Running Head: BEREAVEMENT IN LONG-TERM CARE

Death and Bereavement in Northern Ontario's Long-Term Care Facilities

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Abstract

The formal and informal supports available to families, staff, and residents of long-term care facilities, along with how death was handled, were examined. With the assistance of long-term care staff, a survey was developed to gather this information. The results indicated that a variety of formal and informal resources were used by the 3 groups to cope with bereavement. Nurses in direct care of dying residents carried the responsibility of notifying the family, staff, and other residents of the impending and subsequent death of a resident. The average turn-around time to admit a new resident was 48 hours. The findings are consistent with the previous literature, and provide a basis on which standards of practice for bereavement can be developed.

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Incidence and Prevalence of Bereavement

Canada has an aging population. In 2001, just over 34 percent of the population (approximately 10 million people) were aged 60 and older (Statistics Canada, 2001 a). As Canada's population continues to increase, so too does the number of deaths of Canadians. In 2001, the death rate was 7.1 per 100,000 people, resulting in 219,538 deaths. Approximately 91,000 of those individuals were married, resulting in the same number of new widows and widowers (Statistics Canada, 2001 a). In the province of Ontario, 81,214 people died in 2001 (Statistics Canada, 2001 b). Over 83 percent of those who died were aged 60 and older. There were 35,748 new widows and widowers in this province (Statistics Canada, 2001 a).

While bereavement affects the spouse of the deceased, death also impacts other family members and friends. In a large sample of community-dwelling elders, over half of the respondents reported a bereavement experience, be it a relative or friend, in the prior year. Twenty-five to 31% of the respondents had experienced the death of a friend (Hays, Gold, & Pieper, 1997). For the elderly, the death of a significant other occurs much more frequently than for younger people (Osterweis, 1985), and occurs much more frequently in hospitals and nursing homes than in the home. Historically, approximately 70% of all deaths took place in the home, yet now approximately 80% of all deaths take place in hospitals or nursing homes (Nelson, 1994-1995). The effects of bereavement in institutions on staff and other residents have been under-researched, and the majority of research in long-term care (LTC) was conducted in the United States. Due to differences in funding and policy, it is unknown if the way death and bereavement are handled in the United States is similar or different to how death and bereavement are handled in Canada. The present research examines bereavement issues using survey data from Northern Ontario LTC facilities.

Definitions of Bereavement, Grief, and Mourning

Bereavement has been commonly defined as a state or objective situation wherein one has experienced a loss (e.g. Corr, 1998; Stroebe, Hansson, Stroebe, & Schut, 2001). While bereavement is an objective state of loss, grief has been defined as the reaction to a loss. Much emphasis has been placed on the emotional reaction to loss, and in some instances grief has been defined solely as an emotional reaction to the death of a loved one (e.g. McCall, 1999). However, reactions to loss can encompass more than emotions, and often extend to behaviours, cognitions, somatic/physical sensations, and social and spiritual functioning (Corr, 1998). Thus, the term "grief" pertains to all natural and usual reactions to bereavement. Although grief is commonly identified and referred to by its symptoms, Kastenbaum (1999) points out that:

> Grief is basically a human process that should not be treated entirely as a set of symptoms to be managed. Rather, grief is inherent to the capacity for attachment, the experience of love, and the achievement of maturation and wisdom. (p. 182)

The terms grief and mourning are often used interchangeably. Indeed, it is sometimes difficult to make a distinction between the two terms. Mourning has been differentiated from grief as the social expression of grief, often shaped by the society and/or culture of which the bereaved individual is part (Stroebe et al., 2001). Rituals and activities associated with the grieving process, such as funeral rites and public expressions of grief, are a product of culture and society. Similarly, the ways in which individuals cope with and manage loss are influenced by culture. Thus, we can extend the definition of mourning from the social, or cultural, expression of grief to the process of coping with loss and learning to manage one's bereavement (Corr, 1998). Therefore, grieving rituals such as memorial services and reminiscing are also part of the coping process.

Grief may take forms considered as typical or complicated. Terms which are used in the literature to denote complicated grief include pathological, atypical, traumatic, abnormal, neurotic, and unresolved grief. As the terminology varies, so do nuances in the definition of complicated grief. Throughout this thesis, the term "complicated grief" refers to bereavement responses that deviate from forms of grief considered normal. Such deviations may pertain to the time course, intensity, or symptoms present in the grieving process (Stroebe et al., 2001). The term "grief" therefore subsumes typical and complicated grief.

The term "bereavement" is included in the Diagnostic and Statistical Manual of Mental Disorders (4th edition – text revision; DSM-IV-TR) because clinical attention may focus on reactions to the death of a loved one (American Psychiatric Association, 2000). The manual acknowledges that while bereaved individuals often display depressive symptoms, a diagnosis of Major Depressive Disorder is contra-indicated unless the symptoms are still present two months post-loss. The DSM-IV-TR also lists several symptoms that are not associated with a typical response to bereavement. These symptoms include feelings of worthlessness, suicidal ideation, psychomotor retardation, and/or marked functional impairment (Nelson, 2001). However, the attributes that differentiate typical from complicated grief remain a matter of debate in the relevant literature (Horowitz, Siegel, Holen, & Bonanno, 1997; Prigerson, Frank, Kasl, Reynolds, Anderson, Zubenko, et al., 1995; Viederman, 1995; Stroebe et al., 2001).

Theoretical Perspectives

Theoretical perspectives of bereavement can be divided into two general categories: theories of grief and theories of coping. Theories of grief attempt to explain the manifestations and phases of grief, while coping theories attempt to explain how individuals manage the stressful experience of bereavement. However, as theories of grief attempt to explain the phenomenology of grief, they also, either explicitly or implicitly, include theories of coping in an attempt to add explanatory power to the overall theory (Stroebe & Schut, 2001).

Two theories of grief, developed from psychoanalytic and attachment perspectives, remain highly influential on bereavement research. Freud (1917/1957) proposed a theory of grief with his concept of "grief work", which refers to the manner in which bereaved individuals work through their loss. He proposed that when a significant other dies, the bereaved individual must sever his/her ties to the deceased and disengage from the energy previously invested in the deceased. Grief, therefore, functions to help the bereaved detach from the deceased. This task is performed gradually, as the bereaved individual reminisces of the past and thinks about the deceased person (Freud, 1917/1957).

The concept of grief work resurfaced in Bowlby's (1980) theory of grief, which was based on attachment theory. He postulated that grief was the result of the severance of the bond of attachment between the deceased and the bereaved. The bereaved individual is left to rearrange his/her representation (i.e. memories) of the deceased and break affectional bonds. Bowlby suggested that because the bereaved person's attempts to re-establish proximity to his/her loved one are not possible (due to the loved one's death), the bereaved individual experiences the various symptoms of grief, such as yearning, protest, and despair. Although Bowlby focused primarily on attachment between a child and parent (Weiss, 2001), his theory of bereavement has been extended to most forms of attachment and has been widely researched (e.g. Bradley & Cafferty, 2001; Stroebe, 2002; Stroebe, Stroebe, Abakoumkin, & Schut, 1996).

General theories of coping have been adapted to explain coping during bereavement. In cognitive stress theory, bereavement is the stressor that the bereaved person must cope with. If the stressor places demands that exceed the individual's resources, he/she must employ a range of coping strategies to deal with the challenge. Trauma theory suggests that coping strategies are employed in response to traumatic life events, such as bereavement (Stroebe & Schut, 2001). A variety of bereavement-specific coping theories have been developed that include intrapersonal models such as the popular task models (e.g. Worden, 1991), stage models (e.g. Kubler-Ross, 1969; Bowlby, 1980), interpersonal models that incorporate social dimensions (e.g. Parkes, 1996), and integrations of these models (e.g. Bonanno & Kaltman, 1999).

Consequences of Bereavement

While theorists have attempted to describe the way in which individuals experience bereavement, there are differences in the intensity and duration of grief. In a review of the literature, Bonanno and Kaltman (2001) found that between 50 and 85 percent of bereaved individuals experienced a similar grief pattern. Bereaved individuals commonly experienced four types of disruption in the first year after their loss that include cognitive disorganization, dysphoria, health deficits, and disruptions in social and occupational functioning. The majority of bereaved individuals experienced moderate disruptions in the initial months after a loss, with most returning to baseline functioning within 1 year. A small minority (15%) experienced continued disruptions in functioning after 1 to 2 years (Bonanno & Kaltman, 2001).

In a sample of recently-widowed men, more than 75% of the participants reported experiencing a sense of nostalgia, intrusive thoughts about the deceased person, feelings of sadness, preoccupation with images of the deceased person, yearning or pining, and distress at reminders of the deceased person 6 weeks post-loss (Byrne & Raphael, 1994). A need to talk about the deceased person, crying, and feelings of anxiety were among the experiences reported by 50 to 75% of the men. A reduction in the overall frequency of these phenomena was evident, as fewer bereavement-related symptoms were reported at 13 months post-loss. However, a subgroup (8.8%) of the widowers reported levels of bereavement phenomena at 13 months post-loss that were similar to that of the total group at 6 months post-loss, suggesting that these men suffered from complicated grief (Byrne & Raphael, 1994).

Most of the bereavement literature has focused on the negative consequences of bereavement. This research has typically compared groups of bereaved individuals to non-bereaved groups, and has examined mental health (particularly depression), social participation, physical health, and mortality rates.

