of coping. Coping style was postulated to influence the choice of coping strategies that were used in a particular situation. There were two main styles of coping reported: emotion-focused and problem-focused. These further divided into confrontive, palliative, and emotive coping styles. Though individuals used a combination of these styles in a specific situation, one style usually predominated. A link between coping style and grief resolution was established. The relationship between anticipatory grief and coping style has yet to be examined.

Hope

The phenomenon of hope was first discussed in the research literature by Marcel (1962), who stated that hope could not exist in isolation, but was dependent upon an affiliation with another individual. Building on Fromm's (1968) definition of hope as an inner readiness, Stotland (1969) conceptualized hope as a "personal expectation greater than zero of achieving a goal" (p. 2). Researchers and clinicians have since found that hope also includes an orientation and commitment toward future life (Herth, 1989; Rines & Montag, 1976), a belief in the existence of a personal tomorrow (Hinds, 1984; Miller, 1989; Staats & Stassen, 1986), a redefinition of the meaning of the future (Owen, 1989), a sense that others will offer assistance (Vaillot, 1970), and a sense of uncertainty or other related uncomfortable feelings (Dufault & Martocchio, 1985; Stanley, 1978).

Farran (1985) reviewed the literature on hope and identified four main attributes: suffering; transcendence and strong spiritual belief; a logical thought process; and an interactive process. More recently, the central, critical attributes of hope have been identified as a focus on the future; an energized, action orientation; a generalized or specific goal; and a feeling of uncertainty or discomfort (Hasse, Britt, Coward, Leidy, & Penn, 1992; Yates, 1993).

Dufault and Martocchio (1985) developed a theoretical model of hope based on a longitudinal study of 82 terminally ill persons. It expanded on the concept of hope as depicted in other models (Craig & Edwards, 1983; McGee, 1984) and conceptualized it as two interrelated spheres (generalized and particularized) and six common dimensions (cognitive, behavioral, contextual, affective, temporal, and affiliative). Generalized hope was described as a general sense of future good, but non-specific, developments. In contrast, particularized hope was viewed as a specific valued outcome, feeling or state of being. Dufault and Martocchio's (1985) study suggested that some element of hope is always operative in an individual. They indicated that as unrealistic hopes are relinquished for new hopes "the associated grieving is a part of the hoping process." (p. 384). They did not elaborate on what was meant by "grieving." Consequently, it was not known if it was grieving for lost hopes or losses in general. Their research raised questions about the relationship of hope to grief.

The hoping process was described as paradoxical (Dufault, 1981; Ersek, 1992). For example, Ersek (1992) reported that individuals maintained hope by confronting and experiencing the negative possibilities inherent in illness and by handling the impact of illness and its treatment by managing both the illness and the treatments. In addition, Ersek reported that individuals never lose all hope and they do not focus on or think about the possibility of reaching specific hopes.

Antecedents, sources, and threats of hope. Life-threatening situations, suffering, uncertainty, loss, personal characteristics such as believing in positive outcomes, a belief that others will help when needed, and the use of coping strategies such as self-talk were recognized as circumstances preceding hope, or antecedents of hope (Christman, 1990; Dufault, 1981; Farran, Salloway, & Clark, 1990; Herth, 1989; Miller, 1983; O'Malley & Menke, 1988; Owen, 1989; Raleigh, 1992). Spiritual and religious beliefs, a belief that a mistake was made by the doctor, medical and technological advances, faith in one's ability to heal oneself, and deception were identified as sources of hope, in other words, where hope originated (Klenow, 1991). Despite the overlap between antecedents and sources of hope, there was consensus that physical and mental deterioration, feeling no one cares, and lack of information are viewed as threats to hope (Herth, 1990b; Klenow, 1991; Miller, 1989; O'Malley & Menke, 1988; Raleigh, 1992).

Various researchers identified keeping busy, having spiritual beliefs, cognitive reframing, establishing attainable goals, recalling uplifting memories, feeling lighthearted, reaffirming one's worth, and believing in positive outcomes as strategies that influence the hoping process (Dufault, 1981; Ersek, 1992; Herth, 1990b; Herth, 1993; Hinds & Martin, 1988; Miller, 1989).

Outcomes of hope included feeling able to meet goals, feeling a sense of peace, feeling able to overcome the impossible, feeling positive about life, and trying out new things in life (Herth, 1989; Owen, 1989; Stanley, 1978).

Operationalization of hope. Stotland's (1969) definition of hope provided the theoretical underpinning of many early instruments developed to operationalize hope (Beck, Weissman, Lester, & Trexlar, 1974; Erickson, Post, & Paige, 1975; Gottschalk, 1974). Following the lead of Obayuwana and Carter (1982), various researchers based their instruments on hope as goal attainment and hope as a multidimensional concept (Miller & Powers, 1988; Nowotny, 1989). Limitations of earlier instruments stimulated Herth (1989) to develop the Herth Hope Scale (HHS), which was based on Dufault and Martocchio's (1985) model of hope. Herth recognized that previously developed instruments failed to capture the time-specific and global aspects of hope. The original tool has since been revised, resulting in the Herth Hope Index (Herth, 1991).

Hope and anticipatory grief. Although hope has not been examined quantitatively in relation to anticipatory grief, researchers and clinicians found that these two concepts coexist (Davies et al., 1990; Friedman et al., 1983;

Kubler-Ross, 1969). Davies and her colleagues (1990) used a grounded theory approach to examine the experience of families caring for a terminally ill individual who was receiving palliative care at home or in the hospital. Findings revealed that family members were in transition: a transition described as commencing with an ending of the previous way of life, progressing through a neutral zone, and ending with a beginning of a new perspective on life. It was during the neutral zone that family members struggled with paradoxes. Among those paradoxes most frequently cited by family members was the paradox of how to maintain hope while facing the reality that a loved one is dying (Reimer, Davies, & Martens, 1991).

Hope and coping. Some researchers and clinicians identified hope as a prerequisite for effective coping whereas others considered it an important coping strategy (Jalowiec & Powers, 1981; Kim, 1989; Korner, 1970; Miller, 1989; Stoner & Keampfer, 1985; Weisman, 1979). In two different studies, Herth (1989, 1990b) examined the relationship between hope and coping. In her earlier study, she found a positive correlation ($r=.80$, $p<.001$) between hope, measured with the HHS, and coping response, operationalized as a summative score on the Jalowiec Coping Scale (Jalowiec, 1979), in individuals receiving chemotherapy for cancer regardless of setting (home, hospital, or outpatient department). Others also found a positive relationship between hope and coping (C. Steele, personal communication, November 6, 1992). In addition, Herth (1990b) found that those individuals with strong faith/beliefs had significantly higher hope and coping. Higher hope was also found in individuals whose disease did not interfere with their ability to function within the family.

More recently, Herth (1990a) added grief resolution, measured by The Grief Resolution Index (Remondet & Hansson, 1987), in a study of 75 bereaved elderly individuals. She reported a direct relationship between hope and the use of palliative and confrontive coping styles (r=.79, p<.001) and an inverse relationship between hope and emotive coping. She found a positive relationship between level of grief resolution and level of hope (r=.71, p<.001). As well, she found that spouses of individuals who died in hospital or a nursing home had significantly lower levels of hope than spouses of individuals who died in hospice settings (p<.05).

Other variables associated with hope. The most consistent research finding between hope and other variables was that personal control correlated directly with level of hope (Brockopp, Hayco, & Wincott, 1989; Hinds & Martin, 1988; Miller, 1989; Rabkin, Williams, Neugebauer, & Remier, 1990). Though different statistical techniques were used, results were similar, offering strong support for the relationship between hope and control.

Rideout and Montemuro (1986) found a significant correlation between hope and social function (defined as social participation and leisure time, such as hobbies, and feelings about health) in their convenience sample of 23 chronically ill adults. A relationship was not found between hope and physical functioning.

Findings on relationships between social support and hope have been inconsistent. Although Stoner (1982) found a positive relationship between social support and hope, the most consistent finding was that a relationship did not exist (Brandt, 1987; Raleigh, 1980). Brandt did find that individuals who received adequate support from family and friends had higher hope levels, but unfortunately, she did not identify what "adequate" support meant. Therefore, one could have interpreted her conclusion to mean that those individuals with another level of adequacy or another source of support had a decreased level of hope.

Researchers found that hope level in cancer patients decreases as time following diagnosis increases (Greene, O'Mahoney, & Rungasamy, 1982; Zook & Yasko, 1983), but that phase of illness is not significantly correlated with hope (Stoner & Keampfer, 1985). Not all researchers agreed that a significant relationship exists between hope and time following diagnosis (Herth, 1993; Raleigh, 1980). Conflicting results might be due to several reasons: namely, the difference in how length of illness was measured and the fact that some instruments were untested. All of the studies, except Herth's, were cross-sectional in design. Herth found that overall hope scores for family caregivers of terminally ill persons were low within the first two weeks after admission to hospice, increased significantly when the family member began to stabilize and stabilized during the projected two week period before death. Herth's results, strengthened by the methodological triangulation design, were of particular relevance to this study because of the selected sample.

Research findings showed a positive relationship between depression and hopelessness in samples of HIV positive homosexual men and healthy students (Prociuk, Breen, & Lussier, 1976; Rabkin et al., 1990). Further research needs to be conducted to see if this relationship exists in other populations. In addition, a longitudinal study would offer more insight about the changing nature of depression and hope.

Summary. A review of the literature on hope revealed that hope is a multidimensional construct. To date, only a few studies were found that discussed grief and hope concurrently (Davies et al., 1990; Herth, 1990a). Hope was explored in relation to grief resolution in one study and observed by qualitative methods to occur simultaneously with anticipatory grief in the other. The relationship between hope and anticipatory grief has yet to be examined. Clearly, further study is required to identify relationships, if they exist, between these two concepts to gain a better understanding of them.

Conceptual Framework

The literature suggests that grief and hope are situation-specific coping strategies that emerge during terminal illness. Furthermore, there has been some speculation in the literature that an individual's general style of coping will create variation in anticipatory grief and hope responses (Antonovsky, 1985; Lazarus & Folkman, 1984; Levy, 1991; Pfost et al., 1989).

Researchers, such as Davies and her associates (1990), have established that as family members cope with the transition from "living with cancer to dying with cancer", they experience feelings of grief in response to actual or potential losses associated with the imminent death of a loved one. Grief before death, which is anticipatory grief, has been conceptualized as feelings of despair, anger/hostility, somatic distress, loss of control, social isolation, and death anxiety.

Anticipatory grief has been observed to co-exist with hope. Although the co-existence of these phenomena during the period of terminal illness has been confirmed by various researchers, the exact relationship between the two is unclear (Davies et al., 1990; Friedman et al., 1983; Kubler-Ross, 1969).

Herth (1990a) found a positive relationship between hope and grief resolution, an outcome of grief, raising the question of a potential relationship between hope and anticipatory grief. An inverse relationship was found between hope and despair (Prociuk et al., 1976). Based on these findings, one could postulate that an inverse relationship would exist between hope and each dimension of anticipatory grief.

The literature also implies that general coping style may be related to hope and anticipatory grief. It has been found that general coping style, an antecedent of situation-specific coping, along with hope and grief, each situation-specific coping strategies, are related during the bereavement period. Herth (1990a) found that emotive coping was inversely related to grief resolution, whereas palliative and confrontive coping were directly related to grief resolution. Similar relationships were found between the general coping styles and hope. These findings offered support for the existence of potential relationships between general coping style, hope and anticipatory grief during terminal illness.

