The Impact of Informal Care and Caregiver Burden on Place of Death in Palliative Home Care

by

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A thesis
presented to the University of Waterloo
in fulfilment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Health Studies & Gerontology

Waterloo, Ontario, Canada, 2008

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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ABSTRACT

BACKGROUND: Literature suggests that many palliative home care patients wish to die at home. This study investigated determinants of caregiver burden among palliative home care patients, with particular interest in its relationship with place-of-death. Previous research has examined how patient care, health conditions, and characteristics of informal support relate to caregiver burden or place of death in palliative home care. However, none of the existing literature has focused on the role of caregiver burden on place of death or congruency between the patients' preferred vs. actual place of death. It seems likely that, in light of the high dependence on informal care during the last days of life, that caregiver burden plays a significant role in place of death. A number of factors may contribute to the incongruence between preferred versus actual place of death. For example, informal caregivers may lack the necessary skills and/or knowledge to provide adequate care to terminally ill loved ones. They may also be unable to cope with the type of care required by his or her loved one. Longitudinal studies indicating increasing home death rates among palliative home care patients. Research attributed the increased rate of home death to expanding home care programs rather than improving home care services. The goal of this study was to provide home care agencies the means to increase rates of home death among home care patients who wish to die at home by better directing existing types of services to lessen caregiver burden and improving congruency between preferred versus actual place-of-death.

OBJECTIVES: The aim of the research was four fold. First, it validated the caregiver burden items in the interRAI Palliative Care (interRAI PC) with self-report caregiver scales. The second section examined the determinants of caregiver burden. The third section examined the determinants of place of death and congruency between preferred vs. actual place-of-death. The final section examined the role of caregiver burden and place-of-death.

METHODS: This was a prospective cross-sectional study that employed the Caregiver Burden Scale, the Burden Inventory, and the interRAI PC tool. The sample included all palliative home care patients and their caregivers who received formal care from one Ontario community care access centre. Health information was collected by case managers during regular assessment intervals.

RESULTS: The three interRAI PC items measuring caregiver burden are an adequate measure of subjective stress burden. The sum of these items can be used to construct a caregiver burden scale. Determinants of caregiver burden were limited to unstable health and higher levels of self-reported depression, anxiety, and anhedonia. Patients who preferred to die at home were more likely to suffer IADL impairment, but not ADL impairment, and they were more likely to have completed a do-not-hospitalize order or do-not-resuscitate order. Patients whose caregiver was not a spouse or child relative were less likely to prefer home death. Further analyses showed a high level of agreement between preferred versus actual place of death. Overall, 57% of patients died at home, 68% of those patients who wished to die at home had managed to do so. Determinants that increased the likelihood of home death included completion of a do-not-hospitalize order, preference to die at home, and excessive sleep. However, the presence of a caregiver who was unable to continue providing care decreased the likelihood of home death.

CONCLUSION: The purpose of this study was to examine the role of caregiver burden in place of death among recipients of palliative home care. Studies such as this are important to the patients, caregivers, and the agencies that provide home care. Results of this study confirm many of the determinants of home death reported by earlier research. It is unique in that it identifies the caregiver’s ability to continue providing care as an important determinant of home death. These results support that notion that the needs of the caregiver should also be examined when determining the needs of the patient and that the patient and caregiver should be considered a unit of care. It also illustrates the important role of advanced directives, more specifically do-not-hospitalize orders, among patients receiving palliative home care.

Acknowledgements

I would like to thank each person who supported me and was involved in one way or another in the preparation of this manuscript.

I would especially like to thank my supervisors Dr. Trevor Frise Smith and Dr. John P. Hirdes for providing a stimulating and fun environment in which to learn and grow

I would also like to thank my good friend and fellow graduate student (Norma Jutan) for helping me get through the difficult times, and for all the support, entertainment, and caring she provided.

Lastly, and most importantly, I wish to thank my parents, Gerrit and Alice Brink. They raised me, supported me, taught me, and loved me.

Dedication

This manuscript is dedicated to a dear friend who died from cancer at a young age…God speed.

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CHAPTER I. INTRODUCTION

Due to a demographic shift, the number of persons over the age of 65 will continue to grow (Gomes & Higginson, 2008), and rates of terminal illness are likely to increase accordingly. Research suggests that roughly half of all cancer patients prefer to remain at home during end of life (Higginson & Sen-Gupta, 2000). Terminally ill home care patients must often rely on informal care to remain in their own homes. Consequently, the role of informal care is gaining importance in the Canadian health care system. However, a greater reliance on informal care may result in caregiver burden or caregiver burnout.

This study investigates the impact of caregiver burden in community-based palliative care and how such burden influences patient's preferred place of death. This topic is important because although many home care patients wish to die at home, caregiver burden may preclude achievement of this goal. This study also examined the consequences of caregiver burden and how it relates to preferred versus actual place of death. Literature suggests that that this topic is not yet fully examined. Studies have examined factors associated with caregiver burden and place of death independently; however, it is plausible and likely that these two domains are related.

This manuscript describes a three-stage study that examined the role of caregiver burden on place of death among palliative home care patients. The first stage looked at four proxy items measuring caregiver burden in the interRAI Palliative Care (interRAI PC) instrument (described in following sections). This was done by comparing the four items contained within the interRAI PC to established self-report measures of caregiver burden. The next step was to examine the determinants of caregiver burden and preferred place of death.

The final step was to examine predictors of home death, with caregiver burden as an independent variable.

Many studies referred to in this manuscript independently investigated caregiver burden and place of death but reported only a single primary caregiver (Cameron, Franche, Cheung, & Stewart, 2002; Emanuel et al., 1999; Frias, Tuokko, & Rosenberg, 2005; C. Given et al., 1993; Goldstein et al., 2004; Hwang et al., 2003; Jansma, Schure, & de Jong, 2005; Pruchno & Resch, 1989; Wilson, Curran, McPherson, 2005). However, terminally ill patients may have more than one caregiver. These secondary caregivers can include children, extended family members, friends, neighbours, and others as secondary caregivers or extended caregivers. Primary caregivers may depend on secondary and extended caregivers when they themselves are unable to care for their loved ones. Rather than study a single caregiver, it may be more appropriate to examine how secondary caregivers contribute to both the care of terminally ill patients and to the care of the primary caregiver.

?Bias may occur when studies only focus on individuals who are referred to an agency by a physician, hospital staff, family members, or friends. Studies examining place of death may be at particular risk of this predisposition (Constantini et al., 1993; Dunlop, Davies, & Hockley, 1989). Home care agencies providing palliative care often require physician referrals from eligible patients. Survival rates are often difficult to determine and lead physicians to inaccurately assign a prognosis (Homsi & Luong, 2007). Patients who may be eligible for home care services may not be referred to home care because of the difficulty determining their prognosis (Homsi & Luong, 2007). Other patients may simply favour hospice care.

No studies were found that explicitly examined the impact of caregiver burden on place of death. Similar results were found when researching the impact of caregiver burden on patient's preferred place of death. To date, any increase in the rate of home deaths has been attributed to *increased access to* palliative home care rather than to *improvements in* palliative home care services (Costantini et al., 1993). Research has shown that among caregivers, burden is associated with:

A) poor caregiver health (Grbich, Parker, & Maddocks, 2001; Pruchno & Resch, 1989);
B) emotional distress (Cameron et al., 2002); and
C) disruption to the caregiver's schedule (Frias et al., 2005).

Alternatively, patient characteristics associated with caregiver burden include:

A) a high level of care,
B) severe symptoms, and
C) deteriorating functioning (C. Given et al., 1993; Gott, Seymour, Bellamy, Cleark, & Ahmedzai, 2004).

Caregiver burden may be mediated by the caregivers' perception of burden (Goldstein et al., 2004). It seems plausible that caregiver burden influences congruency between the patient's preferred place of death and actual place of death. It is likely that caregiver burden plays a large role in the patient's preferred versus actual place of death. Perhaps home care agencies can elevate rates of home death among their palliative patients by dealing with the role of caregiver burden on place of death.

Two studies have examined place of death comparing home care to hospice care (Carrlsson & Rollison, 2003; Dunphy & Amesbury, 1990). They found that hospital patients are more likely to be referred to hospice care than non-hospital patients (Dunphy & Amesbury). Length of survival in home care also differs between hospital and hospice care (40.5 days vs. 21.8 days, respectively; Dumphy & Amesbury). Subsequent research by

Carrlsson and Rollison used a mail-out survey to compare the experiences of patients who died at home to those who died in hospice. When comparing home care patients to hospice patients, the length of time that home care patients were in contact with a home care agency was significantly longer than hospice patients (52 days vs. 20 days, respectively). Therefore, it may be inappropriate to compare differences in place of death between hospice and home care patients because the number of days in hospice is consistently shorter. Many patients who receive home care also use hospice care and the number of days these patients use home care and hospice care is similar or longer than patients who use either (Carrlsson & Rollison). Some patients enter home care at an earlier stage of decline may then enter hospice at the same stage as patients who were not enrolled in home care. This suggests that, for many home care patients, home care is additive to, rather than replacing, institutional based care.

Having patients' achieve their preferred place of death remains a social and medical challenge. It is important that patients' wishes be congruent with their actual place of death. However, the level of care and treatment palliative patients require at home may be a significant barrier to overcome. For example, pain symptoms may be unmanageable because the equipment is not available or the caregiver may be unable to cope with the responsibilities of providing care.

Home care disrupts the caregiver's personal life and adds significantly to their daily responsibilities. The social impact is also significant, whereby the caregiver role restricts the caregiver's social, personal, and vocational desires, especially when the primary caregiver is female, is a spouse, and/or co-resides with the patient (Brazil, Bedard, Willison & Hode, 2003; Cameron, Franche, Cheung, & Stewart, 2002).

The level of subjective burden may be highly related to the caregiver's willingness to provide home care. Subjective burden is the perception of burden and the emotional impact of providing care. Perhaps caregivers who willingly support in-home palliation report less subjective burden, irrespective of the number of tasks required, type of tasks performed, or status of their own health. Alternatively, many caregivers who are not comfortable providing home care may report high levels of subjective burden that relate to the incongruence between their new role as caregiver and their own personal wishes. Spouses view the caregiving role more favourably (Carrlsson & Rollison, 2003). Patients are also more comfortable receiving intimate care from spouses compared to other types of caregivers (Gott et al., 2004). Patients may prefer using formal home care services when they are unable to care for themselves or when a caregiver is unavailable or unable to continue with such assistance.