Mental Health

Parkes (1997) proposed that psychiatric disorders may be precipitated by bereavement, mainly due to pre-existing vulnerabilities to certain conditions. For example, the loss of a loved one may induce alcoholism in a person who was already a heavy drinker (Parkes, 1997). Pre-existing psychological disorders are also likely to worsen following the loss of a loved one (Morgan, 1994). Much of the literature on mental health after bereavement has focused on depression; however, bereavement impacts all areas of mental health, as reviewed below.

Depression is a significant psychiatric disorder among the elderly; 2% of the entire elderly population experience a full major depressive episode, and another 2% experience dysthymia (Zisook & Downs, 1998). However, these rates are considered conservative estimates, as among other things they exclude depressive episodes that occur less than one year after bereavement (Zisook & Downs, 1998). Rates of depression in the elderly may therefore be under-reported, as depression in the first year post-bereavement is common and not included when calculating population prevalence rates. As previously mentioned, the DSM-IV-TR does not allow for a diagnosis of depression to be given unless the symptoms are still present 2 months post-loss. However, regardless of the time since the loss of a loved one, depression should always be considered a serious illness and not a normal reaction to bereavement (Zisook & Downs, 1998).

Research has shown bereavement to be a major risk factor for depression in the elderly. In a meta-analysis of 20 prospective studies examining risk factors for depression, bereavement was found to be a significant risk factor for the community-dwelling elderly. The odds ratios listed by each study were pooled, and the attributable risk for depression by bereavement was 69.4% (Cole & Dendukuri, 2003). Therefore, 69% of the depression among community-dwelling elders was attributable to bereavement loss. Another community survey found an association between the number of life events experienced in the previous year and depression in the elderly. Bereavement, illness, and theft were the most frequent events experienced (Prince, Harwood, Blizard, Thomas, & Mann, 1997). In a study comparing bereaved and non-bereaved elderly, bereavement was positively correlated with depressive symptomatology both at baseline and 12 months later (Prigerson, Reynolds, Frank, Kupfer, George, & Houck, 1994).

Bennett (1997) reviewed the literature, and found that bereavement affected mental health not only in the short term, but also in the medium and long term for elderly female widows. In the medium term, defined as 1 to 4 years post-loss, depression was more prevalent in widowed females when compared to non-bereaved females. Four years post-loss, significant effects of bereavement on mental health were found to linger. Depression severity peaked shortly after a loss and gradually improved, although the widowed women were still significantly more depressed at 4 years post-loss (Bennett, 1997).

Likewise, elderly men are also affected by loss. Bennett (1998) measured personal disturbance and affective status in elderly men prior to their spousal bereavement, and again 4 years later (during these four years the men were widowed). Compared to their age-matched still-married controls, the widowers showed higher levels of personal disturbance, as measured by levels of depression and anxiety (Bennett, 1998). Thus, mental health was negatively affected by spousal bereavement.

For some people, the bereavement period becomes more difficult and prolonged by the development of depression. Symptoms shared by grief and depression (e.g. sadness, appetite loss) make it difficult to distinguish between the two (Gilewski, Farberow, Gallagher, & Thompson, 1991). Gilewski et al. (1991) examined the interaction between depression and bereavement in 2 bereaved groups (spouses bereaved through suicide and spouses bereaved through other causes) and a non-bereaved control group over 2.5 years. People in both bereaved groups who were initially only mildly depressed were classified within the normal range 6 months post-loss. People in both bereaved groups who were initially moderately-severely depressed also experienced a reduction in symptoms over time, although over a longer time span (2.5 years for the bereaved by suicide group, 6 months for the natural death group followed by another increase and decrease throughout the following year; Gilewski et al., 1991). An interaction between bereavement and initial level of depression was present in both bereaved groups, with findings that persons with moderate-severe depression at the outset were at higher risk for other psychiatric symptoms. Similarly, in a large sample of spousally-bereaved elders, depressed persons had worse health, more functional difficulties, more social difficulties, and a longer course of grief than those who were not depressed (Zisook & Shuchter, 1992). Assessing level of depression at the time of a spouse's death may be helpful in identifying individuals at greater risk of bereavement complication (Gilewski et al., 1991).

Bereavement can also impact other areas of mental health. A team of Brazilian researchers sampled 66 community-dwelling elders aged 80 to 95 years (Xavier, Ferraz, Trentini, Freitas, & Moriguchi, 2002). Participants were divided into a control group and "grief group" – the latter group consisted of participants who described themselves as being emotionally affected by a recent loss, and were observed by a caretaker to exhibit day-by-day behaviours and emotions impacted by the loss. Contrary to the findings of Bennett (1997, 1998), presence of grief was not associated with increased depressive symptoms but with a more frequent diagnosis of age-associated cognitive decline (a cognitive decline of more than one standard deviation compared to age- and education-matched persons; Xavier et al., 2002). However, cause and effect were not established because the data were correlational. Grief may augment aging-associated cognitive decline, or cognitively compromised individuals may be more strongly affected by grief (Xavier et al., 2002). Future research is needed to clarify the relationship between grief and cognitive functioning.

As is evident from the previously-mentioned literature, the loss of a significant other has been found to be associated with an increase in depression, anxiety, and other forms of psychopathology. One study attempted to examine the different dimensions of psychological distress by examining depression, psychopathology, and grief independently (Thompson, Gallagher-Thompson, Futterman, Gilewski, & Peterson, 1991). Spousally bereaved elders reported high levels of grief-specific symptoms (e.g. yearning for the deceased) over a 30-month period, while levels of depression and psychopathology were elevated for only the first 12 months. These data suggest that the effects of bereavement include symptoms unique to the grieving process, and that these grief-specific symptoms last well beyond the individual's return from depressive symptomatology.

This study also compared the effects of spousal bereavement with those of non-spousal bereavement (e.g. close friend, family member). Spousally bereaved elders reported higher levels of distress than the comparison group throughout the first year of bereavement; severity of depression and psychopathology returned to levels consistent with the comparison group at 12 months post-loss. However, spousally bereaved elders reported a higher severity of grief-specific symptoms for 30 months post-loss (Thompson et al., 1991). These findings suggest that grief after spousal loss may be augmented over the grief associated with other types of bereavement.

Social Participation

It has been suggested that social support can predict adjustment to the loss of a loved one (Osterweis, 1985), and there has been some support in the literature for this idea. In a longitudinal study of elderly bereaved men, social functioning was assessed using a dichotomous rating scale with items on the quality of social networks, vacationing, and other indicators of social participation (Bennett, 1998). Widowers reported lower levels of social engagement post-bereavement. They also differed significantly when compared to an age-matched non-bereaved control group who reported lower levels of social engagement. Thus, the decline in social participation was deemed to be a result of bereavement, and not an age-related decline (Bennett, 1998).

In contrast to the preceding findings, an earlier study by Bennett (1996) found that social engagement declined similarly over time for both bereaved and non-bereaved elderly females. This finding suggests that declines in social engagement in widows are a result of temporal factors rather than bereavement. In fact, in a review of the literature, Bennett (1997) found that social participation remained fairly stable before and after bereavement both over medium and long term intervals. Consequently, Bennett's findings are equivocal with respect to causal effects of bereavement on social engagement.

Utz, Carr, Nesse, and Wortman (2002) compared the social participation of widowed persons to that of continually married persons. Six months after the loss of a spouse, widowed persons reported an increase in the amount of informal social participation they experienced, such as time spent with friends and relatives, and telephone contact, compared to still-married controls. On the contrary, levels of formal social participation (such as volunteer work, attendance of club/group meetings, and attendance of religions services) did not fluctuate in response to bereavement, or over time (Utz et al., 2002). After the loss of a spouse, friends and family often rally around the bereaved spouse, and may account for the increase in time spent with friends and relatives and telephone contact. A great majority of the widowed persons (87%) indicated that they purposely kept busy as a way of coping with grief associated with the loss of their spouse (Utz et al., 2002).

Physical Health

Changes in physiological functioning as a result of the normal aging process provide an important perspective from which to view bereavement in the elderly (Moss, Moss, & Hansson, 2001). With aging, physical functioning may become increasingly impaired with loses in function in the cardiovascular, respiratory, excretory, and digestive systems (Whitbourne, 1999). Reduced immune system functioning results in a decreased ability to repair after illness, and makes the elderly more vulnerable to disease (Aldwin & Gilmer, 1999). Differentiating between the effects of aging on physical health and the effects of bereavement is particularly important when working with the elderly, and use of a control group is essential. For example, Bennett (1998) assessed the physical health of elderly men before and after spousal bereavement. A dichotomous information and symptom checklist, noting the presence/absence of medical problems such as heart and stomach problems, headaches, urinary incontinence, arthritis, and insomnia, was used to assess physical health. Widowers were no more likely to suffer from these physical health problems than their aged-matched non-bereaved counterparts. The results suggested that any declines in physical health were due to temporal factors rather than bereavement (Bennett, 1998).

These findings were consistent with an earlier study of elderly widows, which found declines in physical functioning due to time but to not bereavement (Bennett, 1996).

However, bereavement has been noted to exacerbate existing illness, and even to precipitate new illness (Osterweis, 1985). Bereaved individuals may experience insomnia, decreased appetite, weight loss, lack of energy, and sleep disturbance (Browning, 1995). Respiratory problems and symptoms that mimic the experience of the deceased person have also been noted (Osterweis, 1985). A team of researchers in the United Kingdom examined the medical records of 100 patients who lost a spouse for the periods of 12 months pre- and post-bereavement. They found that bereaved spouses consulted with their family physician significantly more frequently in the year after bereavement compared to the year before bereavement. The majority of these consultations were for physical illnesses (Charlton, Sheahan, Smith, & Campbell, 2001). However, these data must be interpreted with caution, as a control group was not used and thus the effects of advancing aging could not be partialed out.