Since grief resolution is generally perceived as a positive outcome of grief, compared to the commonly negative perception of grief and anticipatory grief, it was anticipated that palliative and confrontive coping would show inverse relationships to each dimension of anticipatory grief during terminal illness. A positive relationship would be expected between emotive coping and anticipatory grief. Relationships between general coping and hope would be expected to be the same as those relationships reported by Herth (1990a).

There is some evidence to suggest that a wide array of demographic, social, and personal variables influence coping, hope and grief. Overall, findings have been inconsistent. Since these variables could exert an effect on coping, hope, and grief responses, it was important to explore their potential influence on these variables. Figure 1 identifies the demographic variables and presents the conceptual framework that guided this study.

Conclusion

A comprehensive review of the literature on grief, anticipatory grief, coping, and hope provided the basis for suggesting that there were possible relationships between general coping style, hope, and anticipatory grief. It was also identified that there were limits on existing knowledge of general coping style, hope, and anticipatory grief. Thus, this study was designed to explore and describe the relationship(s) among general coping style, hope, and anticipatory grief in family members of individuals with terminal cancer and to examine the influence of specific demographic variables (age, gender, birth place of parents as a measure of ethnic origin, relationship to terminally ill

Figure 1

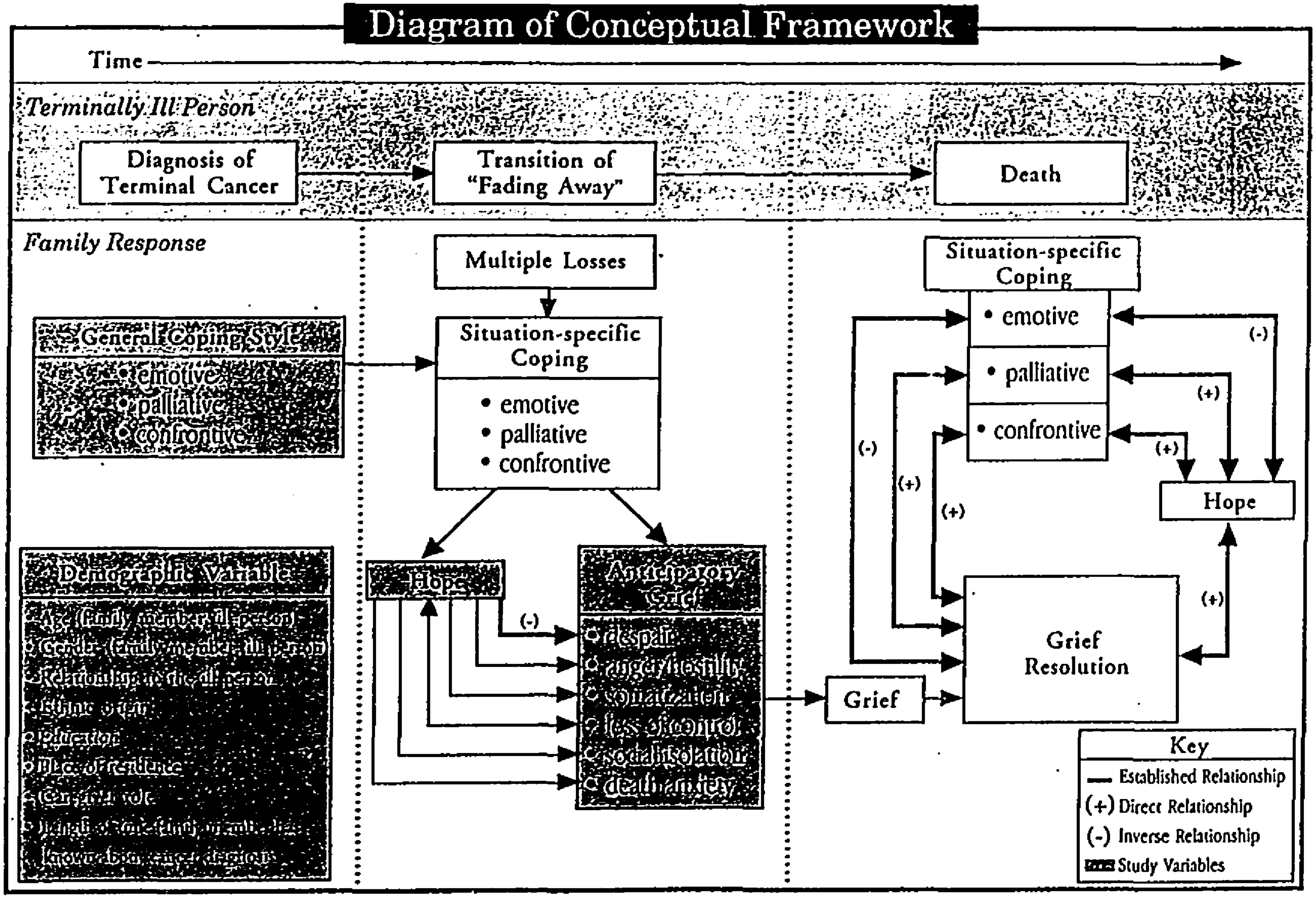


Diagram of Conceptual Framework
Time
Terminally Ill Person
Diagnosis of Terminal Cancer
Transition of "Fading Away"
Death
Family Response
General Coping Style
• emotive
• palliative
• confrontive
Demographic Variable
• Age (family member, ill person)
• Gender (family member, ill person)
• Relationship to the ill person
• Ethnic origin
• Education
• Place of residence
• Caregiver role
• Length of time family member has known about cancer diagnosis
Multiple Losses
Situation-specific Coping
• emotive
• palliative
• confrontive
Hope
(-)
Anticipatory Grief
• despair
• anger/hostility
• somatization
• loss of control
• social isolation
• death anxiety
Grief
Situation-specific Coping
• emotive
• palliative
• confrontive
(-)
(+)
(+)
(-)
(+)
(+)
Hope
(+)
Grief Resolution
Key
Established Relationship
(+) Direct Relationship
(-) Inverse Relationship
Study Variables

individual, education, place of residence, caregiver role, and length of time family member has known about the diagnosis of cancer) on anticipatory grief.

The following questions were addressed:

(1) What, if any, are the relationships between the demographic variables (age, gender, relationship to the terminally ill individual, birth place of parents as a measure of ethnic origin, education, place of residence, caregiver role, and length of time family member has known about the diagnosis of cancer) and general coping style, hope, and the scores on the Non-Death Version of the Grief Experience Inventory (NDGEI) of family members of individuals with terminal cancer who are receiving palliative care at home?

(2) What, if any, are the relationships among general coping style, hope, and the grief profile as measured by the NDGEI (Sanders et al., 1985) subscales, in family members of individuals with terminal cancer who are receiving palliative care at home?

Method

Purpose and Design

An exploratory, cross-sectional, correlational design was used to examine general coping style, hope, and anticipatory grief in family members of individuals with terminal cancer and to assess the relative effect of demographic variables.

Sample

The target population was family members of individuals with terminal cancer receiving home care. A family member was conceptualized as a person living within the same household as the ill individual or biological family, who may or may not be living in the same household. Subjects were selected from the Palliative Care Home Care Service of the Royal Victoria Hospital (RVH), Association d'Entraide Ville-Marie (AEV), and The Victorian Order of Nurses (West Island Branch) (VON). These services include nursing care for individuals with terminal cancer at home.

Family members meeting the following criteria were asked to participate in the study:

(1) they had another family member who had been diagnosed with terminal cancer, that is, the cancer was irreversible and the individual with cancer was not receiving any further curative treatment;

(2) they lived within the urban transport network of Montreal and suburbs but not necessarily with the individual with cancer;

(3) they were able to read and comprehend English;

(4) they were 18 years of age or older;

(5) the individual with cancer was receiving home care;

(6) the individual with cancer was 21 years of age or older; and

(7) the individual with cancer and each family member in the study were aware of the diagnosis and prognosis.

Exclusion criteria included concurrent losses not associated with the diagnosis of cancer in the family member, such as loss of a limb due to a motor vehicle accident.

Sample size was determined using tables which take into consideration the number of independent variables, the significance level, the power associated with the test, and the anticipated effect size (Cohen, 1992). A sample size of 84 was calculated for four independent variables to assure a medium effect size at the .05 significance level with a power of .80.

Instruments

Non-Death Version of the Grief Experience Inventory. Anticipatory grief was conceptualized as the physical, psychological, and social responses occurring prior to imminent death of a family member. It was operationalized with the Non-Death Version of the Grief Experience Inventory (NDGEI) (Sanders et al., 1985), a shortened version of the Grief Experience Inventory (GEI) (Sanders at al., 1979) (see Appendices A, B, C, and D). The NDGEI was a broad, multidimensional measure of grief designed to assess grief through self-report. It consisted of 104 statements that were found to be frequently associated with grief and bereavement. These statements reflected six bereavement scales, three validity scales, and six research scales. Each item was answered true or false. True responses gave summative subscale scores.

The NDGEI had been tested with 127 individuals (42 separated women, 30 divorced women, 30 adult children who had placed their aged parent in a long-term facility and 25 parents of disabled children). Despite the small sample size, Sanders and her associates (1985) concluded that the NDGEI was useful in measuring the grief response of these individuals.

Zinner, Ball, Stutts, and Mikulka (1991) confirmed construction of the NDGEI and offered support for the validity and strength of the NDGEI as a tool for measuring grief in a variety of loss situations. They used the NDGEI in a cross-sectional study of grief reactions of mothers' of brain-injured adolescents and young adults ($\underline{n}=102$).

Reliability and validity of the NDGEI were based on the GEI. A panel of experts evaluated content validity of the GEI. A comparison of the subscales of the GEI with similar scales from the Minnesota Multiphasic Personality Inventory (MMPI) determined convergent validity. It was found that the GEI was measuring similar constructs to the MMPI, yet the factors identified by factor analysis were different for the GEI and the MMPI. Factor analysis also demonstrated that the GEI was measuring grief and not clinical depression (Sanders et al., 1979). Further support for the validity of the GEI was shown by its ability to distinguish bereaved from non-bereaved. Construct validity was established by the GEI's sensitivity to differences in the type of bereavement experienced. Discriminant validity was established by comparing scores of bereaved and non-bereaved subjects on the subscales. T-test results were significant on all subscales ($p < .001$).

Coefficient alpha values between .52 and .84 demonstrated moderate internal consistency of the bereavement scales in the GEI. Test-retest reliability coefficients ranged from .53 to .87.

Although the NDGEI has not been tested with individuals anticipating the death of a family member due to terminal illness, the present study subjects shared something in common with the populations who had tested the NDGEI - they were all experiencing losses not due to death. The NDGEI was preferred to the Anticipatory Grief Experience Inventory (Levy, 1991), which did not have established validity and reliability, because of its ability to offer an in-depth, comprehensive picture of grief.

Jalowiec Coping Scale. Coping style was conceptualized as an individual's usual way of using a specific group of strategies identified as confrontive, palliative or emotive to deal with stress across life events. It was operationalized with the Jalowiec Coping Scale (JCS) (Jalowiec, 1987). (See Appendices E, F, and G). The JCS was a 40-item, 5-point, Likert scale (1 = does not apply or not used; 5 = used a great deal) which measured the frequency with which a wide range of thoughts and acts were used by individuals to deal with the internal and external demands of stressful situations.

The JCS has shown stability over a two-week and one-month intervals. The homogeneity of the JCS has been supported by alpha reliability coefficients of .85 (n=150 dialysis patients) and .86 (n=141 emergency room patients) (Baldree, Murphy, & Powers, 1982; Jalowiec & Powers, 1981; Murphy, 1982; Swanson, 1982). According to Jalowiec, Murphy and Powers (1984) the diverse and large number of items used in the tool along with the way the tool was systematically developed confirmed content validity. Construct validity has been supported by the reliability coefficients (.85 for problem-oriented, .79 for total coping score, and .86 for affective-oriented coping) and factor analysis with varimax rotation revealing two factors: factor I consisted of 80% of the problem-oriented items, and 56% of the affective-oriented items loaded on factor II. These results were similar to those found by Folkman and Lazarus (1980).