Agencies must acknowledge the needs of the caregiver and must incorporate into the care plan the notion that the caregiver may not want to be conscripted into providing a high level of personal care to a family member or friend at home. The high level of care required by a patient suffering from terminal disease may exceed the skill and/or comfort level of the caregiver, resulting in feelings of being overwhelmed, burdened and/or burnout.

The role of the primary caregiver may be that of a 'lynch pin' that determines the ability of the patient to remain at home. For example, not having an informal caregiver greatly reduces the likelihood of remaining at home (Dunphy & Amesbury, 1990). When an informal caregiver is present, the length of time the patient is able to remain at home may depend on the characteristics of that caregiver and the relationship between the patient and the caregiver. Secondary informal supports are also essential to in-home palliation (Gomes & Higginson, 2006); an inadequate support network (secondary informal care and formal care) may have dire consequences on the health of the primary caregiver, especially during the final 3-months of the patient's life. The role of the informal caregiver in palliative care is not yet fully understood and research that examines the interaction between informal and formal care warrants further investigation..

Study Rationale

Existing literature shows that factors such as the patient's symptoms and caregiver's characteristics are associated with caregiver burden in palliative home care. Literature shows that many of these same factors influence place of death. A review of the literature indicates that little, if any, research has explicitly examined the relationship between caregiver burden and place of death. McWhinney, Bass, and Orr (1995) state that "further research should be done into the levels of care needed for patients dying at home" (p. 366). Examining levels of care must also include the role of informal caregivers and the impact of caregiver burden. Hirdes et al. (n.d.) state "[s]ubstantially more research is needed to determine whether there is some threshold of burden that leads to dramatic shifts in the ability of caregivers to cope" (n.p.). Marginal increases in the targeted services provided by formal care providers may be able to reduce the level of caregiver burden that results from symptom management and functional impairment.

The present study examined caregiver burden in the context of place of death in palliative home care. It posited that higher levels of care are associated with higher levels of subjective burden. Subsequent steps show that higher levels of subjective burden are associated with incongruence between preferred vs. actual place of death among home care patients who expressed a wish to die at home. In addition, the caregiver's subjective perspective of burden largely depends on his or her temperament or personality rather than on the type of care required to sustain home support. This study also examined the relationship between a caregiver's self-perceived health and subjective burden.

Community care access centres (CCAC) might be able to achieve higher rates of home death among patients who wish to die at home by determining how caregiver burden influences place of death. This study provides the groundwork to identifying factors associated with caregiver burden with the aim of enabling patients to achieve their preferred place of death by reducing levels of burden placed on the caregiver. Reducing caregiver burden might inadvertently improve the perception that the home is a safe and appropriate place to die among patients and their caregivers.

Research Questions

This study is based upon four sub-studies or sections. The first section examined the relationship between proxy items indexing caregiver burden contained within the interRAI PC and more established measures of caregiver burden. The first section examined whether the interRAI PC measures of caregiver burden reflect objective burden, subjective stress burden, or subjective demand burden.

The second section identified factors associated with caregiver burden (objective, subjective stress, and subjective demand burden). Potential factors associated with caregiver burden include care tasks, the functional status of patients, symptom management, and health condition of the patient and the caregiver. This section determined if and how the patient's level of care or the caregiver's characteristics influenced levels of objective, subjective stress, and/or subjective demand burden. This section also set out to determine whether a burden threshold leads to dramatic shifts in the caregivers' ability of to cope.

The third section examined place of death and congruency between preferred vs. actual place of death. It first examined and contrasted factors associated with home death compared to institutional death. It then examined congruency between preferred vs. actual place of death among patients whose intention was to die at home. Many of the aforementioned studies suggest that lower rates of home death are associated with reduced functioning (impaired ADL, impaired IADL, cognition), health conditions (e.g., higher levels of pain and a greater need for symptom management), and caregiver characteristics (relationship, resident status). Analyses in this section established whether the sum of all care giving tasks are related to place of death or whether specific types of tasks influence place-of-death. It served to identify the characteristics of informal caregiver that may be associated with home death.

The final section examined how the general concept of caregiver burden and the specific domains of caregiver burden relate to caregiving, place of death, and congruency between preferred versus actual place of death. It served to determine if caregiver burden (or its domains) acts as a mediator between the provision of care and the ability of the patient to die at home.

The underlying premise of this manuscript was that the domains of caregiver burden are, to a degree, independent of each other whereby even though caregivers may experience high levels of objective burden, only subjective burden is associated with place of death. For example, compared to a co-resident caregiver, it is unlikely that a non-resident caregiver can provide 24-hour assistance indefinitely. This study also assumed that the domain of caregiver burden depends on the type of care provided, for example, toileting, bathing, or personal hygiene (Hooyman, Gonyea, & Montgomery, 1985).

The type of burden reported by caregivers may have implications for home care agencies. Objective burden may indicate that the patient/caregiver dyad needs more home support. Subjective stress burden may suggest that the caregiver would benefit from increased social support or counselling. Finally, a caregiver reporting subjective demand burden might benefit from information and skill development to help reduce the demands of caregiving. The four study sections, discussed previously explicitly focus upon four research questions:

1. Do the interRAI PC measures of caregiver burden reflect objective burden, subjective stress burden, or subjective demand burden?
2. What are the factors associated with caregiver burden (objective, subjective stress, and subjective demand burden)?
3. What are the determinants of home death and which of those influence congruency between preferred vs. actual place of death?
4. How does the general concept of caregiver burden relate to caregiving, place of death, and congruency between preferred versus actual place of death?

CHAPTER II. REVIEW OF THE LITERATURE

End of life care is concerned with the type of care delivered to all persons who are nearing the end of life (Lynn, 1999). Palliative care is a philosophy of care that includes treatments and therapies meant for comfort and/or support for end of life persons (Canadian Hospice Palliative care Association [CPCA], 2002). The principles of palliative home care include the provision of independence and dignity to home care patients receiving palliative treatment at home.

Palliative home care enables patients to make informed decisions about their own health care needs in an effort to sustain the patient's support system. Palliative care is inclusive, it is designed to meet the psychological, social, and spiritual needs of the caregiver and his/her loved one while remaining sensitive to "personal, cultural, and religious values, beliefs and practices (Condie et al., 2003, p. 3). The World Health Organization defines palliative care as "the active care of patients whose disease is not responsive to curative treatment" (Johnston & Abraham, 1995, p. 124).The Commission on the Future of Health Care in Canada defines informal care as "family members and friends who provide support on an unpaid basis" (Romanow, 2002, p. 183). The purpose of in-home palliation is to allow patients suffering terminal disease to stay in their own familiar surroundings longer and/or to die at home.

Lower costs to the Canadian health care sector and patients' willingness to utilize in-home palliation are driving support for community-based services. Clearly, the emergence of palliative home care is beneficial to patients and the health care system. However, the effect of palliative home care on informal caregivers, whether family or friends, is yet to be fully understood.

The trajectory toward death is often unpredictable (Cassel et al., 1997). Three common trajectories exist: 1) the dying process can be sudden and unexpected; 2) it can be a slow, steady decline relatively free of crises; or 3) it can be a slow decline marked by occasional, periodic crises, any of which eventually result in death. The trajectory toward death has a significant impact on informal caregivers. When a family member or friend dies unexpectedly, the focus for the informal caregiver is bereavement. However, under the rubric of palliative home care, the trajectory toward death is frequently uncertain and the need for care is great.

The number of programs that provide palliative home care in Canada continues to grow. In the past, longitudinal studies have indicated that the proportion of non-hospital cancer deaths has gradually increased (Burge, Lawson, & Johnston, 2003; Fainsinger et al., 2003). Although many deaths continue to occur in hospitals, the trend toward non-hospital death has been noticeable, particularly within the last 5-year period (Burge et al.). The trend in increasing rates of home death is even more noticeable within specific groups. For example, Fainsinger et al. stated that “access to palliative care services has increased from 45 percent to 81 percent for terminally ill cancer patients between 1993 and 2000 as a result of introducing comprehensive, regional palliative care programs in two large urban centers” (p. 1).

In Ontario, the delivery of home care services is coordinated by Community Care Access Centres or CCACs . These CCAC’s deliver services to several different client groups: maintenance clients, short service clients discharged from acute care, and palliative care. Unfortunately, home care in general, and palliative home care programs specifically, are not standardized by the government and often lack consistency. Canadians have limited access to in-home palliation (CPCA, 2001), and the level and type of home support often depends on the patient's location (Burge et al., 2003; Huang et al., 2002). Many Canadian home care agencies only offer specialized services to patients suffering terminal disease whose life expectancy is 6 months or less (Cantwell et al., 2000). The patient's experience receiving palliative home care is often quite variable; some receive excellent palliative care, whereas others receive care that may not meet their needs. Their experience depends on their diagnosis, their trajectory of illness, health conditions, characteristics of their informal caregivers, and the type of formal care provided to them.

Palliative care begins when a life-threatening disease becomes terminal (Jeffrey, 1995). The ability to prognosticate remains difficult for all health care professionals and defining 'when' a patient is terminally ill is problematic (Llobera et al., 2000). Prognostication remains a central criterion for placement to palliative home care programs. Unfortunately, a potential indicator of poor quality care may be only providing care to patients whose death is imminent. Conversely, early entry into palliative home care allows for a higher level of palliation not found in the general home care stream (McKinlay & McBain, 2007). Such care allows for enhanced symptom management, a higher level of quality of life, and helps patients meet their goals of care.

Many home care agencies only provide services to patients who have family members who are able and willing to provide informal care at home (Brown, Davies, & Martens, 1990). This restriction indicates that home care agencies provide formal care that complements patients' existing informal care. Agencies only offer extensive services such as 24-hour nursing when death becomes imminent. Earlier research on the caregivers' ability to provide care indicates that "the ability to carry out the caregiving role [is] determined, in part, by the nature of the local home care program" (Brown et al., p. 25). Clearly, there exists a need for more standardization within palliative home care so that agencies offer similar programs that are both comprehensive and inclusive. As the number of palliative home care programs increase, so too does the choice to die at home (Burge et al., 2003). Studies reviewed argue that the capacity to provide care depends on the characteristics of patient (Wilson et al., 2005); caregivers (Carrlsson & Rollison, 2003; Emanuel et al., 1999; Goldstein et al., 2004; Grbich et al., 2001); and health care professionals (Sharpe, Butow, Smith, McConnell, & Clarke, 2005).