Mortality

Mortality rates are consistently high among widows and widowers, which may be a consequence of bereavement. Cross-sectional studies comparing mortality among various marital status groups and major sociodemographic variables typically show consistent patterns (Stroebe & Stroebe, 1993). Death rates are typically lowest for people who are married, and highest for those who are divorced; people who are widowed have the second highest death rate. Gender differences can also be seen, as the excess in mortality for widowers is higher than that for widows. Longitudinal studies have confirmed higher mortality rates among the bereaved when compared to non-bereaved control groups, and have indicated that mortality rates peak in the first year post-loss. This suggests that excess mortality in older bereaved groups is not simply a consequence of advancing age, but is related to bereavement. Of further concern is the finding that bereaved individuals are at elevated risk of suicide (Stroebe & Stroebe, 1993).

Contrary to the findings stated above are the results of a recent analysis of mortality rates after widowhood. In a large sample of spousally bereaved men and women aged 60 and over, no significant difference between mortality and expected mortality rates were evident (Bowling & Windsor, 1995). As expected, the most significant predictors of the bereaved group's mortality were age, sex, and functional ability. However, the number of living siblings and the number of telephone contacts with relatives or friends were associated with mortality – the greater the numbers, the greater the chance of survival (Bowling & Windsor, 1995). These forms of social support may act to protect the bereaved from negative bereavement outcomes.

Summary

In summary, bereavement has a significant impact on mental health, social support, physical health, and mortality. The death of a loved one may precipitate a psychological or physical illness, or it may exacerbate any pre-existing difficulties. Although grief and depression share similar characteristics, it is possible to distinguish between the two. Bereavement is a risk factor for depression, and much of the research regarding mental health during bereavement has focused on depressive symptomatology. The literature regarding social support during bereavement is less clear, although having social support has been demonstrated to be a protective factor. The recently bereaved are also at increased risk of mortality. The average person exhibits a moderate disruption in functioning in the initial months after a loss, and usually returns to baseline functioning within one year. Some groups, however, continue to experience difficulties after the first year.

Risk Factors for Aggravated Bereavement Responses

Richardson and Balaswamy (2001) examined several factors in an attempt to explain adjustment to loss during the second year of bereavement. Circumstances surrounding the death of the spouse were evaluated, including use of medical care, place of death, and whether the spouse suffered. Among men widowed for less than 500 days, widowers whose spouse required minimal medical care and died in a location other than their home reported more negative affect than widowed men whose spouses died at home (Richardson & Balaswamy, 2001). Reinvestment variables were also measured, consisting of whether the bereaved had a confidant, maintained contacts with friends, attended social events at church, dated, and interacted socially with neighbours. Among men widowed for more than 500 days, those who reported support from their neighbours and were dating had higher levels of well-being (Richardson & Balaswamy, 2001). Thus, it appears that circumstances surrounding the death of a spouse, along with reinvestment variables, may explain adjustment to loss.

Based on a review of recent literature, Parkes (1997) suggested that several factors may account for poor outcome after bereavement in the elderly. Experiencing an untimely death, multiple losses at the same time, poor physical and mental health, low self esteem and multiple prior losses may place the elderly at special risk of poor bereavement outcome (Parkes, 1997). Lack of social support, past history of depression, current life events that interfere with the grieving process, and poor physical health are factors which have been proposed to place the elderly at increased risk of experiencing complicated grief (Shuchter & Zisook, 1993). Similarly, the ability of the bereaved person's social network to provide the needed support has a significant impact on adjustment to loss – lack of a social network or its inability to provide the necessary support have been identified as risk factors for complicated bereavement (Raphael, Minkov, & Dobson, 2001).

Bereavement in Long-Term Care (LTC)

A significant number of LTC residents die each year, resulting in a high-death environment for those who reside or work there. Little is known about the impact this type of environment has on individuals. While residents may or may not be particularly close friends of the deceased, the death of a resident does not go unnoticed (Osterweis, 1985). Although LTC facilities are a place where life is lived, they are also a place where death is frequently encountered (Froggatt, 2001). In a Manitoba study examining LTC and mortality, 72 percent of the community-dwelling elderly population died in hospital, compared to only 34 percent of the LTC population (Montgomery, Kirshen, & Roos, 1988). Therefore, in this large sample, 66 percent of people residing in LTC facilities died there. In the United Kingdom, it has been estimated that one third of residents die in long-term care facilities annually (Clough, 1981). In the United States, it has been estimated that up to one half of all deaths occur in LTC facilities or hospitals (Lohmann, 1977).

While both living and dying occur in the same place, the way they interact is not always clear. Froggatt (2001) suggested that placing dying persons in facilities such as nursing homes is one way in which society copes with the reality of death, by separating the dying from the living. Lohmann (1977) has suggested that LTC facilities often strive to overcome their image as places to die, thus appearing to be in denial regarding death with possible negative implications for the dying resident. However, many LTC facilities have recently incorporated hospice and palliative aspects of resident care as part of an effort to embrace their role in end-of-life issues. Regardless of changes in practice, there has been minimal research on grief and bereavement in LTC facilities. Instead, researchers report that recent trends in thanatology emphasize death at younger ages because of cancer, AIDS, and other terminal illnesses (Ingebretsen & Solem, 1998). Furthermore, little has been written about the impact of loss on older adults aside from the loss of a spouse (Morgan, 1994). The information currently available about bereavement in LTC facilities is limited indeed.

There are two myths that may influence thinking about bereavement in LTC. The first is that older people have attenuated grief responses compared with younger people. The second is of an attenuated grief response if the death is anticipated. Because LTC residents are elderly, and because LTC facilities are places where death occurs quite frequently, it may be assumed (albeit incorrectly) that adjustment to loss is easier because death is more or less expected. However, the literature does not support either assumption. First, Sable (1991) found that older women who lost their spouses reported more distress such as depression and anxiety than younger women. The results also indicated that grief persisted over the 3 years of the study. Therefore death that occurred at a more-or-less expected time in the life span, compared to younger deaths, lead to more distress. Second, Carr, House, Wortman, Nesse, & Kessler (2001) examined psychological adjustment to sudden versus anticipated spousal loss in the elderly. They found that prolonged forewarning (i.e. knowing that death of a spouse was likely more than 6 months in advance) was associated with higher anxiety levels post-bereavement. Thus, knowing that a person was ill and that death was imminent did not ease the effects of grief.

The effect of bereavement on non-relatives has scarcely been studied. However, as previously mentioned, one study showed that grief associated with spousal bereavement may be distinct from grief associated with other types of bereavement such as the loss of a close friend or roommate. Although Thompson and colleagues (1991) reported that grief associated with the death of a family member or close friend was not as severe as grief resulting from spousal bereavement, the former type of grief was still significant and persistent. Non-spousally bereaved elders experienced elevations in depressive symtomatology, psychopathology, and grief-specific symptoms at 2, 12, and 30 months post-loss (Thompson et al., 1991). These data suggest that other types of loss, such as the death of another resident, can also have a negative long-term impact on the bereaved.

Doka (1989) noted that most of the literature on bereavement and grief has focused on loss experienced by a spouse, parent, or child. He proposed that these roles are socially recognized and thus have a socially recognized capacity to grieve. However, some people suffer a loss but do not occupy these socially recognized roles (e.g. in homosexual relationships, prenatal death); Doka called the grief experienced by these individuals "disenfranchised." The concept of disenfranchised grief recognizes that society often specifies who can grieve, for whom, and for how long, and may occur when the relationship between the deceased and the bereaved is not recognized, when the loss is deemed insignificant, or when the griever is not recognized as experiencing grief (Doka, 1989). We can extend the concept of disenfranchised grief to the residents and staff of LTC facilities. These people do have relationships with the deceased, and recognition of their need to grieve is often overlooked.

Several risk factors for poor bereavement outcome may be particularly salient to residents of LTC facilities.

- *Loss of significant other.* Osgood and Brant (1990) studied suicidal behaviour in LTC facilities, and found that loss of a spouse or a child was a significant factor for the residents who committed suicide.
- *Multiple losses.* Parkes (1997) indicated that multiple losses constitutes a risk factor associated with poor bereavement outcome in the elderly. Multiple losses are common in LTC facilities because of the high mortality rate.
- *Poor physical and mental health.* LTC residents are typically old, frail, and at increased risk of mental illness (Osgood & Brant, 1990).
- *Low social support.* Percieving one's family as unhelpful and having few social supports such as the proximity of a child or family may place the elderly at increased risk of poor bereavement outcome (Parkes, 1997).

Very few researchers have investigated bereavement in LTC. One such study surveyed bereavement practices among member hospices of the California Hospice and Palliative Care Association (Foliart, Clauesn, & Siljestrom, 2001). The survey collected information regarding services available to bereaved families, program content, training of bereavement staff, and fees associated with participation. The findings showed that almost all hospices provided brochures about the grieving process, telephone support, and scheduled mailings. The next most common form of bereavement support was pastoral visits. Larger hospices were more likely to offer support groups and workshops than smaller hospices. In addition, most bereavement support workers were regular employees with professional training in the area. Most of the bereavement support was available free of charge; if fees were associated with a service they were typically less than $50 per session (Foliart et. al., 2001).