The original dichotomous classification has been modified through further factor analysis using data on fourteen hundred subjects. The new model consisted of three factors: emotive, palliative, and confrontive. Palliative strategies referred to trying to accept and/or forget the situation, whereas emotive strategies attempted to deal with the distressing emotions. Confrontive strategies, focused on the problem, included trying out solutions and seeking information. Emotive strategies were exemplified by getting nervous or worrying, and palliative strategies were depicted by sleep, not worrying, and compromise. Discrimination was considered good based on Cronbach's alpha coefficients of .85, .70 and .75. Spearman's test-retest reliability was .79 at a two-week interval.

The JCS was selected because the objective of this study was to measure individual general coping styles. Since the lead question was not situation-specific, it was possible to measure usual behavior.

Herth Hope Index. Hope was conceptualized as a cognitive, action-oriented expectation that a positive future goal is possible. It was operationalized with the Herth Hope Index (HHI) (Herth, 1991). (See Appendices H and I). The HHI was a 12-item, 4-point Likert scale developed to evaluate the multidimensional aspects of hope in adults. Scores ranged from 12-48, with a higher score reflecting greater hope. The scale was a refinement of the Herth Hope Scale (Herth, 1989).

Content validity of the HHI has been established by measurement and content experts, nurse experts in the area of hope, and clients. The readability, the explicitness and simplicity of each item, and the congruence of each item with the conceptual definition in the original HHS have been evaluated by three experts in measurement and instrument construction. The HHI has yet to be evaluated for the influence of social desirability.

Internal consistency reliability has been supported with Cronbach's alpha (.90 to .97). The two week test-retest reliability co-efficient ranged between .89 and .91. In a study exploring the meaning of hope in terminally-ill hospice adults, Herth (1991) obtained a Cronbach's alpha of .89 showing internal consistency with this population. The HHI had a negative correlation (r=-.73) with the Beck Hopelessness Scale (Beck, Weissman, Lester, & Trexlar, 1974). High correlations with the HHS (Herth, 1989), r=.92, the

Nowotny Hope Scale (Nowotny, 1989), r=.81, and the Existential Well-Being Scale, r=.84, established criterion-related validity. Construct validity was evaluated by using maximum-likelihood factor analysis with varimax rotation on the combined data from all three studies (N=367). Three factors (positive readiness and expectancy, temporality, and interconnectedness) were found to explain 51% of the variance. The average score for well persons (M=39.62, SD=6.21) differed significantly from that of ill persons (M=34.49, SD=9.61). Further psychometric testing is currently being done on the HHI with acute, chronic and terminally ill adults in a variety of settings.

The HHI was selected since it was short but it captured the multidimensionality of hope. Additionally, it had established validity and reliability.

Background Information Sheet. Information about demographic characteristics was obtained from a questionnaire developed for this study (See Appendix J).

Comparison of instruments. The JCS, HHI, and NDGEI were examined for overlap of items (See Appendix K). The overlap between the JCS and the HHI was less than 1%. A 5% overlap was found between items on the JCS and the NDGEI. There was an 8% overlap identified between items on the HHI and the NDGEI.

Procedure

Upon receiving scientific and ethical approval from the McGill School of Nursing Scientific and Ethical Review Committee and the Ethical Review Board of the various institutions where recruitment was done (see Appendix L), the researcher asked nurses to identify family members who met the eligibility criteria. The nurse distributed a letter (see Appendix M) to each eligible family member, either directly or through the patient, approximately one to two weeks after the patient was admitted to the Home Care Service (HCS). Family members interested in finding out more about the study were asked to put their name and telephone number on the letter and return it to the nurse. If they wished, they were also able to contact the researcher directly.

The researcher contacted each interested family member within one week to arrange a visit. Family members who refused to participate were asked the reason for their decision. Measurements were made no sooner than two weeks following the ill individual's acceptance to the HCS based on the nurses' request to establish a rapport with the family before introducing them to the study. It was also believed that there would be confounding of results during this time since the family was undergoing a transition into the HCS, as well as coping with the imminent death of one of its family members. The transition into the HCS, like all transitions, would have evoked feelings of loss, stimulating the grief response (Davies et al., 1990; Parkes, 1971).

Pre-testing of the procedure was done on the first five family members who consented to participate to assess feasibility and usefulness of using the instruments, especially the NDGEI. These participants were included in the final sample since there were no required changes in the way the NDGEI was administered. The questionnaires took about 30 minutes to complete.

A complete verbal explanation of the study was given to each family member during the interview. Informed written consent (See Appendix M) was obtained before administering the instruments; the demographic sheet, the JCS, the NDGEI, and the HHI. Since participants would vary in reading levels and the elderly might have visual impairment, the researcher was available in person to answer questions or address any concerns. Face-to-face contact ensured a higher return rate in comparison to mailed questionnaires. In addition, it ensured that the individuals who agreed to participate were the ones who actually completed the questionnaires and that family members did not discuss their answers to the questionnaires as they filled them out.

Assumptions

According to clinical experience and the literature on grief and loss, it was assumed that family members of individuals with terminal cancer gradually experienced some or all of the phases of normal grief as they coped with the illness.

Ethical Considerations

Family members' rights were protected through an informed consent. Family members were given all information essential for making an informed decision about whether to participate or not. They were informed that participation in the study was completely voluntary and that they might withdraw any time.

Anonymity and confidentiality were maintained by keeping all data in a locked file cabinet; only code numbers were used on the questionnaires. Data were accessible only to the study personnel.

There were no direct benefits of participation in this study. However, the results might benefit other people who have a family member with terminal cancer by increasing knowledge and understanding of the phenomenon. Because of this, the risks appeared small, and the potential outcomes might benefit many family members. The opportunity to talk to the researcher following testing was provided in case the family members wished to share their feelings with a concerned person. If necessary, referrals were made to the home care nurse.

Data Analysis

Data analysis was performed using the SAS statistical package (SAS, 1987). Analysis was conducted through a combination of Pearson correlation coefficients and regression techniques. Missing data were replaced by mean scores to reduce the chance of finding false positive results.

Descriptive data for coping included mean total scores for each style of coping, mean scores across items within each style to show comparability of styles and to identifiy an individual's predominant style of coping, as well as frequency of a predominant style in the population. In addition, mean scores for each anticipatory grief subscale were computed to provide individual and group anticipatory grief profiles. For comparison of the anticipatory grief profile and the grief profile, raw scores were converted to T-scores.

Examination of the data for outliers (standard deviation from the mean of greater than two) showed more than one positive outlier on each dimension of anticipatory grief. Therefore, square root transformations were performed on each dimension of anticipatory grief for use in the stepwise regression analysis (Tabachnick & Fidell, 1989).

Correlation and/or regressions were performed between each of the demographic variables and interactions of demographic variables with the general styles of coping, hope, and anticipatory grief. Those demographic variables that were significantly correlated with more than three of the anticipatory grief variables at a significance level of .05 or lower were considered as covariates in the multiple regression of coping styles and hope on the dimensions of anticipatory grief. Two variables, age and relationship, met the criteria.

Coping styles, hope, age, and relationship were regressed on each of the six dimensions of anticipatory grief. They were entered stepwise with the following criteria: (1) overall regression equation significance of .05 or lower and, (2) independent variable included in the equation accounted for significant variance not accounted for by the other variables. Correlations between the styles of coping, hope, and the anticipatory grief variables were calculated to identify the strength and direction of relationships.

Findings

The findings are presented in four sections. First, information about the sample size is presented. Second, a description of the sample characteristics is given. The last two sections report results of data analysis according to each research question.

Sample Size

One hundred and fifty-seven family members expressed interest in the study and agreed to be contacted by the researcher. Forty-two of these refused to participate and 32 did not meet eligibility criteria. Overall, 83 individuals participated.

Data from three of the 83 family members were excluded because of denial scores exceeding seven. Sanders and her colleagues (1985) incorporated a denial scale into the NDGEI to identify an unwillingness to acknowledge or confront socially desirable weaknesses and feelings. The scale was designed to measure general denial, not only denial of grief or denial of imminent death. The developers of the NDGEI indicated that denial scores exceeding seven (T-score greater than 70) made the bereavement scales uninterpretable.

Data from the 80 participants were examined to see whether multiple participants from the same family showed a family pattern. Overall, 19 participants constituted additional family members in a total of 14 families.

Relative scores computed on coping styles for each family member within a family unit showed potential family patterns (see Appendix N). Nine of the fourteen families showed similar relative scores on confrontive coping suggesting the existence of a family pattern. Yet, mean scores computed on the three styles of coping for individual family members within ten family units revealed some variation offering evidence of individual variation. Given that the data suggested that family patterns might exist, the decision was made to retain only one family member per family for the study sample to avoid lack of statistical independence. Therefore, data from the first family member interviewed in each family were used in the analyses ($\underline{N}=61$).

Sample Characteristics

Demographic data about family members themselves are summarized in Table 1 (see Appendix O for demographic and descriptive data on the extra 19 family members). The sample comprised mainly middle-aged daughters. More than 80% of family members had a minimum of high school education. The birth place of most participants' parents was outside North America. Most respondents lived with the ill family member, and in over 30 cases, the participant was the main caregiver. However, the main caregiver did not always reside in the same household as the ill person. Frequently, family

Table 1

Descriptive Statistics of Demographic Variables for Family Members

Demographic Variables	n	%
Relationship		
spouse	19	31.15
child	32	52.46
other	10	16.39
Gender		
female	37	60.66
male	24	39.34
Level of education		
some high school or less	10	16.39
high school/college diploma	24	39.35
university degree	27	44.26
Place of residence		
resides with ill person	33	54.10
resides elsewhere	28	45.90

Table 1 continues

Table 1 continued

Demographic Variables	n	%
Birth place of parents		
North America	29	47.54
Europe	24	39.34
Asia	5	8.20
Africa	1	1.64
South America	2	3.28
Time aware of cancer diagnosis		
< 6 months	11	18.03
6 months-2 years	20	32.79
> 2 years	30	49.18
Caregiver role		
Primary	33	54.10
Non-primary	28	45.90

Demographic Variable	M	SD	Min	Max
Age	48.02	18.30	18 yrs.	81 yrs.

members had been aware of the patient's diagnosis of cancer for more than two years.

The average age of ill family members was 63.50 with a range between 39 years and 81 years. Thirty-two (52%) of the ill family members were female.

Family members who did not participate said they had changed their minds and refused to participate because they were "too busy" or "it was not a good time for me due to changes in the ill family member necessitating increased care." Some did not meet eligibility criteria (ill family members were hospitalized or died before a visit could be made, family member did not understand enough English to complete the questionnaire, and one family member was blind). Some family members who met the eligibility criteria were not referred by the nurse because they were perceived as too vulnerable and emotionally unable to cope with the stress of completing the questionnaires.

Description of Coping Styles, Hope, and Anticipatory Grief

The Jalowiec Coping Scale (JCS) (Jalowiec, 1987) measured three styles of coping: emotive, palliative, and confrontive as individual variables and as relative scores showing a predominant style. Table 2 shows descriptive

Table 2

Descriptive Statistics for the Jalowiec Coping Scale

Scale	no. items	M	SD	M scores across items	frequency of predominant coping style
Emotive Coping	9	21.21	5.60	2.36	16%
Palliative Coping	19	42.11	7.64	2.22	7%
Confrontive Coping	12	38.21	9.15	3.18	77%

data for the JCS. Overall, the participants were predominantly confrontive copers who used palliative coping strategies the least.