The importance of informal care cannot be understated. However, the role of informal care in care planning and needs assessment is often overlooked (Brown et al, 1990). Research has stressed the importance of considering the patient-caregiver relationship as a unit of care (Grbich et al., 2001; Hwang et al., 2003; Stajduhar & Davies, 1998). As the demands of care increase, so do the needs of the patient and the caregiver. The ability of the caregiver to provide effective care is often not assessed.

The impact of in-home palliation on informal care is likely to grow if agencies continue to download many of the caregiving responsibilities on to family caregivers. The demands of caregiving are physical, psychological, and financial. The need for external support increases exponentially during the last month of life (Huang et al., 2002). Care quality might be at risk because of the heavy reliance on informal care when death is imminent. Caregivers may feel conscripted or obligated into providing care, often feeling subjugated by the home care agency (Stajduhar, 2003), compromising the caregivers' health when the caregiving responsibilities become too great (Grbich et al., 2001).

The role of informal care in palliative home care may be difficult to study because of the sensitive nature of end-of-life issues. A major limitation to conducting informal-formal care research is the shortage of appropriate, accurate data (Paice, Muir, & Shott, 2004). Even the definition of "palliative" is not yet standardized. For example, some organizations define palliative as 'end-of-life,' while others define it as 'an incurable disease'" (Dudgeon et al., 2004, p. 1). The first implies close proximity to death while the second speaks to the patient's illness.

Based on the previous discussion, the purpose of this study is to increase understanding of the caregiving role, investigate how caregiver burden affects informal care networks, and recognize how they might influence place of death among palliative home care patients. Studies have discussed the factors associated with caregiver burden, the patient's preferred place of death, or the place of death. Although many factors associated with caregiver burden also appear in place-of-death literature, none acknowledge that they may be related.

A number of journal articles cited in this study examine non-palliative samples because the relationship between informal and formal care in palliative home care remains underdeveloped. To an extent, the findings of those studies will be generalized to palliative home care in the literature review.

Caregiver Burden

The goal of this section is to examine the general concept of caregiver burden in palliative home care. Caregiver burden can be physical, emotional, and/or financial. Each of these categories is divided into objective or subjective burden, concepts that are defined and addressed in a subsequent section.

Caregivers often report moderate levels of burden. Carrlsson and Rollison (2003) compared the caregiving experiences of three groups of caregivers providing end of life care:

A) caregivers of home care patients who later died at home,

B) caregivers of home care patients who later died in hospice, and

C) caregivers of patients who did not receive home care and died in hospice.

They found that caregivers in Group A experience higher levels of burden. Caregivers in Group A also experience significant sleep disturbance and physical burden in comparison to Group B. This finding was not surprising because in-home palliation may often require 24-hour supervision and the demands of caregiving increase as the illness progresses (Weitzner, McMillan, & Jacobsen, 1999). Specific types of assistance, such as toileting, are required on an "as needed" basis and cannot be confined to a specific time when a personal support worker is present.

Often patients require higher levels of care because of reduced physical functioning and health conditions (Carrlsson & Rollison, 2003; Huang et al. 2002; Weitzner et al., 1999). Carrlsson and Rollison found that caregivers in Group C (those whom did not receive home care and died in hospice) report high levels of psychological burden, implying that the act of transferring a patient to hospice is emotionally distressing to the caregiver and may result in a sense of failure in the caregiving role.

The trajectory toward death has a significant impact on the caregiver (Cassel et al., 1997). Acute symptoms associated with terminal illness are often responsible for the transition from home care to hospice care (Carrlsson & Rollison, 2003). Ill-equipped caregivers may have trouble dealing with the complexities of advanced illness during an acute episode. To a lesser extent, the effect of long-lasting symptoms can be similar. They likely wear down the caregiver and, in conjunction with sleep disturbance, improper eating habits, and mental exhaustion, result in a breakdown of the patient's social network, a premise that is consistent with Grbich et al.'s (2001) finding that caregivers often report poor health brought on by little time to relax and few opportunities to cook and eat properly.

The size of the patient's social network plays a significant role on caregiver burden. Research suggests that patients with larger social networks have more caregivers to provide care (Goldstein et al., 2004). Primary caregivers who are able to depend on extensive social networks (i.e., family, friends, neighbours, and others) are less affected by the needs of the patient because they are able to depend on the assistance of others (Goldstein et al.). Montgomery, Gonyea, and Hooyman (1985) found that restricted freedoms resulting from care-giving tasks are a critical factor in the perception of burden. They reported that the size of the caregiver's social network mediates the level of perceived burden.

Caregivers with extensive social networks are less likely to restrict their own activity levels (social or occupational). Goldstein et al. (2004) found no association with the cumulative amount assistance provided to the patient, but they did identify a higher level of burden among caregivers who restrict their activities because of caregiving responsibilities. This finding suggests that although the amount of assistance provided to the patient may be less important, the caregiver's circumstances, such as family and occupational concerns, play a significant role in the perception of burden.

Cameron et al. (2002) investigated the influence of restricted activity on caregiver burden among caregivers of patients with terminal cancer. Cameron et al.'s research suggests that levels of restricted activity among caregivers may act as a mediator between the patients' need for care and the caregivers' perception of burden. Caregivers with fewer obligations are less likely to report caregiver burden. For example, in a 6-month prospective study, Nijboer et al. (2000) sought to identify patterns in caregiver experiences among the partners of patients with colorectal cancer. They discovered that the impact of care-giving on caregivers' daily routines decreases over time, signifying that the caregivers might be disengaging from their regular routines.

Caregiver burden is also dependent upon the age of the caregiver. For example, younger caregivers experience higher levels of caregiver burden (Goldstein et al., 2004) and report more disruption to their schedules than older adults (Nijboer et al., 2000). However, in an assessment of caregivers' physical and mental reactions to the caregiving role in a sample of non-palliative adults aged 63 to 94, Frias et al. (2005) found that older caregivers have greater difficulty fulfilling the caregiver role. One may conclude that caring for patients who are terminally ill impacts younger and older caregivers differently. Family obligations and career interruptions likely impact younger caregivers, whereas health concerns and frailties impact older caregivers. However, because Frias et al.'s study sample was non-palliative, one can only infer from their findings to palliative home care, where patients' needs might be far greater. Clearly, when assessing the level of assistance required by patients receiving in-home palliation, home care agencies must take into account the age and the health status of the caregiver(s). Contradictory evidence indicates the need to further explore the relationship between age and caregiver burden.

Caregivers often describe the experience of providing care to terminally ill patients as an *emotional roller coaster*. Grbich et al.'s (2001) qualitative study investigated the influence of emotions and coping strategies on the family members of patients suffering terminal cancer. Grbich et al.'s research reports that the caregivers in their study expressed pleasure in being able to do things that would normally be impossible if the death had been sudden or unexpected even when the level of care is exhaustive and intensive. Patients and caregivers were still able to share precious moments during the final stages of death.

The Commission on the Future of Health Care in Canada (Romanow, 2002) identified the need to recognize the significant role of informal support in home care. The members on the commission also recognize that women, most often wives and daughters, are responsible for fulfilling this role. High levels of physical burden are common among female caregivers (Carrlsson & Rollison, 2003). Female caregivers may be older and may experience greater difficulty providing care to family members who are suffering terminal disease (Carrlsson & Rollison). Female caregivers are more likely to report problems with strength as the illness progresses (Nijboer et al., 2000). However, female caregivers often experience a higher degree of satisfaction with their caregiving achievements than do males (Carrlsson & Rollison).

Emanuel et al. (1999) examined the type of care that informal caregivers provide and how often older adults receive care from family and friends. Although the majority of caregivers are women, they remain less likely than men to receive assistance from family or friends. Lower levels of family assistance are associated with being female, unmarried, and over 65 years of age. One can easily hypothesize that this may be because women who are older are also more likely to be widowed. Formal care is used more often among married women who are palliative, indicating that women in general rely more heavily on formal support, even when family caregivers are available. However, they might prefer to use formal support rather than rely on spouses or children. Husbands may be incapable of providing the type of care necessary to maintain home support because they traditionally did not participate in homemaking. As stated earlier, adult children may find the level of support they are able provide restricted by their own family, career obligations, and/or greater social mobility.

Cameron et al. (2002) in their study of familial caregivers of advanced cancer patients found no gender differences: Men were just as willing to fulfill the caregiver role however, the duties that they perform were not examined in this study. The proportion of male and female caregivers in Cameron et al.'s sample was equal: one third of their sample were retired, one third were still employed, and the remainder comprised homemakers. For these reasons, it is difficult to generalize their findings to the general palliative home care population. Perhaps a disproportionate number of men were retired or secure in their employment, making the impact of an extended leave less precarious, thereby reducing the likelihood of finding gender differences.

Pruchno and Resch (1989) reported on the differences between husbands and wives as caregivers to their spouses. Although the caregivers in their study were providing care to Alzheimer's patients, similarities existed between this type of non-palliative care and palliative care. Alzheimer's patients are older and often require extensive support, factors that highlight the importance of caregiver health, where levels of depression increase as caregiver health declines. Husbands who are emotionally invested in the marital relationship are often less depressed, whereas emotionally invested wives are often more depressed. Pruchno and Resch conclude that the experience of caregiving is different for husbands and wives. They hypothesize that during the post-parental period, the caregiving role is more congruent with men than women. Although the emotional investment among men is greater, they are more likely to receive assistance with the homemaking tasks (cooking, cleaning, and laundry). Wives are more likely to continue with their traditional roles as homemaker in addition to their role as caregiver.

Compared to male caregivers, the caregiving role adds considerable responsibility to women. In light of this difference, it is not surprising that levels of caregiver stress are often higher among women. Women still perform the majority of homemaking tasks, and the caregiver role is additional to those responsibilities. Caregiver burden may be lower among men because they are unfamiliar with homemaking tasks and so opt for outside assistance. Literature suggests that men's role, especially during the post-parental period, is largely emotional.

Objective and Subjective Burden

Caregiver burden can be described as either objective or subjective. Measurements of objective burden include the quantity of time performing a caregiving task, the type of tasks performed, and the resources (physical and financial) needed to maintain the caregiving role. Objective burden refers to the tangible costs to the caregiver, such as physical demands and disruption to daily routine. It is not surprising that objective burden is detrimental to palliative care, especially in the final stages of a terminal illness when the caregiving role is often intense.