A telephone survey was conducted to determine the prevalence of bereavement services in Michigan LTC facilities (Murphy, Hanrahan, & Luchins, 1997). Approximately half of the 111 homes that responded sent sympathy cards to family members after a resident died; the same percentage coordinated nursing home staff representation at the visitation or funeral of a deceased resident. Ninety-eight percent of the respondent nursing homes did not have any contact (i.e. visits, phone calls, written communication) with family members after the resident's death. Ninety-nine percent of the surveyed facilities did not provide written material about grief and bereavement or send a letter informing families about on-site or community support groups. Finally, seventy-six percent of the homes were unable to offer counselling or psychiatric referrals when deemed appropriate (Murphy et al., 1997). This study indicated that the majority of bereavement services that were offered to families occurred at the time of death and immediately afterwards. However, resources such as referrals to external organizations that may have benefited families in the long-term were not offered.

A combination study involving a survey, interviews with managers, and case studies examined the support needs of staff, residents, and relatives when a LTC resident is dying (Katz, Sidell, & Komaromy, 2001). The majority of managers indicated that they did not object to other residents visiting a dying resident. However, deaths were concealed from other residents in 80% of the homes. When a resident died, the majority of LTC staff thought that it was management's responsibility to inform the family. Although over half of the managers conceded that it was part of their job to support their staff, most felt they were unprepared to deal with bereavement issues.

Only 38.5% of the surveyed homes indicated that they had written policies for end-of-life care (Katz et al., 2001). These findings suggest a gap in policy when it comes to death in LTC.

Katz, Sidell, and Komaromy (2000) also examined the bereavement needs of residents, staff, and families after a resident dies. Through interviews with home managers, Katz and colleagues (2000) found that although the managers stated that they preferred openness regarding the death of other residents, there was significant variation in the way residents were informed, who relayed the information, and the timing with which residents were informed. There was also variability in the type and amount of support provided to family members. The level of support provided to families depended on how well the staff knew the family; a pre-existing good relationship enabled staff to support the family (Katz et al., 2000). Most managers recognized the need for bereavement support for staff members, and suggested that staff need this support to cope with the emotional burden of loss, as well as to ease the strain which can affect job performance. However, managers stated that staffing and time constraints kept them from adequately supporting the bereavement process for residents, staff, and families (Katz et al., 2000).

The Present Study

LTC facilities provide the opportunity for relationships to form between fellow residents as well as with staff. However, due to their nature, these facilities also form a high-death environment for both the residents who live there and the staff who work there. As reviewed above, bereavement can have serious implications on mental and physical health, particularly for the elderly. Yet little formal literature exists on the topic of death in LTC. The present study was conducted to explore how death in LTC facilities is dealt with from both a logistical and emotional perspective.

Little information is available about the decisions that are made when a resident is near death, and who makes those decisions. Katz and colleagues examined methods in which residents, staff, and families were notified of the impending and actual death of a resident, yet no quantitative data was provided. Of particular interest are the "formal" and "informal" resources that residents, staff, and families have access to and use to cope with death. While the presence of "formal" bereavement resources have been reported to be numerous in hospice settings (e.g., facility-run and administered programs such as memorial services; Foliart et al., 2001), it is expected that LTC facilities will have fewer such services available due to their different mandate.

There is no previous research on "informal" bereavement resources in LTC (i.e., individual-initiated supports such as rallying around the bereaved). Lohmann (1977) recognized long ago that in LTC, residents form personal relationships with the staff; the staff then become "survivors" with grief that may sometimes rival that of the deceased resident's family. It is, therefore, important to examine not only how residents deal with the death of other residents, but also how the staff members cope with this experience.

After a resident dies, contact between the LTC facility and the resident's family often ceases, even though bereavement services at this point might be valuable to the family (Lohmann, 1977). This study therefore explored the resources available to families of deceased residents.

Method

Participants

The sampling frame for the study was all the LTC facilities identified within the northern Ontario region by the Ontario Ministry of Health and Long-Term Care. There are 53 such facilities that range in geography from as far south as Gravenhurst, as far north as Longlac, as far east as Mattawa, and as far west as Rainy River. Because one administrator was unavailable within the timeframe of this study, 52 facilities were identified as potential participants.

Because the nature and extent of contact that LTC staff have with residents and their families varies with the type of position held by the staff member, the study sought participation from 3 groups of employees: administrators, directors of nursing (DON), and front-line staff. Because in LTC facilities with 60 or fewer beds the administrator also fulfills the DON position, participation in such facilities was sought from only 2 types of employee (administrator and front-line staff). Also, because 4 administrators held their position at more than one facility, these administrators were asked to fill out only one survey. All administrators were initially contacted by telephone to introduce the study, to request participation by their facility, and to distribute and return the survey tool used in the study.

Procedure

Questionnaire Development

The main tool used in the study was a questionnaire designed to gather information on current practices relating to bereavement in LTC facilities (see Appendix A). The procedure used to develop the survey tool was as follows. First, a key informant interview was held with a LTC facility administrator to discuss the questionnaire's general content and from whom (i.e. what employee groups) to seek participation. Two focus groups were then held to identify the requisite content: the first was with 3 facility administrators and 1 DON; the second was with 3 front-line staff members and 1 DON. In order to facilitate the recording of information, the focus groups were tape-recorded and later transcribed by the researcher.

The intent of the focus groups was to obtain information about bereavement practices in LTC facilities and suggestions for questionnaire items. The employees also provided information regarding "informal" bereavement supports that occurred in their facilities. Both the structure and content of the survey tool was based on the information provided by the key informant and focus groups. For validation of questionnaire content, drafts of the questionnaire were provided to the key informant and focus group participants, who in turn provided feedback to the researcher, who then made any recommended modifications. Involvement of LTC facility personnel in the development of this instrument promoted mutual collaboration in this project, as personnel are significant stakeholders in any present or future bereavement processes within their facilities.

Content of Questionnaire

The first part of the questionnaire contains items on statistical information from the facilities, such as the number of beds, total number of residents that resided in the facility in 2003, and number of residents who died in 2003.

The subsequent section asks about where residents stay when they are near death and who makes that decision. Other items relate to the methods by which other residents, staff, and family members are notified of the impeding and subsequent death of a resident.

The next section addresses information regarding practices that are carried out after a resident dies, such as how his/her body is prepared for transportation to the funeral home, when personal belongings are removed, and how quickly his/her bed is filled.

Finally, the questionnaire asks about the formal and informal resources that are available and/or used by residents, staff, and families post-bereavement. Space was provided for participants to indicate barriers to service and what supports and/or services they would like to see implemented in their facilities.

Administration of Questionnaire

Administrators were initially contacted by telephone to briefly introduce the study and request that they fill out the bereavement questionnaire. If interested, an informed consent form (Appendix B) and questionnaire was sent to them by mail, fax, or email. The administrators were asked to administer the survey to the DON (if the facility had 60 or more beds) and one front-line staff member in their facility. The completed surveys were returned to the researcher via mail, fax, or email. Three $100 draws were held to encourage participants to return the surveys in a timely manner.

Data Analyses

The purpose of data analyses was to identify general trends. The first step was to determine response rate, with a rate of >60% considered adequate (Huston, 1996). The next step was to examine differences between types of respondent. Without convincing evidence that the number of items with significant differences between respondents exceeded chance expectations, the intent was to pool the data across type of respondent. Next, the data for the Likert-type and dichotomous survey items were analyzed for differences from the midpoint value using t-tests and chi square, respectively, in order to identify directional trend. In the case of the Likert items, the midpoint value of 3 corresponds to a rating of "sometimes".

Results

Response Rate

Eighty-nine questionnaires out of the possible 140 were returned, resulting in an overall response rate of 63.57%. A 62.50% response rate was observed for administrators, a 65.00% response rate for DON's, and a 63.46% response rate for front-line staff. One or more questionnaires were returned from each of 42 facilities (80.77% response rate). Only 2 administrators declined to participate and did not administer the questionnaire to the DON, and 1 front-line staff, and one administrator declined to participate but did administer the questionnaire to the DON and one front-line staff. It is unknown if respondents differed from non-respondents, as data were not available for non-respondents. It is possible that non-responses were due to vacations and related effects during the summer period.

Differences Between Respondents

Data were collected from administrators, DON's, and front-line staff. Each Likert-type survey item was analysed to determine if there were differences between the responses of these three groups. One-way analyses of variances (ANOVA's) revealed that there were differences between groups only on 4 questions. These questions reflected how frequently the resident and LTC facility decided where the resident stayed when death was imminent, how quickly the deceased resident's belongings are removed from his/her room, and how frequently residents rallied around staff members after another resident died. Because it is expected that any 3 responses out of 57 questions could differ significantly simply by chance (p = .05), there was no compelling reason to conclude that systematic differences occurred between the respondent groups.

Similarly, each dichotomous (yes/no) question was examined for differences between the three groups. Chi square analyses revealed that there were differences between groups on 3 questions. These questions reflected whether resources were in place to aid residents who wished to attend the funeral of a deceased resident, whether sympathy cards were sent to bereaved staff, and whether family members had access to hospice involvement. However, because it is expected that 2 responses out of 39 questions could vary by chance (p = .05), there was no convincing evidence for systematic differences. Thus, all subsequent analyses used the pooled responses of participant types.