A total score was computed for the Herth Hope Index (Herth, 1985), with higher scores indicative of higher levels of hope. The mean score was 37.38 (SD=5.30, range=23-48).

The Non-Death Version of the Grief Experience Inventory (NDGEI) (Sanders et al., 1985) had six bereavement scales and three validity scales. A summary of the descriptive analysis is displayed in Table 3. Individual anticipatory grief profiles were generated in two ways: (1) by computing percentage scores to reflect the picture of anticipatory grief for the present sample as individuals and group means, and (2) by converting raw data on each bereavement scale into a standard T-score provided by Sanders and her associates (1985) to allow for comparisons with their sample. See Appendix P for comparison with work by the developers of the NDGEI.

Examination of the profiles revealed that anticipatory grief, as defined by the presence of at least four of the six dimensions measured by the NDGEI, was experienced by all family members. The range of scores on each subscale indicated that not every family member experienced feelings of despair, anger/ hostility, loss of control, and social isolation.

Table 3

Descriptive Statistics for the Subscales of the Non-Death Version of the Grief Experience Inventory

Scale/Subscale	no. items	M	SD	Range
Bereavement				
Despair	17	5.31	3.59	0-16
Anger/Hostility	7	3.39	1.95	0-7
Somatization	19	6.90	1.99	3-11
Loss of Control	7	2.69	1.30	0-5
Social Isolation	7	2.93	1.48	0-7
Death Anxiety	11	6.00	1.91	2-10
Validity				
Denial	11	3.69	1.90	1-7
Social Desirability	6	3.87	1.20	1-6
Atypical Responses	20	8.20	1.84	5-11

Note. Higher score = greater use of the subscale

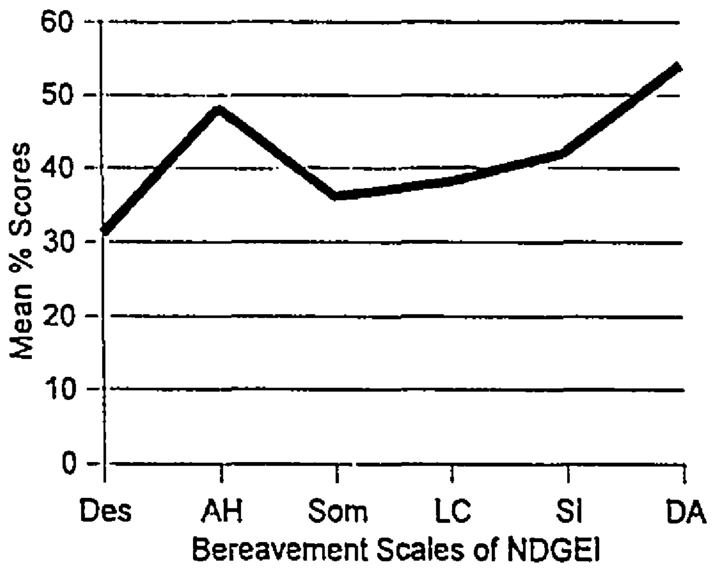
Overall, the anticipatory grief profile showed a picture of moderately high anticipatory grief for family members (see Figure 2). Death anxiety had the highest mean percentage score with accompanying feelings of anger/hostility and social isolation.

Profiles for men and women revealed higher mean scores for women on all dimensions of anticipatory grief except social isolation (see Figure 3), but only despair and anger/hostility showed significant differences. Profiles for spouses and children showed that children experienced more of the dimensions of anticipatory grief than spouses (see Figure 3).

Pearson correlation coefficients among the three general styles of coping, hope, and the dimensions of anticipatory grief are displayed in Table 4. The correlations show a moderately high relationship between emotive coping and anticipatory grief except death anxiety, a moderate correlation between hope and confrontive coping, low to moderately high correlations between lack of hope, emotive coping and all dimensions of anticipatory grief except death anxiety, and moderately high associations between all the dimensions of anticipatory grief except death anxiety.

Figure 2

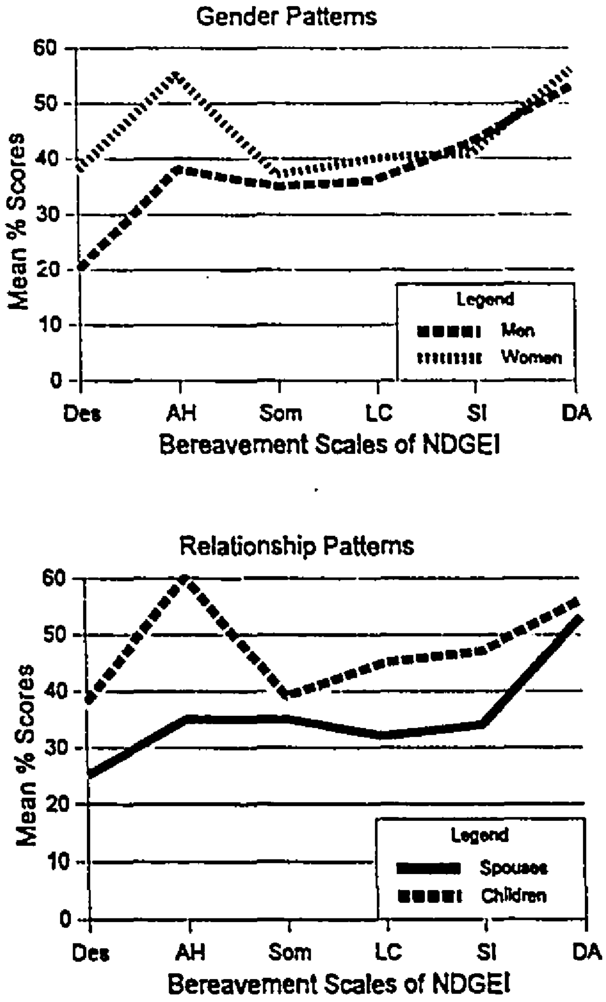
Anticipatory Grief Patterns as Defined by the Bereavement Scales of the Non-Death Version of the Grief Experience Inventory (NDGEI)



Note. Des=despair, AH=anger/hostility, Som=somatization, LC=loss of control, SI=social isolation, DA=death anxiety

Figure 3

Gender and Relationship Anticipatory Grief Patterns as Defined by the Non-Death Version of the Grief Experience Inventory (NDGEI)



Note. Des=despair, AH=anger/hostility, Som=somatization, LC=loss of control, SI=social isolation, DA=death anxiety

Table 4

Pearson Correlation Coefficients for Hope, the Six Dimensions of Anticipatory Grief (NDGEI), and the Three Styles of Coping (JCS)

	Hope	NDGEI Bereavement Scales						JCS Scales		
		Des	A/H	Som	LC	SI	DA	Emot	Pall	Conf
Des	-.57**	---	---	---	---	---	---	---	---	---
A/H	-.28*	+.55**	---	---	---	---	---	---	---	---
Som	-.43**	+.59**	+.48**	---	---	---	---	---	---	---
LC	-.52**	+.55**	+.49**	+.64**	---	---	---	---	---	---
SI	-.42**	+.42**	+.27*	+.28*	+.42**	---	---	---	---	---
DA	-.18	+.24	+.22	+.22	+.23	+.22	---	---	---	---
Emot	-.43**	+.77**	+.58**	+.45**	+.42**	+.36**	+.17	---	---	---
Pall	-.03	+.24	+.03	+.07	+.02	+.13	+.12	+.28*	---	---
Conf	+.33*	-.02	+.13	-.04	-.07	-.14	+.02	+.12	+.26*	---

Note. Des=despair, AH=anger/hostility, Som=somatization, LC=loss of control, SI=social isolation, DA=death anxiety, Emot=emotive, Pall=palliative, Conf=confrontive, * = $p<.05$, ** = $p<.001$

Relationships Between the Demographic Variables and General Coping Style, Hope, and Anticipatory Grief

Correlation coefficients were computed between the demographic variables (age, gender, relationship, birth place of parents, education, place of residence, caregiver role, and length of awareness of cancer diagnosis), hope and each style of coping (see Table 5). Demographic variables were hierarchically regressed on each dimension of anticipatory grief. Findings for the regressions are presented for main and interaction effects with a minimum significance level of .05.

General coping style and hope. Correlations revealed a moderate relationship between emotive coping and age and gender of the participating family member (see Table 5). Women used more emotive coping strategies than men. Younger adult children reported the use of more emotive coping than older adult children.

Results for palliative coping showed a moderate correlation with level of education. Palliative coping strategies were used more frequently by participants who had less than a high school education. Confrontive coping was used more by participants who did not reside with the ill person. Higher levels of hope were reported by older participants.

Table 5

Correlation Coefficients for the Demographic Variables, Hope, and the Three Styles of Coping (JCS)

Demographic Variables	Hope	JCS Scales		
		Emotive	Palliative	Confrontive
Age of Family Member	+.39**	- .39**	+.21	+.30
Gender of Family Member	+.02	+.36**	+.20	+.18
Relationship	- .07	+.05	- .05	+.14
Birth Place of Parents	+.10	- .02	+.09	+.09
Level of Education	+.09	- .18	- .28*	+.24
Place of Residence	+.11	+.03	- .11	+.31*
Caregiver Role	- .13	+.20	- .21	+.00
Time Aware of Cancer Dx.	- .10	- .07	- .02	- .03
Age of Ill Person	+.12	- .19	- .10	+.05
Gender of Ill Person	- .05	- .10	- .10	+.05

Note. * = $p<.05$, ** = $p<.001$; Dx. = diagnosis; Canonical correlations were performed on relationship and birth place of parents, Spearman correlations were computed for education and time aware of diagnosis, and Pearson correlations were performed on the remaining variables.

Anticipatory grief. Three main effects were found for despair: gender, relationship to the ill family member, and age (see Table 6). Women reported more despair than men, and children more than spouses. An inverse relationship was found between age and despair. The only interaction effect did not contradict or add any information to the main effects.

Anger/hostility was experienced differently based on relationship to the ill family member, age, level of education, place of residence, caregiver role, and gender (see Table 7). Anger/hostility was expressed more by children than by spouses, younger individuals more than older, participants with a higher level of education, individuals not living with the ill family member, non-primary caregivers, and women.

Several interaction effects were found. While all interaction effects are reported in Table 7, only the one with a significance level of .05 and at least five subjects per cell is described. The eighteen less educated children reported more feelings of anger/hostility than the thirteen university educated spouses or other relatives.

Somatization was expressed more by children than by other friends or relatives, providing the only main effect (df=2, $\underline{R}^2=.10$, $\underline{F}=3.40$, $\underline{p}<.001$). Interaction effects were not found.

Table 6

Hierarchical Regression of Demographic Variables on Despair

Demographic Variables	df	R^2	*F*	*p*
Main Effects				
gender	1	.20	14.39	<.001
relationship	2	.15	4.96	<.05
age	1	.13	8.96	<.001
Interaction Effects				
age of ill person/gender	1	.20	4.04	<.05

Table 7

Hierarchical Regression of Demographic Variables on Anger/Hostility

Demographic Variables	df	R^2	F	p
Main Effects				
relationship	2	.20	7.54	<.001
age	1	.12	7.99	<.001
level of education	2	.12	3.83	<.05
place of residence	1	.09	5.64	<.05
caregiver status	1	.08	5.07	<.05
gender	1	.07	4.63	<.05
Interaction Effects				
level of education/ relationship	4	.38	2.80	<.05
relationship/ethnic origin	3	.37	3.26	<.05
age of ill person/place of residence	1	.09	4.96	<.05

Note. Degrees of freedom are lower than expected for the interaction between relationship and ethnic origin because some cells are missing data.