In addition to coping with the demands of patient care, the emotional distress associated with caring for a patient suffering terminal disease can be overwhelming. Subjective stress burden refers to the caregiver's perception of burden and is influenced by the caregiver's appraisal of the situation and the emotional impact that it has on the caregiver. The definition of subjective stress burden makes it difficult to measure. Subjective demand burden refers to the extent to which the caregiver perceives the responsibility of providing care to a family member or friend as overwhelming.

Objective burden refers to the physical and financial demands of providing care, and subjective stress burden refers to the emotional impact on the caregiver, and subjective demand burden refers to the extent to which the caregiver perceives his or her role as overly demanding. As illustrated in this manuscript, subjective stress burden may be a more important concept than objective burden in the framework of the patient-caregiver relationship.

Montgomery et al. (1985) studied the experiences of caregivers assisting elderly relatives suffering Alzheimer's disease. Although their focus was on Alzheimer's patients, one may assume that their findings extended, at least partially, to in-home palliation. Lower levels of objective burden are associated with the presence of a secondary caregiver and the types of care required by the patient (Montgomery et al., 1985). While examining the aspects of objective burden, Montgomery et al. reported that the total number of tasks is less important than the types of tasks performed. For example, they found a significant relationship between objective burden and nursing care, bathing, dressing, walking, transportation, and errands.

High levels of subjective burden are related to younger age, higher income, and bed and wheelchair transfers (Montgomery et al., 1985). Caregiver burden may be related to age and income because caregiving increases the responsibilities of younger caregivers who already have to manage employment and family obligations. Bed and wheelchair transfers are considerable tasks for lay persons to perform, but also indicate a higher level of need (i.e., 24-hour support) and may act as an indicator of the patient's overall state of health. The caregiver of a patient whose condition is deteriorating may perceive the situation as burdensome because the tasks go beyond what the caregiver can reasonably provide. Interestingly, tasks not related to objective burden or subjective burden are typical of everyday household activities (e.g., housework, yard care, laundry, meal preparation, money management, personal business, medications, and feeding; Montgomery et al.), suggesting that the construct of burden and caregiving is independent of everyday activities.

Objective burden is laden with tasks that occur in addition to everyday household activities, however, objective and subjective burden are somewhat related but must be considered distinct constructs. The degree of subjective burden is dependent on the characteristics of the caregiver, the size of the caregiver's social network, and the variety of care-related tasks.

Patients Self-Perceived Burden

Self-perceived burden is the extent to which a patient might see him or herself as a burden to others. Patients suffering terminal disease often have to depend on family and friends to help with many of the tasks they would normally do themselves. Many home care patients view themselves as a burden to the caregiver (Wilson et al., 2005). In a sample of palliative inpatient-outpatients, Wilson et al. found that 39% of the patients were somewhat concerned and 26% were moderately or extremely concerned that they are a burden to their caregivers, indicating that self-perceived burden is a significant problem that affects roughly 65% of the patient population.

Evidence suggests that viewing oneself as a burden has very little to do with the severity of the patient's symptoms. Patients are often concerned about burden even in the absence of severe symptoms (Wilson et al., 2005), indicating that the patient-caregiver relationship is more important than the patient's overall condition. Married patients report higher levels of self-perceived burden than unmarried patients (Wilson et al.). These feelings are associated with a loss of control, loss of dignity, hopelessness, depression, and anxiety (Wilson et al.), suggesting that self-perceived burden may be a mental construct of the patient, not the result of problems associated with caregiving. A major limitation to Wilson et al.'s study was that they did not assess the congruence in perceived burden between the care recipient and the caregiver.

It appears that the relationship between perceived and actual burden does exist; Wilson and McPherson (2007) found that the relationship is significant but not robust. Their study found that patients had a difficult time recognizing burden (r = 0.29). An examination of the relationship between the caregivers appraisal of burden and the patient's perception of burden was also low (r = 0.28), this lead to the conclusion that the perception of burden is a cognition or belief that may not be a reality. Cousineau, McDowell, Hotz, and Hebert (2003) stated that self-perceived burden is a "multi-dimensional construct arising from the care-recipients' feelings of dependence and the resulting frustration and worry, which then lead to negative feelings of guilt and being responsible for the caregiver's hardship" (p. 111).

Congruence between patient and caregiver perceptions of burden might point toward unmet needs, perhaps necessitating additional formal support. Incongruence, where the patient perceives burden, may suggest a cognitive distortion in the perception of burden or perhaps signal depression. A literature search (PubMed, PsycINFO, and ProQuest) revealed that this topic has not yet been addressed extensively.

Depression and the Caregiver

Montgomery (n.d.) stated that the "emotional impact [of providing care] has been variously called subjective burden, stress or strain and has been linked to depression" (electronic). C. Given et al. (1993) examined the influence of physical symptoms and level of functioning on feelings of depression and overall health of patients and caregivers. The sample in C. Given et al.'s study were non-palliative patients suffering from cancer. The majority of caregivers were female and married. C. Given et al. found that patients' depression and level of symptom severity is strongly related to the caregivers' level of depression. However, a drawback to C. Given et al.'s study was that their definition of caregiver only included one "primary caregiver," who was identified by the patient. Patients who have more than one caregiver may be forced to report and describe the most significant care provider even though multiple caregivers are present. Perhaps depression is less likely when multiple caregivers are present. C. Given et al.'s study fell short in that they were unable to examine this possibility.

Cameron et al. (2002) examined lifestyle interference and emotional distress in the family caregivers of advanced cancer patients. Caregivers experienced high levels of emotional distress, defined as depression and tension that are not related to the amount of external support provided (Cameron et al.). Generalizing the findings from this study is difficult because the participation rate was 46%. How this participation rate impacted Cameron et al.'s study is difficult to determine. Perhaps highly educated participants suffer lower levels of depression and are more likely to participate, whereas less educated people suffer higher levels of depression and are less likely to participate. An indication that their sample differed from the true population was found in the diagnoses reported by patients. The patients in this study had a variety of cancers that are not as sex specific as prostate cancer in men and breast cancer in women (Canadian Cancer Society/National Cancer Institute of Canada, 2005). Clearly, the care requirements of Cameron et al.'s study sample may have been different from the care required by advanced cancer patients.

Wish for Hastened Death

Physician assisted suicide is defined as a medically-assisted death. It requires the assistance of a physician for a patient to commit suicide. The physician can show the patient how to die but the act of self-termination is performed by the patient. Euthanasia is also defined as medically assisted death but is different in that the physician performs that act of terminating the life of a patient. Both forms of death are illegal in most countries. Those that have legalized either forms of death have safeguards in place to prevent any wrongdoing. Both are also surrounded by controversy, with strong beliefs represented by both sides.

Although euthanasia and physician assisted suicide are not legal in Canada, a recent Canadian study examined euthanasia and physician assisted suicide (National Palliative Care Survey, NPCS, Wilson & McPherson, 2007). It was a multi-centre study of cancer patients who received palliative care. It examined a number of domains that included social connections, communication, and sense of burden, financial concerns, and loss of control. The NPCS found that 62% of patients questioned believed that either forms (euthanasia and physician assisted suicide) should be legalized, individuals who favoured euthanasia and/or physician assisted suicide were more likely to be younger and have lower scores on the religiosity index.

The wish for hastened death is not common. Of Wilson and McPherson's (2007) sample of patients with advanced cancer, only 5.8% (22/379) would have asked for euthanasia or physician assisted suicide at the time they were interviewed. When asked which method is most acceptable, euthanasia or physician assisted suicide, most participants believed euthanasia to be more acceptable.

Wilson and McPherson (2007) reported that among the general population, severe or excruciating pain was the main reason for favouring the legalization of euthanasia or physician assisted suicide. Therefore, they expected to find that the wish for hastened death among terminally ill cancer patients is associated with high levels of pain. What they found is that patients who see themselves as a burden to family and friends are more likely to wish for a hastened death, and that the desire for hastened death is associated with feeling unwell, higher levels of fatigue, and weakness. They also found that it was associated with depression and anxiety and co-morbidities of mental illness. These findings are supported by earlier research (Block and Billings, 1994; Chochinov et al., 2002; Marcoux, Onwuteaka-Philipsen, Jansen-van der Weide, van der Wal, 2005). In fact, Chochinov et al. found that the loss of dignity is associated with psychological distress, symptom distress, and higher levels of dependency.

The patient's own sense of burden is clearly related to a wish for hastened death. However, research examining the relationship between the patient's own sense of burden and place of death has yet to be examined. It seems likely that euthanasia and physician assisted suicide, if legalized in Canada, would play a large role in place of death. Patients who opt for euthanasia may be more likely to die in an institutional setting where technology is easily accessible. Alternatively, physician assisted suicide may help terminally ill patients to die at home by assisting patients with the know-how to commit suicide.

Needs of the Patient and Caregiver

The needs of the patient and the caregiver must be met if palliative home care is to remain viable. Because the well-being of both individuals is reciprocal, the patient and the primary caregiver must be considered a "unit of care." When their needs are not met, both the patient and caregiver must depend on external support provided by formal care providers.

Family caregivers identify managing physical decline and symptom control as important to successful in-home palliation (Brown et al., 1990). Hospitalization is often essential when conditions in the home become 'out of control,' as determined by the patient's physical condition and the caregiver's ability to provide care. Brown et al.'s study emphasizes that hospitalization is inevitable when a patient experiences a loss of mobility in conjunction with incontinence problems.

Sharpe et al. (2005) looked at the relationship among the level of available support, unmet needs, and caregiver burden among patients suffering advanced cancer and their primary caregivers. Both patients and caregivers believe that there is more support available to patients than health care professionals do. However, health care professionals may systematically bias their assessments to err on the side of caution in an effort to ensure that adequate formal support is available. Sharpe also reported that, compared to patients, caregivers tend to overestimate the level of unmet needs, believing that patients require more care or a higher level of care than they actually receive or need. The caregiving role may be new to the caregivers, and they may be unsure of their ability to provide care.