Mortality in LTC Facilities

Administrators were asked to indicate the number of beds and number of deaths in their facility in 2003. The facilities ranged in size from 22 to 240 beds, with an average of 97.41 (SD = 50.24) beds per facility. An average of 116.89 (SD = 75.48) people resided in each facility in 2003 (range of 27 to 332 people). The total number of residents who lived in the facility could be higher than the number of beds in the facility, as the former number includes residents who died within the year or were transferred elsewhere, as well as new admissions. On average, 23.06% of each facility's residents died in 2003 (18.44% in the LTC facility and 4.62% at another location).

Procedures When Death is Imminent

All participants were asked to indicate where the dying resident stays (e.g. in a private room, in his/her own room), who decides where the resident stays (e.g. the resident, administration), and by whom family members, staff, and other residents are notified of the impending death of a resident (e.g. administration, front-line staff). Respondents indicated on a 5-pont Likert scale whether these events occurred "almost never" (= 1), "sometimes" (= 3), or "almost always" (= 5). One-sample t-tests were conducted with a reference value of 3 to identify any potential directional trends (i.e. whether events occurred "almost never", "sometimes", or "almost always"). Tables 1 and 2 display the means, 95% confidence intervals, and t-test results for these survey items.

When a resident was near death, he/she was almost always left in his/her own room, sometimes moved to a private room, and almost never moved to a room closer to a nursing station or to a room reserved for palliative patients. When near death, the resident and family almost always decided where the resident would stay, although sometimes the LTC facility made this decision.

When a resident was near death, family members and staff were almost always notified by the nurse(s) providing direct care to the resident. Residents were almost always notified by the nurse(s) providing direct care to the resident and by word of mouth. Administration or the DON almost never notified these groups.

Procedures After Death Occurs

All participants were asked to indicate on a 5-point Likert scale, as above, who notifies the family (if necessary), staff, and other residents after a resident has died (e.g. administration, front-line staff), how quickly the family is notified, how the body of the deceased is prepared for transportation (e.g. shrouded, cleaned), how quickly the resident's belongings are cleared from the room, and how quickly the deceased resident's bed is filled. One-sample t-tests were conducted with a reference value of 3 as above to determine whether events occurred "almost never", "sometimes", or "almost

Table 1

Means, 95% Confidence Intervals, and t-tests Regarding Where Residents Stayed, and Who Decided, Before Death Occurred

Question and sub-item	Mean (SD)	95% C.I. lower	95% C.I. upper	t-test	p-value
Location					
Moved to private room	3.00 (1.54)	-0.33	0.33	0.00	1.00
Left in own room	3.68 (1.28)	0.40	0.96	4.85	<.01
Moved closer to nursing station	2.39 (1.39)	-0.92	-0.30	-3.96	<.01
Moved to room reserved for palliative patients	2.54 (1.66)	-0.84	-008	-2.42	<.01
Decision-Maker					
Resident	3.39 (1.45)	0.08	0.71	2.49	0.015
Family	3.82 (1.20)	0.55	1.08	6.18	<.01
LTC Facility	2.72 (1.32)	-0.57	0.01	-1.91	0.059

Note. One-sample t-tests conducted with a test value of 3.

Table 2

Means, 95% Confidence Intervals, and t-tests Regarding Who Notified Groups of the Impending and Subsequent Death of a Resident

Question and sub-variable	Family					Staff				
	Mean (SD)	95% C.I. lower	95% C.I. upper	t-test	p-value	Mean (SD)	95% C.I. lower	95% C.I. upper	t-test	p-value
Notifier when death imminent										
Administration	1.49 (0.12)	-1.76	-1.26	-12.13	<.01	1.77 (0.15)	-1.53	-0.92	-8.06	<.01
DON	2.27 (0.16)	-1.04	-0.42	-4.66	<.01	2.50 (0.15)	-0.80	-0.20	-3.32	<.01
Nurse(s) in direct care	4.56 (0.11)	1.35	1.77	14.68	<.01	4.58 (0.09)	1.40	1.76	17.36	<.01
Word of mouth	—	---	---	—	—	3.26 (0.14)	-0.03	0.54	1.78	0.08
Notifier after death occurred										
Administration	1.53 (0.13)	-1.73	-1.21	-11.30	<.01	2.08 (0.18)	-1.27	-0.57	-5.25	<.01
DON	2.26 (0.15)	-1.04	-0.44	-4.98	<.01	2.59 (0.16)	-0.74	-0.09	-2.56	0.013
Nurse(s) in direct care	4.72 (0.10)	1.53	1.91	18.01	<.01	4.46 (0.11)	1.23	1.68	12.94	<.01
Word of mouth	—	---	---	—	—	3.61 (0.13)	0.35	0.88	4.70	<.01

Question and sub-variable	Residents				
	Mean (SD)	95% C.I. lower	95% C.I. upper	t-test	p-value
Notifier when death imminent					
Administration	1.53 (0.13)	-1.73	-1.21	-11.47	<.01
DON	1.84 (0.14)	-1.44	-0.89	-8.49	<.01
Nurse(s) in direct care	3.65 (0.13)	0.39	0.90	5.07	<.01
Word of mouth	1.53 (0.13)	0.29	0.79	4.30	<.01
Notifier after death occurred					
Administration	1.79 (0.16)	-1.52	-0.90	-7.74	<.01
DON	2.12 (0.15)	-1.17	-0.58	-5.93	<.01
Nurse(s) in direct care	4.08 (0.12)	0.84	1.33	8.91	<.01
Word of mouth	3.59 (0.13)	0.32	0.85	4.41	<.01

Note. One-sample t-tests conducted with a test value of 3.

always". Tables 2 to 3 display the means and 95% confidence intervals for each of these survey items.

After a resident died, family members were almost always notified (if necessary) by the nurse(s) providing direct care to the resident. Similarly, staff and other residents were almost always notified by the nurse(s) providing direct care to the resident and by word of mouth. These groups were almost never notified by administration or the DON. Participants were also asked if a written standard procedure was in place for notifying family members after a resident dies. The dichotomous response (yes/no) was subjected to equal expectancies Chi-square analysis to identify any possible directional trend. A greater proportion of participants (66.29%) indicated that there was a written standard procedure for notifying family members (if necessary) after a resident died ($\chi^2(1, N=76) = 23.21, p<.01$).

Family members were almost always notified within 1 hour of a resident's death. After a resident died, his/her body was almost always cleaned, and sometimes shrouded or dressed. The deceased's belongings were almost always cleared out of his/her room within 24 hours of death, although sometimes sooner (12 hours) or later (48 hours). If the deceased resident had shared a room, his/her bed was almost always filled within 48 hours of death, and almost never sooner.

Informal Bereavement Resources

All participants were asked to indicate on a 5-point Likert scale (as above) which informal resources (e.g. rallying around bereaved staff/residents, attending memorial services) they had observed staff and residents using to cope with the death of a resident. One-sample t tests were conducted with a reference value of 3 to determine

Table 3

Means, 95% Confidence Intervals, and t-tests for Time to Notify the Family, Remove Belongings, and Fill the Bed, and Treatment of the Body

		95% C.I.			
Question and sub-item	Mean (SD)	lower	upper	t-test	p-value
Time to Notify Family					
1 hour	4.99 (0.01)	1.96	2.01	165.00	<.01
2 – 5 hours	1.96 (0.16)	-1.36	-0.72	-6.52	<.01
6 – 12 hours	1.16 (0.07)	-1.97	-1.71	-28.39	<.01
Treatment of the Body					
Shrouded	2.99 (0.22)	-0.46	0.43	-0.06	.95
Cleaned	4.65 (0.10)	1.46	1.85	16.64	<.01
Dressed	3.05 (0.21)	-0.37	0.48	0.25	.81
Time to Remove Belongings					
12 hours	3.22 (0.53)	-0.08	0.52	1.44	.16
24 hours	3.89 (0.15)	0.58	1.19	5.82	<.01
48 hours	3.04 (0.18)	-0.33	0.41	0.23	0.82

Question and sub-item	Mean (SD)	95% C.I. lower	 upper	t-test	p-value
Time to Fill Bed					
12 hours	1.52 (0.12)	-1.72	-1.23	-11.94	<.001
24 hours	2.64 (0.16)	-0.69	-0.04	-2.24	0.03
48 hours	4.01 (0.13)	0.76	1.27	7.86	<.001

Note: One-sample t-tests conducted with a test value of 3 whether events occurred "almost never", "sometimes", or "almost always". Table 4 displays the means and 95% confidence intervals for each of these survey items.

Staff almost always rallied around bereaved family members, residents, and other staff members. They almost always attended individual memorials and/or funerals, although they almost never attended annual group memorials. Participants were asked if resources were in place to assist staff to attend the funeral of a resident. Dichotomous (yes/no) data were subject to Chi-square analysis with equal expectancies, to identify a possible directional trend. A greater proportion of participants (60.67%) indicated that resources such as time off work and paid leave were not in place to aid staff who wish to attend the funeral of a deceased resident ($\chi^2(1, N=83) = 7.53$, $p=.006$). Staff almost never met outside of work time to reminisce about the deceased, although residents were sometimes observed in this manner.