A negative relationship was found between loss of control and age (see Table 8). Spouses experienced more loss of control than friends or relatives other than children. Interaction effects showed differences based on place of origin of participants' parents. The one woman of South American descent experienced less loss of control than men or women of European descent (n=18).

Age was the only main effect found for social isolation (df=1, R^2=.07, F=4.44, $p<.05$); interaction effects were not found. Younger participants (n=37) experienced more social isolation than older participants (n=24).

The experience of death anxiety differed according to two interactions. Death anxiety was reported more by older participants aware of the diagnosis of cancer for less than six months than by younger participants who had been aware of the diagnosis of cancer for six months to two years (df=2, R^2=.19, F=5.94, $p<.001$). Main caregivers aware of the diagnosis of cancer for less than six months reported more death anxiety than participants who had been primary caregivers for six months to two years (df=2, R^2=.18, F=3.17, $p<.05$).

Comparison with NDGEI norms. Sanders and colleagues (1985) believed that denial would influence one's grief profile. In this study, the mean score for denial was 3.69. All participants scored a minimum of one on

Table 8

Hierarchical Regression of Demographic Variables on Loss of Control

Demographic Variables	df	R^2	F	p
Main Effects				
age	1	.15	10.29	<.001
relationship	2	.10	3.25	<.05
Interaction Effects				
ethnic origin/gender	3	.27	4.05	<.05

Note. Degrees of freedom are lower than expected for the interaction because some cells are missing data.

the scale. Mean scores for denial were also computed separately for men and women, as well as spouses and children. Although significant mean differences were not found for gender or relationship, the data suggested that spouses ($\underline{M}$=4.53) used more denial than children ($\underline{M}$=3.20).

Since the NDGEI had not been used previously to measure anticipatory grief in family members of individuals with terminal cancer, internal consistency was computed and t-tests comparing sample means with Sanders and her associate's (1985) samples were carried out (see Appendix P). A principal components analysis was performed to see if items loaded well on the dimensions of anticipatory grief as defined by Sanders and her colleagues. Items loaded well on six factors supporting Sanders and her associate's identification of six dimensions of anticipatory grief.

Relationships Among General Coping Style, Hope, and Anticipatory Grief

The main purpose of this study was to examine what, if any, relationships existed among general coping styles (emotive, palliative, and confrontive), hope, and anticipatory grief (despair, anger/hostility, somatization, loss of control, social isolation, and death anxiety) in family members of individuals with terminal cancer receiving home care.

The main effects from the regression analyses previously reported revealed that the demographic variables accounted for significant variation in only four of the six dependent variables: despair, anger/hostility, somatization, and loss of control. Overall, the amount of variation in each dependent variable accounted for by individual demographic variables was moderately low. Age and relationship were the only demographic variables that accounted for significant variation in more than three of the dimensions of anticipatory grief, therefore they were controlled for in further regression analyses.

Separate stepwise multiple regression analyses were performed for each dimension of anticipatory grief using the three styles of coping (emotive, palliative, and confrontive), hope, age, and relationship to determine relationships. A predictor variable was accepted if both the part correlation of the subscales and the overall F-ratio were significant ($p < .05$).

Despair. The best linear combination of variables to predict despair was emotive coping and hope. Table 9 shows the correlations associated with each step of the analysis in the development of this predictive model. Emotive coping showed a direct relationship to despair, whereas hope showed an inverse relationship. In combination, emotive coping and hope accounted for 59% of the known variation in despair.

Anger/hostility. Emotive coping, the only variable identified as predictive of anger/hostility, was directly related to it ($df=1$, $R^2=.58$, $F=30.42$, $p<.001$).

Table 9

Stepwise Regression Analysis of Predictor Variables on Despair

Predictor Variable	df	sr^2	F	p	R^2	R	p
Step 1							
Emotive coping	1	.59	83.92	<.001	.59	.77	<.001
Step 2							
Hope	2	.07	12.03	<.001	.66	.81	<.001

Somatization. The specific model for predicting somatization was emotive coping and hope. Emotive coping, which contributed the most significant amount of variation in somatization, was positively related to it. In contrast, hope was inversely related to it. Twenty-seven percent of the variation in somatization was explained by these two predictor variables. Findings also revealed that the interaction between emotive coping and hope added significant variation in somatization. Findings are displayed in Table 10.

Loss of control. The best linear combination of factors to predict loss of control was hope and emotive coping. This set of factors shared a significant combined contribution of 32% of the known variation in loss of control. As indicated in Table 11, hope was the most important variable in contributing unique variation for loss of control. It related inversely to both loss of control and emotive coping.

Social isolation. A stepwise-generated equation revealed that lack of hope was the only variable that contributed significant variation in social isolation (df=1, R^2=.18, F=12.67, $p<.001$).

Death anxiety. Neither the styles of general coping nor hope entered the regression equation.

Table 10

Stepwise Regression Analysis of Predictor Variables on Somatization

Predictor Variable	df	sr^2	F	p	R^2	R	p
Step 1							
Emotive coping	1	.20	14.83	<.001	.20	.45	<.001
Step 2							
Hope	2	.07	5.54	<.05	.27	.52	<.05
Step 3							
Emotive coping/Hope	3	.08	7.21	<.001	.35	.59	<.001

Table 11

<u>Stepwise Regression Analysis of Predictor Variables on Loss of Control</u>

Predictor Variable	df	sr^2	F	p	R^2	R	p
Step 1							
Hope	1	.27	22.15	$< .001$	.27	.52	$< .001$
Step 2							
Emotive coping	2	.05	4.03	$< .001$	.32	.57	$< .05$

Total sample. Analyses were also carried out separately with the larger sample (N=80) including more than one participating family member per family. Findings revealed two differences from the basic sample. First, emotive coping, not hope, accounted for variation in social isolation. Second, emotive coping entered the regression equation before hope for loss of control. However, since these two variables were highly correlated, these differences were not surprising.

Summary

Analyses on general coping style, hope, and anticipatory grief revealed that confrontive coping was the predominate coping style, that all family members experienced some level of hope, and that each family member experienced individual anticipatory grief patterns. Specifically, women used more emotive coping strategies than men. Education was the discriminating factor for palliative coping, whereas place of residence was the discriminating factor for confrontive coping. Older individuals reported higher hope levels. Women experienced more despair and anger/hostility than men. Spouses reported less despair, anger/ hostility, social isolation, and loss of control than children.

A multiple regression performed on each bereavement subscale of the NDGEI revealed that the best predictors for despair, somatization, and loss of control were emotive coping and lack of hope. The latter two variables were highly correlated, but anger/hostility was best predicted by emotive coping and social isolation by lack of hope. None of the coping styles, hope, age, or relationship predicted death anxiety. Additionally, it was found that an interaction effect between emotive coping and hope was significantly correlated with somatization. Since much of the variation in each variable was unaccounted for in the models, apparently other predictors exist.

Discussion

This section includes a discussion of the concept of anticipatory grief, an analysis of results found between the demographic variables and general coping style, hope, and anticipatory grief, and an examination of the findings among general coping style, hope, and anticipatory grief. It also addresses strengths and limitations, research implications, and finally, clinical implications.

There has been ongoing debate in the literature surrounding the existence of anticipatory grief, dating back to the early 1940s when Lindemann (1944) first used the term (Clayton et al., 1972; Kubler-Ross, 1969; Kutscher, 1969; Parkes & Weiss, 1983; Rando, 1988; Vachon et al., 1982). Definitions have varied, as have perspectives on its utility in understanding the bereavement process. Few researchers have attempted to study the concept prospectively in the person with terminal cancer, even fewer in family members. Findings from this study lend support to theoretical discussions in the literature that claim the existence of grief before death.

Findings established that anticipatory grief is experienced by most family members. They presented a moderately high anticipatory grief profile characterized by feelings of despair, anger/hostility, somatization, loss of control, social isolation, and death anxiety. This picture of anticipatory grief corroborates what other researchers have found (Bolwby, 1961; Parkes, 1970, 1972; Welch, 1982). In addition, the profile showed that death anxiety was not only an important component of anticipatory grief, but the most prevalent dimension in this population. Death anxiety has never been consistently reported in the grief literature as a component of anticipatory grief. It is plausible that bereaved individuals in other studies responding retrospectively to questions about anticipatory grief may not be as intensely aware of death.

Some researchers have offered a more comprehensive picture of anticipatory grief that encompasses more than emotional responses. They indicate that it also consists of coping, interaction, planning, and reorganization (Levy, 1991; Rando, 1988). It is possible that anticipatory grief is a more complex phenomena than identified in the present research. Regardless, it is clear, from the present research and reports in the grief literature, that anticipatory grief is a multidimensional phenomenon with some common dimensions across individuals, such as despair, anger/hostility, and somatic distress. Furthermore, findings support others who have found that anticipatory grief is individualistic (Glick, Weiss, & Parkes, 1974; Kubler-Ross, 1969; Zisook, Devaul, & Click, 1982).

The Relationships Between the Demographic Variables and General Coping Style, Hope, and Anticipatory Grief

Relationships were identified between several demographic variables and general coping style. As expected, women reported using more emotive coping strategies than men (Billings & Moos, 1981; Folkman & Lazarus, 1980). Another expected finding was that younger individuals used more emotive coping strategies than older individuals (Gass & Chang, 1989). A new finding was that less education was related to the use of more palliative coping strategies. Contrary to some research findings (Gass & Chang, 1989; Lazarus & Folkman, 1984), education was not related to emotive coping, except in combination with other demographic variables. This may have been due to the small number of participants without a high school diploma. According to coping research (Gass & Chang, 1989; Lazarus & Folkman, 1984), individuals who use predominantly confrontive coping were those having a high level of education. Results showed that education was related to confrontive coping but only in combination with place of residence, offering partial support to previous research findings.

Study results showed that some, but not all, of the demographic variables related to one or more dimensions of anticipatory grief. It was found that women experienced more despair and anger/hostility than men, which is supportive of findings in the grief literature. Although previous studies had explored this relationship with similar findings (Broverman, Vogol, & Broverman, 1972; Glick, Weiss, & Parkes, 1974; Lundin, 1984a; Sanders, 1979-80), comparisons between studies were limited because of differences in the conceptualization of anticipatory grief and grief, and the focus of the studies (pre-death versus post-death).

An unexpected finding was that gender did not make a significant difference in the experience of somatic distress. This suggests that the belief that women experience more intense somatic distress than men be rethought (Broverman et al., 1972; Kirschling & McBride, 1989).

The research literature indicated that young persons experience more grief than middle-aged or older persons (Ball, 1976-77). The present study supported this in that age was inversely related to despair, anger/hostility, and loss of control ($p < .05$). New information about anticipatory grief was contributed by the finding that adult children expressed more intense anger/hostility than spouses. This may be confounded with age in that the mean age of adult children was 35 years compared to 69 years for spouses. Theoretically, a young person would be expected to have less experience with the grief process than an older person. It may also be that older persons have more information about grief from others (Jecker, 1991), stronger spiritual beliefs that foster an acceptance or comprehension of death, or increased ability to openly express grief.

A prevalent, clinical assumption has been that the younger the ill family member the more intensely the well family member grieves (Callahan, 1987; Jecker & Schneiderman, 1994). A contradictory finding was the failure to show that age of the ill family member made a difference in the family member's experience of anticipatory grief.

Unlike findings from a previous study conducted by Steele (1990), length of illness did not make a difference in how anger/hostility was expressed. Differing results might be accounted for by the difference in how length of illness was defined in the studies, that is, length of medical diagnosis of cancer versus awareness of diagnosis. The two definitions are not necessarily synonymous.