Jansma et al. (2005) examined the support requirements of palliative cancer patients in an effort to understand the needs of primary caregivers. They found that caregivers require a high level of communication, practical information, and good health. All caregivers rate their own health as highly important. However, men rate communication as the most important while spousal caregivers place a higher priority on communication and less emphasis on their own health. The relationship between spouses might be unique when compared to other types of patient-caregiver relationships whereby spousal caregivers tend to focus on the health and well-being of the patient and give less thought to their own health compared to other types of informal caregivers (child, relatives, friends, or neighbours). In addition, a large proportion of caregivers want to be included in decisions made by the support program (Jansma et al.). Irrespective of the complexities outlined by Jansma et al., their study added momentum to the argument to consider the patient and caregiver as a unit of care.

Unmet needs related to caregiver burden suggest that caregivers are unable to cope in their role as caregivers. Case workers assessing the needs of the patients must consider not only the needs of the patients but also those of the caregiver(s). When case workers do not consider those needs, or when the needs of the caregiver(s) are different from that of the patient, support from the extended family or health care professionals may not be made available to them.

Caregivers may also have trouble conveying their own needs to the patient and health care professional. Caregivers may attempt to protect patients from the situation by not discussing their own needs. Sharpe et al. (2005) stated, “When patients are not aware of the needs perceived by their caregivers, the carer is at risk of receiving less support from the wider family” (p. 111). This lack of awareness places caregivers at increased risk of receiving lower levels of support from family and results in higher levels of caregiver burden.

A group of researchers (The Support Investigators, 1997) found that by the time the family member or friend had died, 40% of family members were required to quit work, nearly 33% lost at least one source of income, and 25% lost most, if not all, of their savings caring for a family member or friend suffering from terminal disease. Clearly, the needs of the caregiver were not being met.

Location of Death

The Commission on the Future of Health Care in Canada (Romanow, 2002) stated that approximately 80% of Canadians would prefer to die at home. However, home death may be idealized in the general population. Many terminally ill patients wish to remain in their homes as long as possible and only opt to die at home under ideal circumstances (Gott et al., 2004).

Maintaining dignity and autonomy includes control over their place of death and is important to many persons suffering terminal disease. Of patients who indicate a preferred place of death, the proportion of patients wishing to die at home ranges from 38% (Karlsen & Addington-Hall, 1998) to 47% (Cantwell et al., 2000).

Karlsen and Addington-Hall (1998) examined differences between cancer patients who died at home versus those who died elsewhere. They found that a low percentage of the patients reported any preference in place of death (38%). Of those who did express a preference, most indicated death at home as being optimal (78%). Little more than half (58%) of those whose aim was a home death achieved that goal.

McWhinney et al.(1995) considered determinants associated with location of death among patients receiving palliation in their own home. Similar to Karlsen and Addington-Hall's (1998) findings, these researchers reported that 47% of the participants recorded a preference for a home death. Their study differed in that they also recorded the strength of the patients' preference. The preference was strong among 38% and conditional among 16% of the participants. Overall, 28% of the participants achieved a home death.

Many patients who indicate a preferred place of death favour home death. However, terminal disease is not static and the patients' health will deteriorate. Patients may then alter their preference because the trajectory of the illness may become unstable or the symptoms may become severe. The primary caregivers may also influence the patients' preferred place of death. Older caregivers may be unable to cope with the responsibilities of caring for someone with a terminal disease; younger caregivers may have conflicting obligations, such as family and employment.

To a large extent, the ability to die at home depends on the level of home support provided to patients. McWhinney et al. (1995) suggested that patients’ preferred place of death may change during the course of the disease. If adequate home support is made available either through additional informal support (secondary caregivers) or formal support, patients initially favouring a hospital death may later find a home death acceptable. The ability to die at home also depends on other factors, including symptom severity, prognosis, and diagnosis.

Caregivers may not always prefer that the patient die at home. A report by Stajduhar, Allan, Cohen, and Heyland (2008) found that half of terminally ill patient/caregiver dyads preferred to die at home and half of patient/caregiver dyads disagree on preferred place of death. Further research that examines the reasons associated with not preferring home death need to be examined. One of the main goals of palliative home care is to ensure that patients die in their preferred place, then the most appropriate place of death must be based on an informed decision and information on the dying process must be made available to patients and their caregivers.

In a 4-year longitudinal, population-based study examining all cancer deaths in Italy, Costantini et al. (1993) reported that the probability of dying at home is associated with increased:

A) age,

B) level of education,

C) gender, and

D) marital status.

Although the number of patients dying at home increased, the increase was attributed to the expansion of services rather than a change in services.

Brazil, Bedard, and Willison (2002) identified factors associated with home death among home care patients. Patients who prefer to die at home are more likely to do so if their caregivers are co-residents or their physicians make home visits. The odds of dying at home are lower among patients who use palliative hospital beds or whose caregivers are in poor health. The issue of caregiver health is important among older carers who themselves may experience difficulties in everyday functioning. They may have difficulty performing caregiving tasks such as dressing, bathing, and feeding the patients. The ability to remain at home during the dying process is often determined by the presence of a caregiver, but the positive effect of having a caregiver is negated when the level of care is restricted by the caregiver's own poor health.

McWhinney et al. (1995) identified the factors associated with home death. They found that determinants of home death include:

A) accepting the patient's preference to die at home,

B) having a secondary caregiver in addition to the primary caregiver, and

C) using private shift nursing.

Even though the likelihood of dying at home is greater for patients who have more contact with home care nurses, physician contact is not usually associated with home death.

Clearly, the ability to die at home depends on many factors. Central to a home death are the availability and characteristics of the caregivers. Informal care can influence the place of death among patients suffering terminal disease. Cantwell et al. (2000) examined the predictors of home death among Canadian palliative home care patients. They included the caregivers' wishes as well as the patients' wishes. Predictors of a home death include:

A) a desire for a home death by both the care recipients and the caregivers, and

B) the presence of more than one caregiver.

They hypothesized that multiple caregivers lessen caregiver burden by reducing the responsibilities of any one caregiver. Access to resources and financial concerns are not predictors of a home death perhaps because in Canada, home care is offered at no or little cost to patients and is provided on an as-needed basis.

Dunlop et al. (1989) studied the preferred versus the actual place of death among patients referred to a hospital support team. They concluded that patients who die at home more often do so in the presence of an informal caregiver. The caregivers of patients who died at home are more likely to find the caregiving role rewarding (Karlsen & Addington-Hall, 1998). However, it is difficult to determine if the role itself is rewarding because it is successful or because the tasks require a lower level of skill and are associated with a lower level of care.

Tang and McCorkle (2003) examined congruence between preferred and actual place of death. Their study showed that although the majority of patients prefer to die at home, only one third do so. Congruence in preferred place of death is associated with a higher level of support from family caregivers who are more capable of providing home care. The use of formal home care contributes to congruence, but the use of emergency care or readmission to hospital care has the opposite effect. This suggests that the ability to die at home might have a lot to do with the patient's symptom profile (nausea, treatment procedures, etc.).

McWhinney et al.'s (1995) study supported the hypothesis that a higher level of informal support is often associated with home death among patients suffering terminal disease. In addition to a spouse, the presence of a son or a daughter co-resident caregiver greatly increases the chance of a home death. The need for formal support such as shift nursing is often necessary (Huang et al., 2002). Patients who receive very little or no formal support are more likely to die in hospital, irrespective of their expressed wishes (McWhinney et al.). Elsewhere, shift nursing is often available through an employee or a retirement benefit plan. However, home care nurses find that patients who die in hospital rarely have access to these benefits. This last point has implications for Canadians. In Canada, formal care is often free, but the number of hours provided by agencies is limited. Extensive services are only offered when death is imminent. Until then, higher levels of formal care are only available to those who can afford to pay for it.

Even though many patients would rather die at home, others prefer to die in a hospital or hospice setting. Those who indicate a preference to die in hospital are more likely to spend extended periods in the hospital and form a strong relationship with hospital staff (Dunlop et al., 1989). This highlights the significant role of hospital staff in palliation, especially among patients who may not have appropriate caregivers. Institutional death among patients initially voicing a strong preference for a home death is often associated with:

A) family problems,

B) caregiver incapacitation, or

C) inadequate home conditions (McWhinney et al., 1995).

Home death among patients whose expressed wish is to die in the hospital setting is associated with:

A) a rapid deterioration of condition;

B) sudden death (McWhinney et al.); or

C) having a caregiver who is unable to cope (Dunlop et al., 1989).

Tang and McCorkle (2003) found that emergency care and hospital readmission may be indicators of more severe illness. The same indicators may also reflect perceived family support and perceived competency of informal caregivers. For example, caregivers may appear inept because they do not possess the skills necessary to deal with severe symptoms or complex problems characteristic of palliation. Although many people wish to die at home, circumstances must be ideal before patients suffering terminal disease truly believe that a home death is suitable. Symptoms must also be controllable, and appropriate caregivers must be in place.

The role of caregivers in place of death is significant. The characteristics of the caregivers and the number of caregivers greatly influence where patients die. A home death occurs more often when caregivers, along with the patients, believe that a home death is preferable. These same caregivers may also have higher levels of skill or self-esteem that allow them to care for the patients; therefore, they find the caregiving role very rewarding. Because a high number of patients who die in hospital or hospice experience rapid deterioration, caregivers who prefer that the patients die at home may simply be caring for patients with fewer symptoms or symptoms that are easily controlled. These scenarios are not found in the caregiving literature. Many of the existing studies are cross sectional, and the direction of causality cannot be made, but is often assumed. Clearly, more research is warranted.

Home as an Appropriate Place to Die

Many factors influence patients' perception that the home is an appropriate place to die: patients' views, caregivers' views, caregivers' characteristics, and the level of care required to maintain home support. Gott et al. (2004) examined how older people view the home as an appropriate place to die. They found that most patients view the home as an ideal place to receive care during the dying process only under ideal circumstances. Although many spouses also hold this view, it is especially strong among caregivers with prior experience in home based palliation.

Many patients may alter their preference for a home death as the illness progresses because the symptoms may become more severe or in-home support becomes inadequate. Visser et al. (2004) examined the role of informal care and its relationship to place of death in the context of resident versus non-resident caregiver status. They determined that most patients are completely limited during the last 3 days of life. Resident and non-resident caregivers provide different types of care. Resident caregivers are more likely to be older and provide higher levels of personal care; non-resident caregivers are more likely to run errands, wash dishes, do laundry, and help with odd jobs around the house (Visser et al.). Resident caregivers are more likely to be female, a spouse, and the sole provider of care. Hours of informal care differ between resident and non-resident caregivers. Resident caregivers provide more days of care and are less likely to receive help from secondary caregivers. Primary caregivers of patients who do die at home are more likely to use secondary informal caregivers (Visser et al.). Non-resident caregivers are more likely to rely on secondary informal and formal caregivers.