Residents almost always attended individual memorials, funeral services, and annual group memorials. Chi square analysis as above showed that a greater proportion of participants (73.03%) indicated that resources such as transportation were in place to aid residents who wish to attend the funeral of a deceased resident ($\chi^2(1, N=87) = 21.25$, $p<.01$). Residents almost always rallied around other bereaved residents, although they only sometimes rallied around bereaved family members and almost never around bereaved staff. Although staff almost always spent time with the dying resident before death occurred and sometimes after death occurred, residents were almost never observed in this manner. However, Chi square analysis as above showed that a greater proportion of participants (91.01%) indicated that staff were able to pay their respects before the body was moved to the funeral home ($\chi^2(1, N=86) = 67.16$,

Table 4

Informal Resources Available to Staff and Residents

Group and Informal Resource	Mean (SD)	95% C.I. lower	95% C.I. upper	t-test	p-value
Staff					
Rallied around bereaved residents	3.96 (0.12)	0.72	1.19	8.22	<.01
Rallied around bereaved family members	4.22 (0.10)	1.03	1.42	12.47	<.01
Rallied around other bereaved staff	3.90 (0.11)	0.68	1.11	8.29	<.01
Spent time with resident before death occurred	4.53 (0.08)	1.37	1.69	18.72	<.01
Spent time with deceased resident	3.07 (0.13)	-0.18	0.33	0.55	.583
Met outside of work time to reminisce, etc.	2.01 (0.11)	-1.21	-0.78	-9.30	<.01
Attended individual memorials/funeral services	3.30 (0.09)	0.12	0.47	3.33	.001
Attended annual group memorials	2.58 (0.13)	-0.68	-0.17	-3.28	.001
Residents					
Rallied around bereaved residents	3.30 (0.12)	0.05	0.54	2.42	.018
Rallied around bereaved family members	2.87 (0.11)	-0.34	0.09	-1.16	.251

Group and Informal Resource	Mean (SD)	95% C.I.		t-test	p-value
		lower	upper		
(Residents)					
Rallied around bereaved staff members	2.30 (0.11)	-0.93	-0.48	-6.20	<.01
Spent time with resident before death occurred	2.29 (0.11)	-0.94	-0.47	-6.01	<.01
Spent time with the deceased resident	1.52 (0.10)	-1.66	-1.29	-15.61	<.01
Met to reminisce, etc.	2.84 (0.12)	-0.41	0.08	-1.32	.191
Attended individual memorials/funeral services	3.43 (0.12)	0.19	0.67	3.58	.001
Attended annual group memorials	3.46 (0.15)	0.15	0.76	2.98	.004

Note. One-sample t-tests conducted with a test value of 3.

$p<.01$), while residents were observed paying their respects before the body was taken to the funeral home with equal frequency ($\chi^2(1, 84) = 1.19$, $p=.275$).

Formal Bereavement Resources

All participants were asked to indicate on a dichotomous (yes/no) scale the formal bereavement resources (e.g. literature about grief, counselling, sympathy cards) that were available for staff, residents, and families. Chi-square analyses with equal expectancies were conducted to identify directional trends (i.e. whether more participants agreed/disagreed that a resource was available than would be expected with equal frequencies). Table 5 displays the percentage of agreement for each resource, along with significance levels. Facilities offered brochures/literature about grief, pastoral care, and annual group memorials for residents, staff, and families. In addition to these services, families also had access to professional counselling and sympathy cards, staff were able to receive telephone calls and sympathy cards, and residents had access to volunteer visits and were able to attend individual memorials.

Qualitative Data

Three open-ended questions were included with the questionnaire, asking participants to indicate the barriers to providing formal bereavement resources to staff and residents, and asking participants to list the supports and/or services they would like to have in their facility. Space was also provided for participants to include any additional comments. A total of 75 participants (84.27% of the sample) completed this portion of the survey. Several themes emerged from this qualitative data about barriers to providing formal bereavement services to staff and residents, as displayed in Table 6. A lack of resources and/or funding was identified as the main barrier to providing formal bereavement services to both staff and residents. Time and staffing constraints were

Table 5

Formal Bereavement Resources Available to Family, Staff, and Residents: Significant Chi-Square Results

Resource	Family		Staff		Residents	
	% yes	% no	% yes	% no	% yes	% no
Brochures/literature about grief	73.49	26.51**	72.62	27.38**	69.41	30.59**
Pastoral care	89.16	10.84**	63.10	36.90*	94.12	5.88**
Volunteer visits		n.s.	22.62	77.38**	83.53	16.47**
Professional counselling	37.35	62.65*		n.s.		n.s.
Grief support groups	27.71	72.29**	20.24	79.76**	25.88	74.12**
Individual memorials		n.s.		n.s.	62.35	37.65*
Annual group memorials	65.06	34.94**	65.48	34.52**	70.59	29.41**
Telephone calls		n.s.	22.62	77.38**	34.12	65.88**
Sympathy cards	73.49	26.51**	38.10	61.90*		n.s.
Scheduled mailings	14.46	85.54**	8.33	91.67**	12.94	87.06**
Hospice involvement	22.89	77.11**	9.52	90.48**	29.41	70.59**

Note. n.s. = non-significant * p < .05 **p < .01

Table 6

Barriers to Providing Formal Bereavement Services

	Staff		Residents	
Barrier	n	%	n	%
Resources/funding	33	37.08	15	16.85
Time	24	26.97	8	8.99
Staffing	9	10.11	10	11.24
Poor attendance at training events	5	5.62	0	0.00
No barriers	4	4.49	6	6.74
Attitudes	3	3.37	10	11.24
No staff to perform service(s)	3	3.37	10	11.24
Scheduling	3	3.37	0	0.00
Privacy/confidentiality	2	2.25	1	1.12
Location of facility	2	2.25	1	1.12
Space	2	2.25	4	4.49
Knowledge/education	2	2.25	0	0.00

identified as the next most frequent barriers to providing services to staff, while staffing constraints, lack of trained staff to administer bereavement services, and attitudes were identified as the next most frequent barriers to providing services to residents.

Discussion

Summary of the Findings

An overall response rate of 63.57% was achieved. Response rates of between 43% (Osgood & Brant, 1990) and 82% (Foliart et al., 2001) have been reported in the literature for similar pencil-and-paper surveys in LTC facilities; therefore the present study's response rate was considered acceptable. Northern LTC facilities ranged in the number of residents they housed, from 27 to 332 residents in 2003. Mortality in these facilities, at 23.06%, was 3,311 times higher than in the general population.

The results of this survey offer some insight into how death and bereavement are handled in LTC facilities. Before death occurred, the resident and his/her family decided where the resident would stay, and almost always decided on staying his/her own room over being moved closer to the nursing station or to a palliative care room. When a resident was near death, the nurse(s) in direct care almost always notified the family, other staff, and other residents of the situation. The administrator and the DON almost never performed this task. Similarly, after death occurred the nurse(s) in direct care notified the family (if necessary), other staff, and other residents. Staff and residents also found out about the death of a resident by word of mouth.

If necessary, the family was almost always notified within one hour of the death of their loved one. Many participants indicated that notification to families is provided as soon as possible after the death, if the family was not present. The body of the deceased resident was almost always cleaned and was sometimes dressed before removal to the funeral home or other location. The resident's belongings were almost always removed from his/her room within 24 hours of death, and a new resident was almost always placed in the room within 48 hours of death.

Many informal resources were used by staff and residents to help cope with bereavement. Staff almost always rallied around bereaved families, other staff members, and other residents. They almost always spent time with the resident before death occurred, and sometimes after. Staff almost always attended individual memorials and/or funeral services, although most participants indicated that resources such as time off work and paid leave were not in place for such occasions. Staff hardly ever met outside of work time to reminisce about the deceased resident, and hardly ever attended annual group memorials.

Residents also used informal resources to cope with bereavement. As the staff, residents almost always rallied around other bereaved residents. However, different from the staff, residents only sometimes rallied around bereaved family members and hardly ever around bereaved staff. They hardly ever spent time with the resident before death occurred, or after death. Residents attended annual group memorials and individual memorials/funeral services, and participants indicated that although resources were not in place to allow staff to attend the funeral of a resident, resources such as transportation and assistance were in place to help residents attend.

Along with these informal ways of coping with bereavement, facilities also provided formal supports for families, staff, and residents. The majority of participants indicated that their facility provided brochures/literature about bereavement and the grieving process, pastoral care, and annual group memorials. These resources were available to families, staff, and residents. Additionally, professional counselling and sympathy cards were available to families, volunteer visits and attendance at individual memorials were accessible by residents, and sympathy cards and telephone calls were available to staff.

Lack of resources, funding, and time, along with staffing constraints, were the most frequently cited barriers to providing staff with formal bereavement services. These problems were also referred to as barriers to providing formal bereavement services to residents, along with attitudes and a lack of staff to provide the services. Participants indicated that residents' attitudes were barriers to providing them with bereavement services, stating that residents did not think that bereavement services were necessary and did not want to use them. Interestingly, fewer participants indicated that staff's attitudes were a barrier to services.

Implications

Staff and residents of LTC facilities encounter death much more frequently than the general population. Staff are immersed in both a personal and professional high-death environment, and this same environment is part of the culture in which residents must live. There is little literature to inform us of the impact of this environment on people. Within the discipline of law enforcement, one work provided anecdotal information about the relationship between traumatology and thanatology. The authors suggested that high exposure to traumatic deaths created an increased risk of post-traumatic stress disorder and complicated grief in police officers (Sugimoto & Oltjenbruns, 2001). However, it is reasonable to assume that deaths in LTC are not as traumatic as those experienced by police officers, and these results should not be generalized to the LTC setting. Nevertheless, bereavement has a multi-faceted impact on those who experience it, as reviewed in this thesis. Even from a strictly logistical viewpoint, previous literature has suggested that bereavement affects staff's ability to perform their duties (Katz et al., 2000). It is imperative that LTC facilities provide staff and residents with resources to help them cope with bereavement.