Study findings suggested that ethnic origin accounted for some variation in anticipatory grief. Due to small sample sizes for many ethnic origins, generalizations cannot be made about patterns in people with different ethnic origins. It would be of interest to explore this relationship further, especially since it has been identified that culture influences one's expression of grief (Jecker & Schneiderman, 1994; Rosenbaum, 1991), and the findings support this.

The Relationships Among General Coping Style, Hope and Anticipatory Grief

The present study was the first in which effort was made to identify the relationships among general coping style, hope, and anticipatory grief, as well as to include family members regardless of whether they were the primary caregivers. It was not surprising that emotive coping was the only coping style that accounted for variance in anticipatory grief since the dimensions of anticipatory grief are emotional reactions. Findings confirmed the expectation that hope would be negatively associated with anticipatory grief. Furthermore, hope was inversely related to emotive coping and directly related to confrontive coping as had been found by Herth (1990a). Clearly, both simple correlations and multiple regression analyses established associations between general coping style, hope, and anticipatory grief.

Specific patterns were observed for two styles of coping. People who used emotive coping strategies were likely to respond with an anticipatory grief pattern characterized by high levels of all dimensions except death anxiety: despair, anger/hostility, somatization, loss of control, and social isolation ($p<.001$). Additionally, one could see a low level of hope ($p<.001$). People high in palliative coping, on the other hand, displayed a grief pattern characterized only by a high level of despair. Hope may exist, but it is impossible to say to what degree since a relationship was not established between palliative coping and hope. Based on present findings, it is known that those who use confrontive coping also experience anticipatory grief, but confrontive coping was not correlated with any of the dimensions of anticipatory grief. However, one would expect to see a high level of hope ($p < .001$). A stepwise discriminant function analysis to separate the three coping styles did not add anything to these profiles.

Pfost, Stevens, and Wessels (1989) suggested that anger would have a relationship with emotion-focused coping. Study findings revealed that a direct relationship exists between emotive coping and anger/hostility in family members, lending support to this hypothesis. In this study, it was women who used more emotive coping and expressed more anger than men.

Study results confirmed that hope and anticipatory grief co-exist, as previously established by other researchers (Davies et al., 1990; Friedman et al., 1983; Kubler-Ross, 1969). As well, they also supported an inverse relationship between hope and despair (Rabkin et al., 1990).

Many researchers have attempted to find out whether anticipatory grief is beneficial or detrimental to bereavement recovery. Debate is ongoing in the literature. Implicit in much of the thinking is that anticipatory grief is beneficial to bereavement. It is impossible to confirm or dispute the beneficial or deleterious effects of anticipatory grief based on findings from this study because long term effects were not examined.

It is possible to offer some support for Rando's (1983) finding that "too much" or "too little" anticipatory grief is detrimental to bereavement outcome, mindful that correlational relationships, not cause and effect, were identified in the present study. Present findings suggested that individuals who were aware of the diagnosis of cancer for less than six months or greater than two years expressed more intense anticipatory grief but this was not statistically significant. However, diagnosis of cancer and diagnosis of terminal cancer (Rando's definition) are usually not synonymous. During a short anticipatory grief period, feelings of grief might be expected to be intense and emotive coping would likely be high, while hope would be expected to be low. Both emotive coping and low hope have been linked to poor psychosocial recovery (Gass & Chang, 1989; Herth, 1990a; Rideout & Montemuro, 1985). On the other hand, if the anticipatory grief period is too long, anticipatory grief feelings might intensify or resurface, creating a similar pattern as observed for a short anticipatory grief period. Consequences would be similar. Clearly, further research needs to be conducted.

In a prior study, Herth (1990a) found a negative relationship between grief resolution and emotive coping in contrast to a positive relationship with the other styles of coping (palliative and confrontive). In this study a positive relationship was found between emotive coping and anticipatory grief. The theoretical linkages are that coping style influences anticipatory grief which facilitates post-death grief and leads to grief resolution (Herth, 1990a, Lundin, 1984a; Parkes, 1972; Vachon, 1976). The links between anticipatory grief and post-death grief have been inconsistent in empirical data. However, it is "healthy" self-limited post-death grieving that leads to grief resolution (Brock, 1984; Worden, 1991). According to grief theory (Kutscher, 1974; Lundin, 1984a; Parkes, 1972; Vachon, 1976), individuals who grieve before death are more likely to experience less grief after death. In other words, moderate or "healthy" anticipatory grief may lead to less post-death grief, but intense anticipatory grief may be indicative that there will be excessive post-death grief (Ball, 1976-77; Kutscher, 1974).

An opposing thesis is also feasible. Although only correlational results are available from the current study, it is possible that as individuals experience more anticipatory grief, they may use more emotive coping strategies. Herth (1990a) found that individuals who used fewer emotive coping strategies had a higher level of grief resolution. If post-death grief is less, then it might be possible to see the use of fewer emotive coping strategies.

It may be that anticipatory grief and grief are not related to each other, but only to coping style. It would be expected that individuals who use predominantly emotive coping strategies prior to death might also use them during bereavement and would experience higher levels of grief.

Expression of Anticipatory Grief by Family Members in the Same Family

An underlying assumption inherent in family theory literature is that family members within the same family are often expected to share similar feelings and grieve in the same ways (Quinn & Herndon, 1986). Despite this assumption, anticipatory grief profiles computed for each participating family member demonstrated that none of the participants shared identical grief patterns.

Individual coping scores on each style of coping showed that although in some families with more than one participant family members used the same coping styles, this did not hold true for all families. Families with more than two participants showed wide variation. A comparison of relative coping scores, showing the predominant coping style, suggested the presence of possible family patterns in families with two participants. However, given that 77% of all participants had the same predominant coping style, it is likely that similarities between two people in the same family did not constitute a family pattern.

Difference in Regression Findings Between the Two Samples

A comparison of the sample with only one family member per family and the sample comprised of more than one participating family member revealed some differences. Emotive coping, not hope, accounted for variance in social isolation. This finding can be explained by the moderately high correlation between emotive coping and hope (r=-.43). It might also be that the extra family members decrease feelings of social isolation, thereby mitigating the importance of low levels of hope. It was also identified that emotive coping was a more important predictor of loss of control than hope in the sample with more than one family member per family (N=80). Again, it could be that emotive coping entered the regression equation before hope in the sample of 80 because of the moderately high correlation between the two variables.

Strengths and Limitations

The study has both strengths and limitations for several reasons. Sample selection and heterogeneity of the sample led to both strengths and limitations, while problems in measurement created limitations.

Sampling technique, which gave every person in the population of interest the same chance of being included in the sample, strengthened the study by enhancing generalizability of results to this population. Specific strengths of the sampling technique included: (1) family members of terminally ill patients were not limited by the ill family member's type of cancer, and (2) all family members were studied, including those not living with the ill person.

Despite its strength, the sampling technique might have been a limitation in the study. Loss of participants, refusal to participate, and nurses' decisions not to refer family members perceived as too vulnerable resulted in self-selection creating a potentially biased sample. Additionally, all participants had been receiving hospice home care nursing. It is possible that some participants may have felt supported in their participation in a hospice home care program enabling them to report their grief.

Sample heterogeneity, like the sampling technique, was a strength of the study because it could increase generalizability of findings. However, a potential limitation of a heterogenous sample is that it decreases the clarity of results since differences in demographic data across family members could complicate regression results.

Although family members were asked to respond to highly emotional statements about feelings they were experiencing at the time, thereby strengthening study results, it was possible that some participants might have misread or misinterpreted statements leading to inaccurate responses. Due to the nature of the statements on the NDGEI, family members might have responded in socially expected ways.

Although a strength of the NDGEI was that it included subscales designed to identify socially desirable responses and atypical responses, the measure may have been a limitation. Sanders and her colleagues (1985) suggested that grief patterns be interpreted with caution in the presence of high social desirability and atypical response scores. They indicated that high social desirability scores might bias responses in a socially desirable direction, whereas high scores on the atypical response scale might reflect an unusual response set. In the present study scores did not exceed the established limits for either social desirability or atypical responses, but respondents did have moderate levels on these scales.

The presence of a health care professional experienced in caring for terminally ill individuals might have promoted more open expression of one's anticipatory grief. Participants received hospice home care, but this service is not available to everyone. Resources did not allow for the study of anticipatory grief over time or the inclusion of a comparison group from families who did not receive home care.

Research Implications

The findings from this study provide a foundation for designing further studies. For example, additional research is needed to examine anticipatory grief patterns in the same family and patterns of anticipatory grief over time. The relationship between anticipatory grief and setting remains an area for future exploration.

Given that children in this study were young adults or older, the relationship between age and relationship to family member needs to be explored further with adolescents and young children. In addition, there is need for replication of the study with other cultural groups to broaden the generalizability of findings.

Longitudinal studies are important to capture the pattern and essence of the process of anticipatory grief. They can also help identify other relevant variables and determine the effects of anticipatory grief on post-death grief. A longitudinal study would fit well with the transitional aspect of the conceptual framework.

Further validation of the NDGEI is warranted with families of terminally ill people. Although the instrument is a valid and reliable measure of grief, it is lengthy. Over 50% of participants indicated that a shorter tool would have been preferable. A shorter, valid and reliable measure of anticipatory grief needs to be developed.

Clinical Practice Implications

An understanding of the relationship between general coping style, hope, and anticipatory grief provides a base from which to develop appropriate nursing interventions for family members. Findings from this study raised several important issues for clinical practice. For example, findings suggest the need to assess anticipatory grief patterns in family members and the ill individual.

Nurses can offer specific information about anticipatory grief responses and assist families in identifying and anticipating the emotional reactions that they may experience. They can also offer reassurance that anticipatory grief reactions, especially anger/hostility, social isolation, and death anxiety, are natural in people coping with their current and anticipated losses. A frequent clinical observation is that family members often experience difficulty expressing their anger/hostility. Nurses can help family members use present coping strategies or assist them to develop new coping strategies to manage such a reaction.

By knowing that family members who experience somatic distress could have a lower level of hope, nurses can be more cognizant in addressing the family member's somatic concerns. This may appear time-consuming and unrealistic in a hectic clinical setting. Ultimately, it may prove to be time efficient and decrease potential conflicts among family members or between family members and the nursing staff.

Knowledge of a general style of coping, which can be ascertained through identification of past coping strategies, can increase the nurse's sensitivity to possible anticipatory grief patterns related to emotive, palliative, and confrontive coping. Interventions can be tailored to meet specific needs.

Rather than enhancing or preventing the expression of anticipatory grief, it appears more relevant for nurses to acknowledge, address, and choose strategies directed toward expressed feelings. A way of fostering hope, and ultimately health, is to address expressed feelings of anticipatory grief and facilitate coping. Once the grief responses are dealt with (either decreased or eliminated), the level of hope would be expected to increase. Hope provides an incentive for constructive coping with loss. Nurses have the potential to enhance the family's growth during terminal illness as a possible outcome in an otherwise negative situation.

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Appendix A

Non-Death Version of The Grief Experience Inventory

Code Number ________

This questionnaire deals with the experience of grief. The questions are thoughts, feelings and behaviours common in people who have suffered a loss or anticipate a loss. Read each statement and then try to determine how well it describes you during your family member's illness.

If the statement is true or mostly true as it applies to you, circle "T" for true at the end of the statement. If the statement is false or mostly false, circle the "F" for false at the end of the statement. Please try to respond to all the statements as openly and honestly as you can. There are no right or wrong answers.