Gott et al. (2004) found that the relationship between level of care and type of informal caregiver is important. Functional limitation is higher among patients with resident caregivers when compared to non-resident caregivers. Problems with pain control, incontinence, and deteriorating functioning increase the number of care-related tasks that caregivers must perform. Caregiving tasks may differ according to a patient's relationship to the caregiver, be it spouse, child, relative, or other. Patients may view incontinence and activities of daily living care as acceptable caregiving tasks for spouses, but they might be uncomfortable having others provide that type of care (Gott et al.). Many of the tasks performed by the caregivers are without a doubt intimate (e.g., incontinence care), resulting in a loss of dignity and autonomy from reduced functioning.

Dunphy and Amesbury (1990) compared predictors of place of death among home care and hospice patients. They found that when compared to hospice patients, home care patients are often younger and married. They also provided evidence that agencies may bias their referrals: Hospitals refer patients to a hospice, but community services refer patients to home care. The prognosis in Dunphy and Amesbury's sample of home care patients was long, indicating possible systematic biases between patients using hospital-based services and patients using community-based agencies. For example, patients referred from a community-based agency may be in the early stages of palliation and more suited for home care, whereas those directed toward hospice care may be in the late stages of palliation. Hospital referrals may be an indication of symptom control, where hospice and hospitals may better control symptoms that are difficult to manage. In fact, subsequent hospice or hospital admissions may occur because families are unable to cope with caregiving requirements, such as aiding with self-care and symptom control (e.g., pain, dyspnoea, malaise, GI bleeding, confusion, convulsion, dysphagia, or depression).

Gott et al. (2004) found that the most common reasons for transfer out of home care are severe pain, incontinence, and increased disability. More than one third of caregivers need additional assistance to maintain an adequate level of in-home palliative care. Gott et al. recorded a substantial increase in caregiving activity during the last 3 months of life. Patients needing higher levels of care are more likely to be transferred out of home care (Gott et al.).

When transferring to another care setting, the most difficult and upsetting aspect for patients is separation from their spouses (Gott et al., 2004). Patients are more likely to transfer to hospice care when the informal caregiver is his or her child (Gott et al.). Caregivers of patients who transfer and die in hospice or hospital report high levels of burden (Visser et al., 2004). Patients who die in hospital or hospice may have greater needs than patients who die at home. Caregivers of high-need patients may lack the skills necessary or may be unable to provide the level of care necessary. The caregiver is unable to maintain the level of care, resulting in high caregiver burden and high patient unmet needs.

High levels of burden reported at the time of institutionalization may also be the result of the stress common to admitting the care recipient to an alternate care setting. A setting that is incongruent with the patient's wishes may result in the caregiver experiencing higher levels of stress and guilt associated with the institutionalization process. Stressors typical of institutional care replace stressors common to home care. When the patient is admitted to a hospice or hospital setting, the caregiver's tasks associated with palliative home care cease and are supplanted by the need to remain at the patient's side.

Preferred place of death is dependent upon symptom severity and diagnosis. Patients may not view the home as an appropriate place to die because equipment and skills typically found in institutions may be unavailable to home care patients (Gott et al., 2004). When such equipment and skills are available, they may inadvertently transform the home into an institutional-type environment. This transformation may be unacceptable to both patients and caregivers.

When home care agencies make formal support available, residents may also perceive the presence of a health care professional as intrusive and compromising to the ideals of home. The relationship among care recipient, caregiver, and care professional is crucial and necessitates strong connotations of friendship in order to remain viable.

CHAPTER III. METHOD & RESULTS

Study I – Validating Caregiver Burden in the inteRAI PC

Introduction

The purpose of this section was to examine the construct validity - the extent to which a scale measures what it proposes to measure - of the interRAI PC (version 9) caregiver burden items using two established scales: the Caregiver Burden Scale (Montgomery, n.d.) and the Burden Inventory (Zarit, Orr, & Zarit, 1985). The interRAI Palliative Care is a comprehensive assessment instrument used to assess service needs, facilitate care planning, and assist with outcomes evaluation among palliative care clients receiving care in either the community or within institutional settings (Steel et al., 2003).

This study began by confirming the reported sub-domains for both of the two self-report scales using confirmatory factor analysis. Next, items indexing burden which are contained within the interRAI Pallaitive Care assessment instrument were validated against the self-report scales.

Home care recipients are typically referred to as clients. For the purposes of continuity in this and subsequent sections, home care clients will be referred to as home care patients. Information and documents listed in the appendix refer to palliative home care users as clients.

Reasons for selecting the Caregiver Burden Scale to validate the interRAI PC items are addressed subsequently. Reasons for comparing the Caregiver Burden Scale to the Burden Inventory were that the Burden Inventory is a well-known burden scale that has undergone extensive testing, it is considered as the gold standard. The Caregiver Burden Scale is still relatively new and not well validated. It was developed for caregivers of patients suffering from terminal disease. One of the shortfalls of the Burden Inventory is that, even though it is considered the gold standard, it is not developed for palliative populations.

This section tested the construct validity of the interRAI PC caregiver burden items against the Caregiver Burden Scale. An assumption of this section was that the interRAI PC caregiver burden measures reflect one or more of the three domains: objective burden, subjective stress burden, and subjective demand burden. For example, the interRAI PC item posited to measure objective burden describes a situation where the helper(s) is unable to continue caring activities; e.g., the caregiver does not have the capacity to provide care. The next caregiver burden item measures the primary informal helper's feelings of distress, anger, or depression and is posited to reflect subjective stress burden; e.g., the caregiver's perception of burden. The final item seeks to determine whether family or close friends feel overwhelmed by the person's illness. This likely reflects subjective demand burden. Although subjective stress burden and subjective demand burden appear closely related, the later includes the ability of the caregiver(s) to cope with caregiving in addition to their subjective appraisal of burden. Caregivers may continue to care for family members or friends even when faced with a high level of burden. Caregivers who perceive burden but are unable to continue providing care may a) place the family member or friend at increased risk of poor quality care, or b) place the family member or friend at higher risk of transfer to in-patient palliative care, hospital care, or hospice care, or c) place their own health at risk.

This section examined how representative the interRAI PC caregiver burden items are of the level of burden reported by caregivers. When using the interRAI PC to assess home care patients, each assessor must have followed a specific set of instructions to determine the presence or absence of caregiver burden (*see description below*). Accuracy relied on the assessor's appraisal of the situation. The Caregiver Burden Scale measures burden by directly soliciting the caregiver's appraisal of his/her current situation. This section examined the extent that the caregiver burden items in the interRAI PC reflected caregiver burden as defined by the dimensions outlined by the Caregiver Burden Scale. It determined the degree to which assessors were able to identify burden among caregivers providing in-home palliation to terminally ill loved ones.

Methods

Sample

This section targeted all patient/caregiver dyads of two Ontario home care agencies providing care to terminally ill home care recipients. It was mainly concerned with the patient's primary caregiver (Key Informal Helper 1). The primary caregiver may be a family member, friend, or neighbour. The intention of this section was not to identify paid providers of care or agency volunteers. It intended to identify an person that the patient relied upon most. Case managers relied on the home care patient to identify a significant informal helper at the time of assessment.

Caregivers must have met the eligibility criteria in order to participate. Only caregivers who were able to speak and write English were included because the survey was in English. For consensual reasons, caregivers must have been 18 years of age or older. Only the primary caregiver was considered for participation; however, for consensual reasons, both the patient and the caregiver must have been present at the time consent was being obtained. In all other instances, the patient and caregiver were not approached about the study.

The Dillman Tailored Design Method (Dillman, 2000) method of data collection was considered for this study but was considered inappropriate because of the vulnerable population being studied. For example, the Dillman method calls for the researcher(s) to place follow-up phone calls to the caregivers. Such activity may be considered overly intrusive and coercive in a household caring for a terminally ill loved one or friend. The decision to use the caregiver questionnaires as a self-report tool was supported by the Office of Research Ethics at the University of Waterloo. However, a number of techniques were employed to increase response rates among potential participants.

The mail-in survey technique was used to retrieve information on caregiver burden. Response rates are traditionally low when using this technique. For example, Ekwall, Sivberg, and Hallberg (2004) investigated caregiving among elderly Swedish caregivers. Response rates to a mail-out survey ranged from 60% for caregivers aged 60 to 48% for caregivers 90 years of age and older. Casarett, Crowley, and Hirschmean (2003) examined the sensitivity of timing to survey participation. The average age of caregivers ranged from 58 to 60 (at 2 weeks and 6 weeks respectively). Response rates were similar where 54% of caregivers responded to the survey.

Methods were employed to increase response rates. In an analysis examining mail-out surveys and response rates, Edwards et al. (2002) cited a number of techniques that can easily improve rates of response. Firstly, their study indicated that participants are more likely to return short surveys. This is a determining factor for using Montgomery's Caregiver Burden Scale (n.d.) and the Burden Inventory (Zarit, Orr, & Zarit, 1985). As mentioned earlier, the Caregiver Burden Scale and the Burden Inventory are shorter than many of the other tools used to measure caregiver burden. Additional administrative techniques included a personal letter inviting patients and caregivers to participate and return postage on the envelope.

Delivery methods can increase response rates. Protocol stated that caregivers could only be included if they were present during the administration of the interRAI PC. The case manager recorded the delivery of Caregiver Burden Scales to participating patients and caregivers. Caregivers then mailed the survey to the researcher at their own convenience.

To conclude, each package included two information letters and consent forms, one for the patient and another for the caregiver. Surveys were only provided to the caregiver. Self-addressed envelopes with postage were provided to the caregiver. Caregivers were also provided with the phone number and address of the University of Waterloo researchers should they have any additional questions pertaining to the study.

The case manager's role was to contact caregivers after interviewing each patient. The case manager's responsibility included tracking participating patients and caregivers. Each package was assigned a tracking code to accurately merge surveys with the appropriate interRAI PC instruments. To maintain confidentiality, the participating CCAC withheld any information that might identify the caregiver or the patient to the researcher.