Residents and their families made decisions about where the resident would stay before death occurred. This arrangement is considered optimal, and residents and families almost always decided to have the resident stay in his/her own room. This choice may have been made so that the resident would remain in a familiar place, surrounded by his/her belongings.

Nursing staff played a particularly important role by informing families, staff, and residents of the impending and subsequent death of residents. Previous research indicated that staff thought it was the manager's job to inform relatives of a resident's impending and subsequent death, although it was mainly front-line staff who informed other residents (Katz et al., 2000). The present study indicated that the majority of LTC facilities had a written, standard procedure for notifying family members (if necessary) after their loved on died. As most participants indicated that front-line staff were the people who almost always notified the families, it can be concluded that most policies either specified that these staff were to act as notifiers, or that the policies were not so specific and front-line staff simply acted in the manner they deemed most appropriate. These staff members, who work directly with the residents, have the potential to develop relationships with family members. Pre-existing relationships may facilitate communication between the staff and the family, which may account for the finding that these staff almost always notified the family. However, it is unknown how the front-line staff felt about taking on this responsibility.

After a resident passed away, his/her belongings were quickly removed from the room, and a new admission filled the bed within 48 hours of the death. The speed with which these events occur can have a significant impact on other residents. A previous report indicated that residents were often unsettled when a new admission occupied the place of a deceased resident (e.g. sat in their chair; Katz et al., 2000). This situation presents a challenge to LTC facilities, as they must choose between allowing sufficient time for staff and residents to adjust, and filling the bed. Adjustment to a resident's death is not likely to occur within 2 days, and most LTC facilities, particularly in large urban centers, have more people on the waiting list than they have available beds. Because beds are being filled so quickly after death, facilities need to be especially sensitive to the bereavement needs of staff and residents by being open and honest about the situation. Residents and staff have been reported to enquire about the death, and whether the resident had died peacefully and painlessly (Katz et al., 2000). Openness about death can facilitate adjustment by demonstrating that death is a natural and normal phenomenon.

Adjustment was also facilitated through informal processes. Previous literature indicated that staff sometimes needed to view deceased residents and attend the funeral to make their farewells (Katz et al., 2000). The present findings were consistent with these findings, as staff sometimes spent time with the deceased resident, and almost always attended individual memorial or funeral services. Staff rallied around each other in support, and also supported families and residents in this manner. Contrary to previous findings, staff hardly ever met outside of work time to reminisce and talk about the deceased resident, and hardly ever attended annual group memorials. Residents provided each other with support by rallying around other bereaved residents. Although they hardly ever spent time with the dying resident or viewed the resident after death occurred, they almost always attended individual memorials and annual groups memorials, probably because assistance such as transportation was available to them for such purposes. These utilization of these informal resources provide valuable information as to how staff and residents cope with the frequent experience of death.

A variety of formal resources were in place to assist families, staff, and residents with bereavement. However, in contrast to the questions related to informal resources, participants were asked to indicate whether formal resources were available to these groups, not if they were used. Participants indicated that a wide range of resources were available at their facilities, ranging from brochures and literature about grief to formal counselling. In fact, these resources rivalled the supports reported by American hospices (Foliart et al., 2001). The majority of participants indicated that hospice involvement was available for residents, which may explain these findings. While these results indicated that facilities offered a variety of formal bereavement supports, the results did not indicate how frequently these services were utilized.

As bereavement is a universal phenomenon to which most people adapt successfully, researchers have questioned whether intervention is at all necessary. In general, routine bereavement intervention is not justified, because grief is not a disease (Raphael et al., 2001). However, a variety of bereavement interventions have been developed, ranging from individual to group therapies, and prevention to treatment. Most interventions focus on helping the bereaved to work through the loss by various methods such as flooding (Raphael et al., 2001) and cognitive-behaviour therapy (Fleming & Robinson, 2001). Pharmacological interventions have been used with bereaved individuals, although it has been suggested that medications be used only to treat disorders for which they are indicated, when they precipitate from bereavement. Intervention research regarding complicated grief has suggested that a combination of medication and therapy produces the best results (Raphael et al., 2001).

Although a variety of treatments have been developed, the effectiveness and efficacy of these interventions are unknown. Preliminary data suggests that these treatments are not evidence-based, although these conclusions are based on studies with serious methodological flaws (Schut, Stroebe, Van Den Bout, & Terheggen, 2001). Future research may determine the effectiveness and efficacy of bereavement interventions. The present findings indicated that informal bereavement resources are frequently utilized by staff and residents, and although a variety of formal supports are available to these groups, it is assumed that they are accessed only when required.

Prevention strategies for residents at higher risk of developing bereavement complications may be particularly pertinent to long-term care facilities. Prevention aims to reduce risk factors and increase protective factors. Education about the typical bereavement experience has been proposed as a prevention method (Raphael et al., 2001), and 51% of participants in this study indicated that workshops and/or training courses in how to handle death, dying, and bereavement were available for staff to take every 6 to 12 months. Additionally, the majority of participants indicated that brochures and/or literature about grief was available in their facilities. These supports are important and necessary to increase awareness of bereavement issues for families, staff, and residents.

Several studies have examined the effects of death education and training programs on staff and residents of LTC facilities. Downe-Wamboldt and Tamlyn (1997) found that medical and nursing schools in Canada and the United Kingdom integrated death education throughout all years of their programs. Another study examined the effects of a brief training program for nurses which focused on treatment and relation to dying patients, and found an increase in knowledge about death and dying among training group participants (Mullins & Merriam, 1983). Less positive results were seen in a program developed to decrease resident's fears about being institutionalized and help them cope with personal losses (Aday & Shahan, 1995). The program was discussion-oriented and provided education about funeral preparation, living wills, fears about loved ones, and a variety of other death-related topics. The program did not result in significant changes on a depression scale, a death anxiety scale, or a life satisfaction measure, although positive anecdotal reports were received from participants. More research is needed to determine if death education programs are beneficial to LTC residents.

Limitations of the Study

The findings of the present study provided information on how death and bereavement are handled in LTC. However, the findings need to be tempered by the limitations of the questionnaire itself. The questionnaire was developed to collect information pertinent to the present study, and thus its psychometric properties, such as its reliability and validity, are unknown. However, key informants and focus group participants examined the questionnaire, and its content was deemed appropriate. The questionnaire had high face and content validity, and the results suggested that the questionnaire served its purpose.

A selection bias may have lead to the above-mentioned findings. Participants who completed the questionnaire may have had a pre-existing interest in bereavement issues, thus being more likely to return the questionnaire. As previously mentioned, administrators were asked to administer the questionnaire to one front-line staff member of their selection, and thus random selection was not possible. Administrators may have chosen a front-line staff member because they were interested in bereavement, were likely to present views consistent with the administrator's, or any other number of reasons. Although random selection of these participants was preferable, it was not possible as employee lists were not accessible by the researcher.

A reasonable number of LTC facilities participated in the study. However, all facilities were located in the northern LTC region (as identified by the Ministry of Health and Long-Term Care) and therefore the findings may not generalize to other LTC facilities in Ontario or Canada. However, participating facilities ranged in size from quite small (20 beds) to quite large (240), and questionnaire responses did not differ with number of beds.

Many survey items enquired about procedures that were followed when the death of a resident was "imminent." This ambiguity in wording may have been interpreted differently among participants. In some cases the resident's transition to a terminal phase may be quick and obvious, while at other times it may be difficult for medical professionals to determine if and when a resident may die. However, it can be argued that regardless of when the death was considered imminent, or how accurate that prediction was, the outcome and decisions (e.g. calling family members, alerting the staff and other residents, moving the resident to another room) were still present. It was these responses that this thesis attempted to uncover.

This study was also limited by the secondary observations that were collected. Participants were asked to indicate how often they observed the residents engaging in various activities. Future research would benefit from directly asking the residents how they cope with bereavement. Finally, one participant commented on the potential discrepancy between responses from staff on a daytime shift and staff who work evenings and nights, as more deaths may occur at night when there is less staff available. Shift data was not collected, and thus it cannot be determined if responses differed between these groups. Future research may resolve this issue.

Conclusions

This thesis provided information regarding death and bereavement in Ontario's northern LTC facilities. In general, residents and their families chose to have residents reside in their rooms when death was imminent. The nurse(s) in direct care of the dying resident informed the family, staff, and other residents of the impending and subsequent death of a resident. After a resident died, his/her belongings were removed and a new resident was admitted within two days of the death. Both formal and informal resources were available to families, staff, and residents to assist in coping with bereavement.

As of yet, a standard of care specific to the bereavement needs of families, staff, and residents has not been developed or accepted into practice in Ontario's LTC facilities. It is hoped that the knowledge of current bereavement practices discussed in this thesis will be of use to policy and decision makers in the LTC profession. It is only through knowledge of current practice that we can better the practice of the future.

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Appendix A

Bereavement in Long-Term Care Survey

Thank you for your participation in this survey! Please answer all of the following questions about your long-term care (LTC) facility to the best of your ability; your answers will remain completely anonymous.

1. Your position: Administrator DON Front-line staff (specify dep't: ________)

   If you are an Administrator, please answer questions a-d:

   a. Number of beds:

   b. Total number of residents that resided in your LTC facility in 2003:

   c. Number of residents who died in your LTC facility in 2003:

   d. Number of residents who died at a hospital or other location in 2003:

Please answer the following questions by circling the appropriate number.