1. I feel exhausted much of the time. **1. T F**
2. I tend to be more irritable with others. **2. T F**
3. I frequently experience angry feelings. **3. T F**
4. It is not difficult to maintain social relationships with friends. **4. T F**
5. My arms and legs feel very heavy. **5. T F**
6. I am unusually aware of things related to death. **6. T F**
7. I show little emotion at funerals. **7. T F**
8. I feel the strong necessity for maintaining the morale of others in crisis. **8. T F**
9. I feel cut-off and isolated. **9. T F**
10. I rarely take aspirins. **10. T F**
11. I feel reluctant to attend social gatherings. **11. T F**
12. I have a special need to be near others. **12. T F**
13. I often experience confusion. **13. T F**
14. I feel lost and helpless. **14. T F**
15. I have frequent headaches. **15. T F**
16. I find it necessary to take sleeping pills. **16. T F**
17. I cry easily. **17. T F**
18. I have taken tranquillizers. **18. T F**
19. I experience a dryness of the mouth and throat. **19. T F**

Appendix A continues

Appendix A continued

20. I feel restless.	20.	T	F
21. Concentrating on things is difficult.	21.	T	F
22. I have feelings of apathy.	22.	T	F
23. Aches and pains seldom bother me.	23.	T	F
24. I find I am often irritated with others.	24.	T	F
25. I often make the arrangements in our family.	25.	T	F
26. I lack the energy to enjoy physical exercise.	26.	T	F
27. I rarely feel enthusiastic about anything.	27.	T	F
28. I feel that life has aged me.	28.	T	F
29. I am often irritable.	29.	T	F
30. I feel extremely anxious and unsettled.	30.	T	F
31. I feel tenseness in my neck and shoulders.	31.	T	F
32. Sometimes I have a strong desire to scream.	32.	T	F
33. I am very busy with my life.	33.	T	F
34. I feel anger toward God.	34.	T	F
35. I have the urge to curl up in a small ball when I have attacks of crying.	35.	T	F
36. I feel the need to be alone a great deal.	36.	T	F
37. I rarely think of my own death.	37.	T	F
38. I find it difficult to cry.	38.	T	F
39. Life has lost its meaning for me.	39.	T	F
40. I have no difficulty with digestion.	40.	T	F
41. I have had no trouble sleeping lately.	41.	T	F
42. I have a hearty appetite.	42.	T	F
43. I feel healthy.	43.	T	F
44. It comforts me to talk with others who have had losses similar to mine.	44.	T	F
45. I seldom feel depressed.	45.	T	F
46. Life seems empty and barren.	46.	T	F
47. I often take sedatives.	47.	T	F
48. I have frequent mood changes.	48.	T	F
49. The actions of some people make me resentful.	49.	T	F
50. My feelings are not easily hurt.	50.	T	F
51. I am losing weight.	51.	T	F
52. Small problems seem overwhelming.	52.	T	F
53. I frequently have diarrhea.	53.	T	F
54. I have lost my appetite.	54.	T	F

Appendix A continues

Appendix A continued

55. I am not interested in sexual activities. 55. T F
56. At times I wish I were dead. 56. T F
57. It is hard to maintain my religious faith in light of all the pain and suffering caused by illnesses. 57. T F
58. I seem to have lost my energy. 58. T F
59. I dread viewing a body at the funeral home. 59. T F
60. I have problems with constipation. 60. T F
61. I frequently take long walks by myself. 61. T F
62. I avoid meeting old friends. 62. T F
63. I have a special need for someone to talk to. 63. T F
64. It often feels like I have a lump in my throat. 64. T F
65. I seem to have lost my self-confidence. 65. T F
66. I drink more alcohol now than I used to. 66. T F
67. I have nightmares. 67. T F
68. The thought of death seldom enters my mind. 68. T F
69. I have never worried about having a painful disease. 69. T F
70. Funerals upset me. 70. T F
71. I would not feel uneasy visiting someone who is dying. 71. T F
72. I often worry over the way time flies by so rapidly. 72. T F
73. I have no fear of failure. 73. T F
74. I am close with only a few persons. 74. T F
75. The sight of a dead person is horrifying to me. 75. T F
76. I always know what to say to a grieving person. 76. T F
77. I often seek advice from others. 77. T F
78. It does not bother me when people talk about death. 78. T F
79. I cannot remember a time when my parents were angry with me. 79. T F
80. I do not think people in today's society know how to react to a person who is grieving. 80. T F
81. I never have an emotional reaction at funerals. 81. T F
82. I often think about how short life is. 82. T F
83. I am not afraid of dying from cancer. 83. T F
84. I do not mind going to the doctor for check-ups. 84. T F
85. I shudder at the thought of nuclear war. 85. T F
86. The idea of dying holds no fears for me. 86. T F

Appendix A continues

Appendix A continued

87. I never lose my temper. **87. T F**
88. I have always been completely sure I could be successful when I tried something for the first time. **88. T F**
89. I am not usually happy. **89. T F**
90. I feel that the future holds little for me to fear. **90. T F**
91. I cannot ever remember feeling ill at ease in a social situation. **91. T F**
92. I find myself sighing often. **92. T F**
93. It helps me to comfort others. **93. T F**
94. My family seems close to me. **94. T F**
95. My religious faith is a source of inner strength and comfort. **95. T F**
96. I am smoking more these days. **96. T F**
97. I am not a realistic person. **97. T F**
98. I am awake most of the night. **98. T F**
99. I feel exhausted when I go to bed but lie awake for several hours. **99. T F**
100. I lose sleep over worry. **100. T F**
101. I often wake in the middle of the night and cannot get back to sleep. **101. T F**
102. I sleep well most nights. **102. T F**
103. Things seem blackest when I am awake in the middle of the night. **103. T F**
104. I can sleep during the day but not at night. **104. T F**

Appendix B

Items on the Subscales of the NDGEI

	Number of Items	True Items	False Items
Bereavement Scales			
Despair	17	1,5,14,20,22,27 39,46,48,52,55 56,57,58,64,65	45
Anger/Hostility	7	2,3,24,29,34,49, 80	
Somatization	19	15,16,18,19,26 28,31,47,51,53 54,60,66	10,23,40,41 42,43
Loss of Control	7	17,30,32,35	7,38,50
Social Isolation	7	9,11,36,61,62,74	4
Death Anxiety	11	6,59,72,75,82,85 86,90	37,68,78,
Validity Scales			
Denial	11	69,71,73,76,79 81,83,87,88,91	70
Social Desirability	6	8,84,93,94,95,97	
Atypical Responses	20	15,34,39,47,53, 57,60,62,66,75 89,96	4,6,10,23,40 78,82,93,94
Research Scales			
Sleep Disturbance	10	16,67,98,99,100 101,103,104	41,102
Loss of Appetite	3	51,54	42
Loss of Vigor	6	1,26,28,55,58	43
Physical Symptoms	9	5,15,19,31,53 60,64	23,40
Optimism/Despair	4	39,46,56,57	
Dependency	6	12,44,63,77	25,33

(Sanders et al., 1985, p. 29)

Appendix C

Definitions for the Subscales of the Bereavement and Validity Scales of the NDGEI

Despair: an intense feeling of hopelessness and lack of self-worth, low self-esteem, slowed thoughts and behaviours, sense of fear and anxiety, depression, and negative outlook on life

Anger/Hostility: anger, resentment, and a sense of unfairness

Somatization: physical problems which result due to stress

Loss of Control: difficulty concealing emotional expressions

Social Isolation: an emotional and/or physical detachment from others either by choice or by perception of isolation by others

Death Anxiety: awareness of one's personal death

Denial: a reluctance to acknowledge common socially undesirable feelings, weaknesses, and negative attributes

Social Desirability: tendency to reply in a more socially desirable or socially acceptable manner

Atypical Responses: responses that support items which less than 25% of the normal population endorses

(Sanders, Mauger, & Strong, 1985)

Appendix E

Jalowiec Coping Scale

Code Number ________

People react in many ways to stress and tension. Some people use one way to handle stress, while others use many coping methods. I am interested in finding out what things you do when faced with stressful situations. Please estimate how often you use the following ways to cope with stress by circling one number for each item.

1 = Never; 2 = Occasionally; 3 = About half the time; 4 = Often;
5 = Almost always

1. Worry	1	2	3	4	5
2. Cry	1	2	3	4	5
3. Work off tension with physical activity or exercise	1	2	3	4	5
4. Hope that things will get better	1	2	3	4	5
5. Laugh it off, figuring that things could be worse	1	2	3	4	5
6. Think through different ways to solve the problem or handle the situation	1	2	3	4	5
7. Eat; smoke; chew gum	1	2	3	4	5
8. Drink alcoholic beverages	1	2	3	4	5
9. Take drugs	1	2	3	4	5
10. Try to put the problem out of your mind and think of something else	1	2	3	4	5
11. Let someone else solve the problem or handle the situation	1	2	3	4	5
12. Daydream; fantasize	1	2	3	4	5
13. Do anything just to do something, even if you're not sure it will work	1	2	3	4	5
14. Talk the problem over with someone who has been in the same type of situation	1	2	3	4	5
15. Get prepared to expect the worst	1	2	3	4	5
16. Get mad; curse; swear	1	2	3	4	5
17. Accept the situation as it is	1	2	3	4	5

Appendix E continues

Appendix E continued

18. Try to look at the problem objectively and see all sides 1 2 3 4 5
19. Try to maintain some control over the situation 1 2 3 4 5
20. Try to find purpose or meaning in the situation 1 2 3 4 5
21. Pray; put your trust in God 1 2 3 4 5
22. Get nervous 1 2 3 4 5
23. Withdraw from the situation 1 2 3 4 5
24. Blame someone else for your problems or the situation you're in 1 2 3 4 5
25. Actively try to change the situation 1 2 3 4 5
26. Take out your tensions on someone else or something else 1 2 3 4 5
27. Take off by yourself; want to be alone 1 2 3 4 5
28. Resign yourself to the situation because things look hopeless 1 2 3 4 5
29. Do nothing in the hope that the situation will improve, or that the problem will take care of itself 1 2 3 4 5
30. Seek comfort or help from family or friends 1 2 3 4 5
31. Meditate; use yoga, biofeedback, or "mind over matter" 1 2 3 4 5
32. Try to find out more about the situation so you can handle it better 1 2 3 4 5
33. Try out different ways of solving the problem to see which works the best 1 2 3 4 5
34. Resign yourself to the situation because it's your fate, so there's no sense trying to do anything about it 1 2 3 4 5
35. Try to draw on past experience to help you handle the situation 1 2 3 4 5
36. Try to break the problem down into 'smaller pieces' so you can handle it better 1 2 3 4 5

Appendix E continues

Appendix E continued

37. Go to sleep, figuring things will look better in the morning 1 2 3 4 5
38. Set specific goals to help you solve the problem 1 2 3 4 5
39. "Don't worry about it, everything will probably work out fine" 1 2 3 4 5
40. Settled for the next best thing to what you really wanted 1 2 3 4 5

Appendix F

Categorization of the Jalowiec Coping Scale

Scale	no. items	Item numbers
Emotive Coping	9	1, 7, 12, 15, 16, 22, 24, 26, 27,
Palliative Coping	19	2, 4, 5, 8, 9, 10, 11, 13, 17, 21, 23, 25, 28, 29, 31, 34, 37, 39, 40
Confrontive Coping	12	3, 6, 14, 18, 19, 20, 30, 32, 33, 35, 36, 38

Appendix H

Study No. ________

HERTH HOPE INDEX

Listed below are a number of statements. Read each statement and place a [X] in the box that describes how much you agree with that statement <u>right now.</u>

	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I have a positive outlook toward life.				
2. I have short, intermediate, and/or long range goals.				
3. I feel all alone.				
4. I can see a light in a tunnel.				
5. I have a faith that gives me comfort.				
6. I feel scared about my future.				
7. I can recall happy/joyful times.				
8. I have deep inner strength.				
9. I am able to give and receive caring/love.				
10. I have a sense of direction.				
11. I believe that each day has potential.				
12. I feel my life has value and worth.				