Upon completion of the study, the case manager provided the caregivers with the option to be to be debriefed by means of an executive summary. Executive summaries were provided to the CCAC for distribution to interested caregivers. The executive summary outlined the objectives and the significant findings of this study. Using the techniques to track assessments outlined above (interRAI PC and the Caregiver Survey) ensured accuracy, privacy, and confidentiality - while maximizing return rates.

Materials

As previously mentioned, two instruments were used in this section: the interRAI PC (version 9) and the Caregiver Survey (Caregiver Burden Scale, Montgomery, n.d.; Burden

Interview, Zarit et al., 1985; Satisfaction with Life Scale, Diener, Emmons, Larsen & Griffin, 1985). A description of both follows below.

interRAI

InterRAI (www.interRAI.org) is a non-profit organization that involves an international assortment of clinicians, researchers, policy, and government persons from over 20 countries. This organization developed a number of instruments that are designed for specific populations (long-term care, home care, and complex continuing care, palliative care, intellectual disabilities, ect.) and are to be used by health care. The aim organization is to improve the health of the elderly, frail, and disabled using evidence-based practice. InterRAI's instruments are continually updated and enhanced in an effort to remain current. Many of the interRAI instruments are already mandated for use in the United States and Canada. Even though each tool is developed for a specific population they are designed to work together in an integrated fashion.

interRAI Palliative Care

The interRAI Palliative Care version 9 (interRAI PC) is a comprehensive assessment instrument used in the palliative care setting. It is being pilot tested by a number of in-patient agencies and outpatient facilities throughout Ontario, Manitoba, Saskatchewan, and British Columbia. Ontario has contributed greatly to the development of the interRAI PC by pilot testing or adopting the instrument in over half of its CCACs.

Some health care agencies like CCAC currently use the interRAI PC to assess terminally ill home care patients referred to palliative care. Assessments take place upon admission. Subsequent assessment intervals occur at 45 days, 6-months, and yearly thereafter.

Additional assessments may happen in the event of a significant change in condition such as a sudden improvement or deterioration in health.

When assessing caregiver burden, the interRAI PC manual instructs the assessor to consider not only the patient’s current situation but also his/her future needs. The interRAI PC version 9 items that reflect the different domains of caregiver burden and include:

A) Helper(s) unable to continue caring activities - e.g., decline in health of helper makes it difficult to continue,

B) Primary informal helper expresses feelings of distress, anger, or depression, and

C) Family or close friends report feeling overwhelmed by person's illness.

The intent of these items is to assess the “reserve of the informal support system” (Steel et al., 2006). The interRAI PC manual defines - helper(s) unable to continue caring activities - as “the informal helper, the person, or the assessor believes that a support person is unable to continue providing care. This can be for any reason, including personal health issues, lack of desire to continue, travel difficulties, or other competing requirements (e.g., child care, work requirements)” (Steel, Morris et al., 2003).

The second measure of caregiver burden - primary informal helper expresses feelings of distress, anger, or depression - is defined by the interRAI PC manual as “the primary support person expresses (by any means) that he/she is distressed, angry, depressed, or in conflict because or caring for the person” (Steel, Morris et al., 2003).

The third measure of burden measured by the interRAI PC examines whether - family or close friends report feeling overwhelmed by a person's illness, the interRAI PC manual defined this as “family members or close friends indicate to the person or the assessor that they are having trouble coping with the illness. They may report feelings of being *overwhelmed* or *stressed out*" (Steel, Morris et al., 2003)

These three items are measured dichotomously, (0 = No and 1 = Yes). If an informal helper is not recorded, the assessor is instructed to code '0' on all items. Therefore, as part of the inclusion criteria, it is important to note that only patients identified as having a primary and/or secondary helper can be included when analyzing caregiver burden data.

interRAI PC Outcome Measures. The interRAI PC (see appendix B) is a comprehensive assessment tool designed for end-of-life care. It can be used in multiple settings like home care, complex continuing care, or hospice care. Domains within the interRAI PC include psychological, physical, social, and spiritual well-being (Steel & Whang, 2000; Steel, Ljunggren, et al. 2003; Steel, Morris, et al., 2003).

All interRAI instruments contain within them outcome measures. Similar outcome measures are found in other interRAI instruments that are designed to be used in adjacent health care settings, such as the interRAI Home Care, MDS 2.0 (long-term care, and complex continuing care), and the interRAI Community Health Assessment. The outcome measures were developed in other health care settings (long-term care, complex continuing care, and home care). Outcome measures assess patients level of cognition (Cognitive Performance Scale; CPS; Morris et al., 1994), activities of daily living (Activities of Daily Living-Hierarchy Scale; Morris, Fries, and Morris, 1999), depression (Minimum Data Set-Depression Rating Scale; Burrows et al., 2000), and pain (Pain Scale; Fries, Simon, Morris, Flodstrom, & Bookstein, 2001). Other less developed scales measure delirium, social well-being, and behaviour.

Cognitive Performance Scale. Level of cognition is measured using the Cognitive Performance Scale (CPS; Morris et al., 1994). The 4 items needed to calculate this scale are found in the interRAI PC versions 7,8 and 9. The CPS is based on an algorithm that places individuals into seven discrete categories ranging from 0 to 6:

0) Intact,
1) Borderline intact,
2) Mild impairment,
3) Moderate impairment,
4) Moderate/severe impairment,
5) Severe impairment,
6) Very severe impairment.

The algorithm measures patient’s competence for making decisions, memory capacity, and ability to understand others.

Research demonstrates that the CPS can accurately discriminate level of cognition among institutionalized populations (Hartmaier et al., 1995). The CPS algorithm uses the patient’s ability to make decisions, memory length, ability to be understood, and their ability to understand others to assess the level of cognitive impairment. The items used to calculate the CPS have an average inter-rater reliability of .85 (Morris et al., 1994). The CPS is also highly correlated ($r = -.863$, $p < .001$; Hartmaier et al., 1995) with the Mini Mental State Exam.

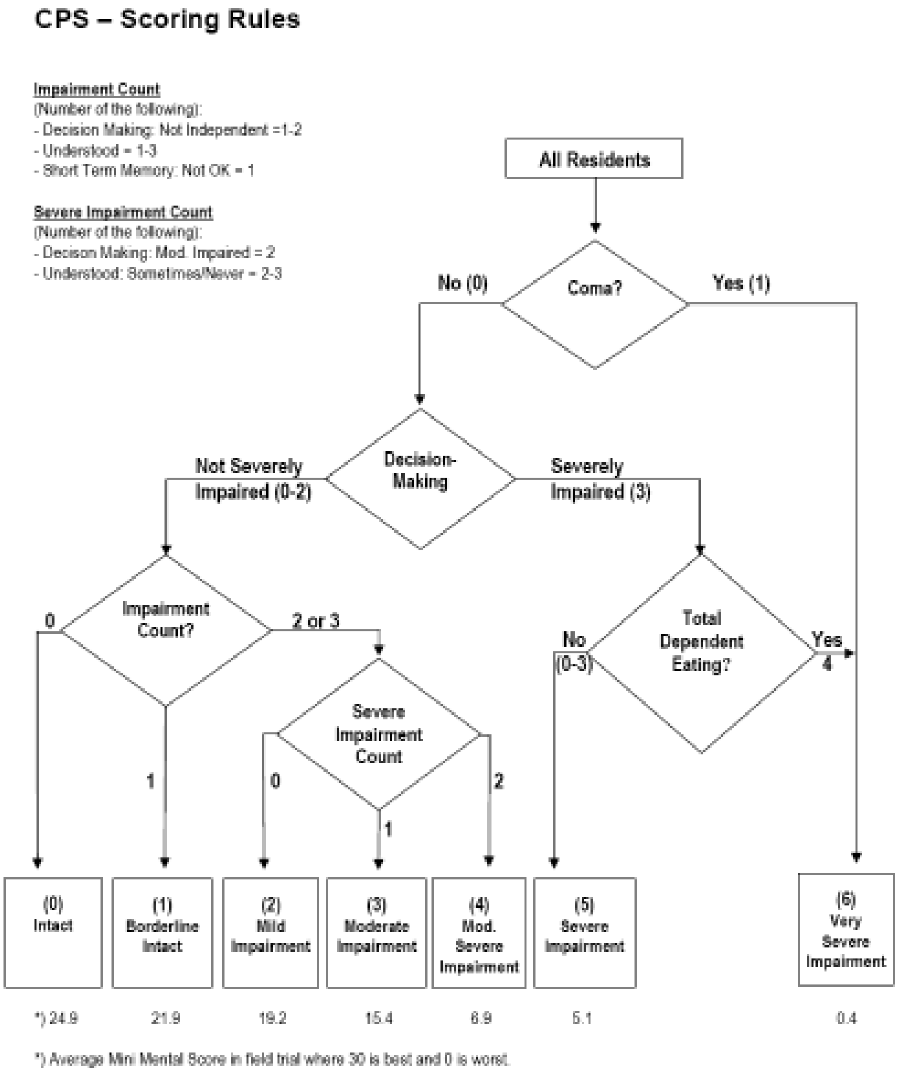

Figure 1. CPS scoring rules[1]

Delirium. Indicators of delirium describe two conditions. The first condition is characterized by a recent change in cognitive functioning; the second is a persistent state that is not of recent onset. The interRAI PC delirium items measure:

A) distractibility,

B) episodes of disorganized speech,

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[1] CPS scoring rules provided by interRAI.org at http://interrai.org/applications/cps_diagram.pdf

C) varying mental functioning over the course of the day, and

D) acute change in mental status from person's baseline.

The indicators of delirium measure whether the:

0) Behaviour is not present,

1) Behaviour present, consistent with usual functioning, or

2) Behaviour present, appears different from usual functioning.

Earlier research indicated excellent consistency (Cronbach's alpha = .89; Brink, 2004).

Minimum Data Set-Depression Rating Scale. The intent of the MDS Depression Rating Scale is to identify minor and major depression. The MDS DRS uses 7 indicators of depression:

A) Resident made negative statement,

B) Persistent anger with self or others,

C) Expressions of what appear to be unrealistic fears,

D) Repetitive health complaints,

E) Repetitive anxious complaints,

F) Sad, pained, worried facial expressions, and

G) Crying, tearfulness.

The indicators measure depression on a 4-point scale:

(0) Not present,

(1) Present but not exhibited in last 3 days,

(2) Exhibited on 1-2 of last 3 days, and

(3) Exhibited days in last 3 days.