2. When a resident is near death:

	Almost never		Sometimes		Almost always
He/she is moved to a private room	1	2	3	4	5
He/she is left in their own room	1	2	3	4	5
He/she is moved to a room closer to the nursing station	1	2	3	4	5
He/she is moved to a room reserved for palliative patients	1	2	3	4	5
Other (specify): ________________	1	2	3	4	5

3. When a resident is near death:

	Almost never		Sometimes		Almost always
The resident decides where he/she will stay	1	2	3	4	5
The family decides where the resident will stay	1	2	3	4	5
The LTC facility decides where the resident will stay	1	2	3	4	5
Other (specify):__________________	1	2	3	4	5

4. When a resident is near death, family members are notified by:

	Almost never		Sometimes		Almost always
The Director of Nursing	1	2	3	4	5
The nurse(s) providing direct care to the resident	1	2	3	4	5
Administration	1	2	3	4	5
Other (specify):__________________	1	2	3	4	5

5. When a resident is near death, other residents are notified by:

	Almost never		Sometimes		Almost always
The Director of Nursing	1	2	3	4	5
The nurse(s) providing direct care to the resident	1	2	3	4	5
Administration	1	2	3	4	5
Word of mouth	1	2	3	4	5
Other (specify):__________________	1	2	3	4	5

6. When a resident is near death, staff are notified by:

	Almost never		Sometimes		Almost always
The Director of Nursing	1	2	3	4	5
The nurse(s) providing direct care to the resident	1	2	3	4	5
Administration	1	2	3	4	5
Word of mouth	1	2	3	4	5
Other (specify):_______________	1	2	3	4	5

7. If necessary, after a resident dies, family members are notified by:

	Almost never		Sometimes		Almost always
The Director of Nursing	1	2	3	4	5
The nurse(s) providing direct care to the resident	1	2	3	4	5
Administration	1	2	3	4	5
Other (specify):_______________	1	2	3	4	5

8. If necessary, after a resident dies, family members are notified within:

	Almost never		Sometimes		Almost always
One hour	1	2	3	4	5
Two to five hours	1	2	3	4	5
Six to twelve hours	1	2	3	4	5
Other (specify):_______________	1	2	3	4	5

9. After a resident dies, other residents are notified by:

	Almost never		Sometimes		Almost always
The Director of Nursing	1	2	3	4	5
The nurse(s) providing direct care to the resident	1	2	3	4	5
Administration	1	2	3	4	5
Word of mouth	1	2	3	4	5
Other (specify):________________	1	2	3	4	5

10. After a resident dies, staff are notified by:

	Almost never		Sometimes		Almost always
The Director of Nursing	1	2	3	4	5
The nurse(s) providing direct care to the resident	1	2	3	4	5
Administration	1	2	3	4	5
Word of mouth	1	2	3	4	5
Other (specify):________________	1	2	3	4	5

11. After a resident dies, his/her body is:

	Almost never		Sometimes		Almost always
Shrouded	1	2	3	4	5
Cleaned by LTC staff	1	2	3	4	5
Dressed by LTC staff	1	2	3	4	5
Other (specify):________________	1	2	3	4	5

12. After a resident dies, his/her belongings are cleared out within:

	Almost never		Sometimes		Almost always
12 hours	1	2	3	4	5
24 hours	1	2	3	4	5
48 hours	1	2	3	4	5
Other (specify):________________	1	2	3	4	5

13. After a resident in a non-private room dies, a new resident is placed in that room within:

	Almost never		Sometimes		Almost always
12 hours	1	2	3	4	5
24 hours	1	2	3	4	5
48 hours	1	2	3	4	5
Other (specify):________________	1	2	3	4	5

14. Which of the following "informal" resources have you observed your staff using to cope with the death of a resident?

	Almost never		Sometimes		Almost always
Staff rallying around bereaved residents	1	2	3	4	5
Staff rallying around bereaved family members	1	2	3	4	5
Staff rallying around other bereaved staff members	1	2	3	4	5
Staff spending time with the dying resident before death occurs	1	2	3	4	5
Staff spending time with the deceased resident	1	2	3	4	5
Staff meeting outside of work time to reminisce, etc.	1	2	3	4	5
Staff attending individual memorials/ funeral services	1	2	3	4	5
Staff attending annual group memorials	1	2	3	4	5
Other (specify):__________________	1	2	3	4	5

15. Which of the following "informal" resources have you observed residents using to cope with the death of another resident?

	Almost never		Sometimes		Almost always
Residents rallying around other bereaved residents	1	2	3	4	5
Residents rallying around bereaved family members	1	2	3	4	5
Residents rallying around bereaved staff members	1	2	3	4	5
Residents spending time with the dying resident before death occurs	1	2	3	4	5
Residents spending time with the deceased resident	1	2	3	4	5
Residents meeting to reminisce, etc.	1	2	3	4	5
Residents attending individual memorials/funeral services	1	2	3	4	5
Residents attending annual group memorials	1	2	3	4	5
Other (specify):________________	1	2	3	4	5

Please answer the following questions by circling the appropriate response.

16. Is there a written standard procedure for notifying family members (if necessary) after a resident dies? Yes / No

    If yes, please specify the procedure: ______________________________

17. After a resident dies, are staff able to pay their respects before the body is moved to the funeral home? Yes / No

18. After a resident dies, are residents able to pay their respects before the body is moved to the funeral home? Yes / No

19. Are resources (e.g. transportation, assistance) in place to aid residents who wish to attend the funeral of a deceased resident? Yes / No

    If yes, please specify which resources are available: ______________________

20. Are resources (e.g. time off work, paid leave) in place to aid staff who wish to attend the funeral of a deceased resident? Yes / No

    If yes, please specify which resources are available: ______________________

21. Workshops and/or training in death, dying, and bereavement are available for staff to take: every month, every 2-5 months, every 6-12 months, other:

22. Is a hospice element integrated into your LTC program? Yes / No

Please indicate which "formal" resources are currently available for staff, residents, and family members by placing a check in the appropriate column:

	Staff	Residents	Family Members
Brochures/literature about grief			
Pastoral care			
Volunteer visits			
Professional counselling			
Grief support groups			
Individual memorials			
Annual group memorials			
Telephone calls			
Sympathy cards			
Scheduled mailings			
Hospice involvement			
Other: (please specify)			
Other: (please specify)			
Other: (please specify)			

What do you think are the barriers to providing "formal" bereavement services to staff in your LTC facility?

What do you think are the barriers to providing "formal" bereavement services to residents in your LTC facility?

Which bereavement supports/services would you like to see in place in your LTC facility?

Additional comments:

Appendix B

Bereavement Support in Long-Term Care

Researcher: K. Amanda Maranzan (Supervisor: Dr. Michael Stones)

You are invited to participate in a research study. The purpose of this study is to determine the types of bereavement support available to residents and staff of long-term care facilities, along with support available to bereaved families. This research study is the subject of a Master of Arts thesis being conducted by K. Amanda Maranzan of Lakehead University. She is being supervised by Dr. Michael Stones, also of Lakehead University. This information letter will explain how we are asking you to participate, the risks and benefits of participation, how we will keep your answers confidential, how the results will be presented, and who to contact for more information. IF YOU DECIDE TO PARTICIPATE IN THIS STUDY, PLEASE FILL OUT YOUR NAME AT THE BOTTOM OF THIS FORM AND SEND IT BACK TO THE RESEARCHER.

INFORMATION

You are invited to complete a questionnaire regarding bereavement-related practices at your long-term care facility. The questionnaire will ask about information such as how the death of a resident is handled, and what types of supports are available to residents, staff, and family members. Once you have completed the questionnaire, you are asked to email it back to the researcher.

The questionnaire takes approximately 15 minutes to complete. This study is taking place in June 2004. 195 administrators, directors of nursing, and "front-line" staff of long-term care facilities in Ontario have been asked to complete this questionnaire.

RISKS

We have not identified any potential physical, psychological, or emotional risks associated with participation in this study.

BENEFITS

Three $100 draws will be held. Participants who return the consent form and survey will be entered into this draw.

A potential benefit of participating in this study may be a sense of contribution to the scientific community. The results of this study may result in changes to bereavement-related policies and procedures in long-term care facilities.

CONFIDENTIALITY

Your questionnaire responses will be kept private and confidential throughout the entire study. Neither your name nor the name of the facility will be included on the questionnaire. To keep track, each questionnaire will be numbered, and a list of which questionnaire has been sent to which participant will be maintained by the researcher.

Please initial that you have read this page: __________

This "participant list" will be kept in a secure, locked room, and accessed only by the researcher and her supervisor. When the research project is over, the data will be kept in a secure, locked room for the time required, and then destroyed.

The results of this study will be reported in the researcher's Masters thesis, and may be presented in conference or journal presentations. To ensure your anonymity in any research publications or other release of this study's findings, individual results will not be reported. Whenever results are reported, all identifying details will be removed to assure your complete confidentiality.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study,) you may contact the researcher, K. Amanda Maranzan, at kafockle@lakeheadu.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Frederick Gilbert, President and Acting Vice-President (Research), Lakehead University, (807) 343-8200.

PARTICIPATION

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

FEEDBACK

You may obtain information about the results of this study by indicating at the bottom of this form that you would like to receive feedback. If you indicate that you would like feedback, you will be sent a description of the research results on or about September 30, 2004.

CONSENT

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

Participant's name: ______________________________ Date ________

Participant's signature ______________________________

Would you like to receive feedback about the results of this study? __________