Appendix J

Code Number ____

Background Information Sheet

I would like to ask you some questions about you and your family member. Please try to answer all the questions.

What is your relationship with the patient?

____ parent
____ husband/wife
____ child
____ brother/sister
____ other relative
____ friend

Are you ____ male ____ female ?

How old are you? ____ years

In what country were your parents born? ____________________

What is your highest level of education?

____ some high school or less
____ high school graduate
____ some college
____ college graduate
____ some university
____ university graduate
____ advanced degree

How old is your ill family member? _____ years

Is your family member ____ male ____ female ?

How long have you known that your family member has had cancer?

____ less than six months
____ 6 months - 2 years
____ over 2 years

Do you live in the same household as the ill person? ___ yes ____no

Are you the main caregiver? ____ yes ____ no

Appendix K

Comparison of Instruments

Overlapping items between the Jalowiec Coping Scale (JCS), Herth Hope Index (HHI), and the Non-Death Version of the Grief Experience Inventory (NDGEI) have been identified as follows:

Instrument:	**JCS**	**HHI**
Item no. & Item:	38. Set specific goals to help you solve the problem.	2. I have short, intermediate, and/or long range goals.
Corresponding subscale:	(confrontive)	

Instrument:	**JCS**	**NDGEI**
Item no. & Item:	2. Cry.	17. I cry easily.
Corresponding subscale:	(palliative)	(loss of control)
	16. Get mad; curse; swear.	24. I find I am often irritated with others.
	(emotive)	(anger)
	22. Get nervous.	30. I feel extremely anxious and unsettled.
	(emotive)	(loss of control)
	14. Talk the problem over with someone who has been in the same type of situation.	44. It comforts me to talk with others who have had losses similar to mine.
	(confrontive)	(dependency)

Appendix K continues

Appendix K continued

Instruments:	**JCS**	**NDGEI**
Item no. & Item:	27. Take off by yourself; want to be alone.	61. I frequently take long walks by myself.
Corresponding subscale:	(emotive)	(social isolation)
	8. Drink alcoholic beverages.	66. I drink more alcohol now than I used to.
	(palliative)	(somatization)
	7. Eat; smoke; chew gum.	96. I am smoking more these days.
	(emotive)	(atypical responses)

Instrument:	**HHI**	**NDGEI**
Item no. & Item:	3. I feel all alone.	9. I feel cut-off and isolated.
Corresponding subscale:		(social isolation)
	6. I feel scared about my future.	90. I feel that the future holds little for me to fear.
		(death anxiety)
	9. I am able to give and receive caring/ love.	93. It helps me to comfort others.
		(social desirability)
	5. I have a faith that gives me comfort.	95. My religious faith is a source of inner strength and comfort.
		(social desirability)

Appendix M

Information for Family Member

Information Letter for Family Member

Dear Family Member,

My name is Kim Chapman. I am a nurse working on my Master's degree in nursing at McGill University. As part of my studies, I am doing a study to gain a better understanding of the grief and hope that people feel when a family member is ill. I hope that results of the study will improve future nursing care of families with an ill family member.

The study involves filling out a four-part questionnaire, which will take about one hour. This will be done in your own home or wherever you would like to meet with me.

If you would like more information about the study please put your name and phone number at the bottom of this letter. Please return the letter to your family's nurse. She will then give the letter to me. Once I receive the letter, I will telephone you to talk about the study. You may also call me yourself. My phone number is 989-8106.

Whether you decide that you do or do not want more information about the study will in no way affect the care you or your family receive from the Home Care Service.

Thank you for your time.

Yours truly,

Kim Chapman

Name: ______________________________

Phone: ______________________________

Best time to phone: morning _____ afternoon _____ evening _____

Appendix M continues

Appendix M continued

McGILL UNIVERSITY SCHOOL OF NURSING

Written Consent Form

The purpose of this study is to gain better understanding of the grief and hope that people feel when a family member is ill. The study is being done by Kim Chapman, Master's student.

If I agree to participate, I understand that:

(1) The researcher will visit me once in my home at my convenience.
(2) I will be asked to complete four parts of a questionnaire.
(3) The visit will take approximately 1 hour of my time.

I further understand that all information I give is strictly confidential and that my identity will not be revealed. Only code numbers will be used on the questionnaire. The information will only be available to the researcher.

If I have any questions or concerns about the study, I can inform the researcher. I realize that while I am encouraged to answer all the questions, I am not obliged to do so.

I understand that there is no direct benefit(s) to me if I participate in this study. Some of the questions may be upsetting to me. While I am encouraged to complete the questionnaires, I understand that I do not have to.

I understand that my participation in this study is voluntary and I can choose not to participate or to withdraw from the study at any time without affecting any care or services that my family may receive from the Palliative Care Service now or in the future. I also understand that the researcher will be available to talk with me after I complete the questionnaire.

The research has been explained to me. I agree to participate in this study on the basis of the above statements.

________________ date

________________________ Signature

________________________ Witness

Appendix N

Mean and Relative Coping Scores and Total Hope Scores for the Additional Family Members

Individuals in Family Units		Styles of Coping						Hope
		Emotive		Confrontive		Palliative		
		M	Relative Score*	M	Relative Score*	M	Relative Score*	Total Score
1	a	3.00	.40	2.42	.32	2.11	.28	38
	b	2.22	.29	3.33	.44	2.00	.26	34
	c	2.00	.30	2.75	.41	1.90	.28	36
	d	3.2	.38	3.30	.40	1.80	.22	33
2	a	1.78	.33	1.92	.36	1.68	.31	38
	b	2.56	.42	2.00	.32	1.58	.26	37
	c	2.67	.32	3.50	.41	2.26	.27	46
	d	3.78	.40	2.83	.30	2.79	.30	30
3	a	1.33	.20	3.75	.56	1.68	.25	41
	b	3.11	.32	4.50	.46	2.16	.22	45
	c	2.56	.31	3.92	.48	1.74	.21	36

Appendix N continues

Appendix N continued

Individuals in Family Units	Styles of Coping						Hope
	Emotive		Confrontive		Palliative		
	M	Relative Score*	M	Relative Score*	M	Relative Score*	Total Score
4 a	2.60	.32	3.60	.44	2.00	.24	40
b	3.30	.38	2.90	.34	2.40	.25	30
5 a	2.60	.29	4.50	.50	1.90	.21	38
b	2.00	.29	3.25	.46	1.74	.25	33
6 a	2.30	.28	3.40	.42	2.40	.30	40
b	1.80	.27	2.75	.41	2.20	.33	36
7 a	2.33	.32	2.92	.40	2.00	.28	35
b	2.40	.32	2.80	.38	2.20	.30	40
8 a	1.90	.29	3.20	.48	1.50	.23	42
b	2.40	.30	3.60	.44	2.10	.26	37
9 a	3.70	.43	3.00	.35	1.90	.22	28
b	3.00	.32	4.20	.45	2.20	.23	40
10 a	3.00	.34	2.80	.31	3.10	.35	29
b	2.40	.29	2.80	.34	3.10	.37	35

Appendix N continues

Appendix N continued

Individuals in Family Units	Styles of Coping						Hope
	Emotive		Confrontive		Palliative		
	M	Relative Score*	M	Relative Score*	M	Relative Score*	Total Score
11 a	2.30	.32	3.10	.43	1.80	.25	43
b	2.44	.29	3.58	.42	2.47	.29	39
12 a	1.60	.23	3.20	.46	2.20	.31	36
b	2.30	.30	2.90	.38	2.40	.32	35
13 a	2.78	.31	3.83	.42	1.68	.32	41
b	2.44	.33	3.17	.43	1.95	.29	41
14 a	2.00	.38	1.58	.30	1.80	.25	28
b	1.89	.28	2.92	.43	2.47	.29	29

Note. * A relative score assigns a proportion of each style relative to the others and allows for identification of an individual's predominant style of coping.

Appendix O

Descriptive Statistics for the Extra 19 Family Members

Demographic Variables	n	%
Relationship		
parent	1	1.63
spouse	2	3.28
child	14	22.95
other	2	3.28
Gender		
female	14	73.68
male	5	8.20
Level of education		
some high school or less	3	15.79
high school/college diploma	13	68.42
university degree	3	15.79
Place of residence		
resides with ill person	6	31.58
resides elsewhere	13	68.42

Appendix O continues

Appendix O continued

Demographic Variables	n	%
Birth place of parents		
North America	11	57.90
Europe	7	36.84
Asia	0	.00
Africa	1	5.26
South America	0	.00
Time aware of cancer diagnosis		
< 6 months	5	26.32
6 months-2 years	6	31.58
> 2 years	8	42.10
Caregiver role		
Primary	5	26.32
Non-primary	14	73.68

Demographic Variables	M	SD	Min	Max
Age	42.05	15.03	19 yrs.	83 yrs.

Appendix P

Comparison of Mean Scores and Standard Deviations for the Bereavement and Validity Scales of the NDGEI for Sanders and her Associate's Non-Death Sample (N=127) and the Sample in the Present Study (N=61)

Category	Sanders et al. M(SD)	Present Research M(SD)
Despair	5.62(3.55)	5.31(3.59)
Anger/hostility	3.19(1.87)	3.39(1.95)
Somatization	5.32(3.19)	6.90(1.99)
Loss of Control	2.32(1.62)	2.69(1.30)
Social Isolation	2.51(1.45)	2.93(1.48)
Death Anxiety	4.96(2.39)	6.00(1.91)
Denial	2.83(2.14)	3.69(1.90)
Social Desirability	3.76(1.29)	3.87(1.20)
Atypical Responses	5.15(3.22)	8.20(1.84)

Note. Means and standard deviations are presented on untransformed data for present research. There were no significant T-test differences.

Appendix P continues

Appendix P continued

Comparison of Coefficient Alpha Scores Between a Combined Sample of College Student Volunteers and Bereaved Community Residents in Sanders and her Associate's Study (1985) (N=135) and Family Members of the Present Research (N=80)

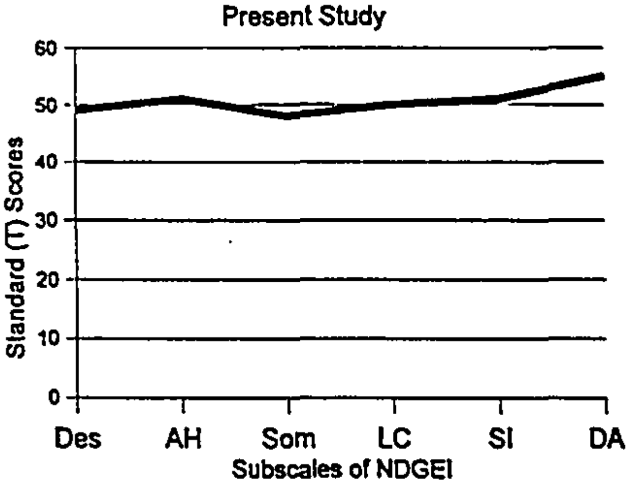
Category	Sanders et al.	Present Research
Bereavement Scales		
Despair	.84	.43
Anger/Hostility	.69	.46
Somatization	.81	.48
Loss of Control	.68	.48
Social Isolation	.54	.49
Death Anxiety	.55	.48
Validity Scales		
Denial	.59	.51
Social Desirability	.34	.50
Atypical Responses	.52	.48

Note. Alpha results are presented on untransformed data for present research.

Appendix P continues

Appendix P continued

Anticipatory Grief Profile



Note. Des=despair, AH=anger/hostility, Som=somatization, LC=loss of control, SI=social isolation, DA=death anxiety