The MDS DRS is a summation of these 7 depression indicators. However, the scores are collapsed where "not present" and "Present but not exhibited in last 3 days" equal 0 and "Exhibited on 1-2 of last 3 days," and "Exhibited days in last 3 days" equal 1 and 2 respectively. A tally of the indicators provide a symptom scale ranging from 0 to 14.

The MDS DRS is highly correlated with the Hamilton Depression Scale (r = .70) and the Cornell Scale(r = .69, Burrows, Moris, Simon, Hirdes, & Phillips, 2000). The MDS DRS also sustains adequate sensitivity for detection of depression (91% against psychiatric diagnosis; Burrows et al.). Earlier research indicates acceptable internal consistency (Cronbach's Alpha) ranging from .71 to .75 (Burrows et al. 2000). Further reliability analysis confirmed acceptable internal consistency among the seven indicators of depression (Cronbach's alpha = 0.75; Brink, 2004).

Activities of Daily Living-Hierarchy Scale. The interRAI suite of instruments assess activities of daily living using one of three scales, the ADL-Hierarchy Scale, ADL-Long Form, or the ADL-Short Form. The ADL Hierarchy Scale (ADL-H; Morris, Fries, & Morris, 1999) uses 4 items to assess the patients level of functioning in activities of daily living. The ADL-H will be used in this study to determine functioning. The scale places patients into one of 7 discrete categories that range from 0 to 6:

0) Independent,

1) Supervision,

2) Limited,

3) Extensive-1,

4) Extensive-2,

5) Dependent, and

6) Total Dependence.

The categories are based on a algorithm that includes items to assess eating ability, personal hygiene, ability to toilet oneself, and walking/locomotion. Earlier research report an internal consistency of .90 (Morris et al., 1999).

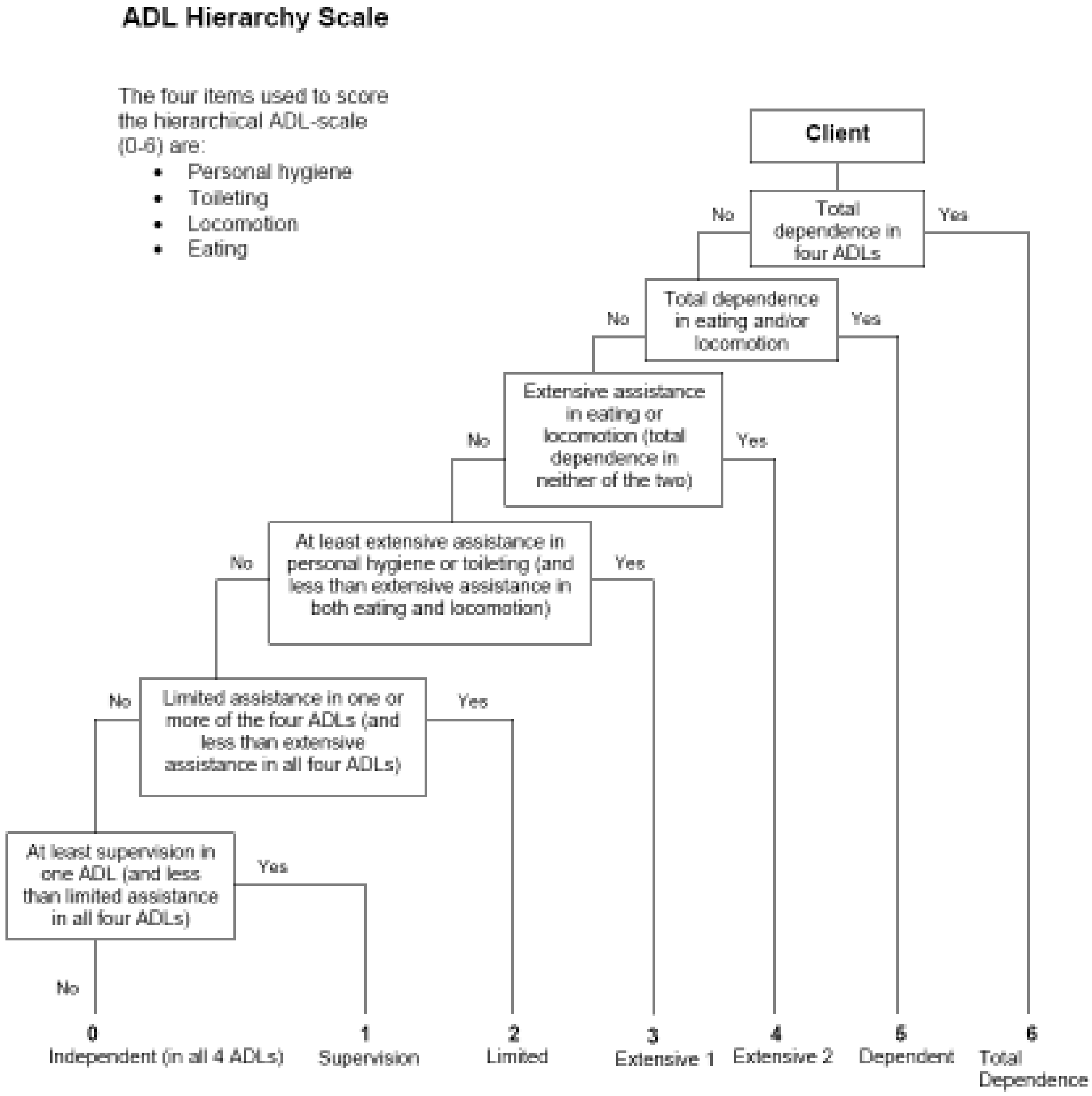

Figure 2. ADL Hierarchy scale scoring rules[2]

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[2] ADL Hierarchy scoring rules are provided by interRAI.org at http://interrai.org/user_files/images/File/ADL%20Hier%20Diagram.pdf

Pain Scale. The interRAI Pain Scale (Fries et al., 2001) measures the intensity and frequency of pain. The purpose of the pain scale is to enable health care professionals to identify and treat pain. Fries et al. (2001) successfully validated the pain scale against the visual analogue scale for pain.

The interRAI PC describes the frequency of pain as that "with which person complains or shows evidence of pain (including grimacing, teeth clenching, moaning, withdrawn when touched or other non-verbal signs suggesting pain" (interRAI PC version 9). This item is measured on a 4-point scale that ranges from 0 to 3:

0) No Pain,

1) Present but not exhibited in last 3 days,

2) Exhibited in 1-2 of last 3 days,

3) Exhibited daily in last 3 days.

The intensity of pain is measured as the highest level of pain present and is measured on a 5-point scale that ranges from 0 to 4:

0) No pain,

1) Mild,

2) Moderate,

3) Severe,

4) Times when pain is horrible or excruciating.

These two items are placed into an algorithm (see Figure 1) referred to as the Pain Scale. Similar items measuring pain are found in version 7, 8, and 9 of the interRAI PC. The pain scale ranges from 0 to 3.

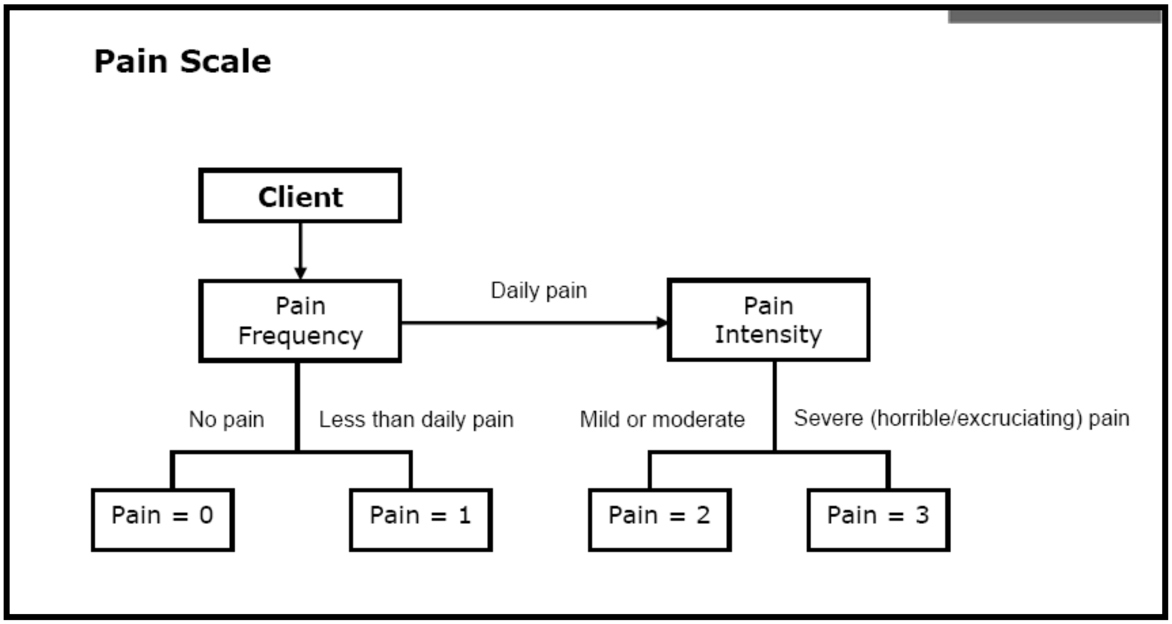

Figure 3. Pain Scale algorithm

Chess Scale. The Chess scale has been adapted from earlier work on long-term care. It is designed to identify individuals who are at risk of serious decline (www.interrai.org). Scores from the Chess Scale range from 0 to 5, where: 0 = not at all stable, and 5 = highly unstable. The interRAI Group states that "higher levels are predictive of adverse outcomes like mortality, hospitalization, pain, caregiver stress, and more self-rated health" (www.interrai.org).

Caregiver Survey

The Caregiver Survey is comprised of 3 surveys plus supplementary questions. The items are described below.

Caregiver Burden Scale. Instruments to measure caregiver burden in palliative home care are few. One appropriate measure of caregiver burden is the “Caregiver Burden Scale” (Montgomery, n.d.; see Appendix A). Reasons for using the Caregiver Burden Scale are numerous. As stated previously, the Caregiver Burden Scale is a multidimensional instrument that measures objective burden, subjective stress burden, and subjective demand burden. It also has excellent face validity, whereby questions appear to reflect concerns specific to that of a loved one providing care to a terminally ill loved one. The scale includes 14 questions that ask whether the caregiver has experienced:

1) had a lot less,
2) a little less,
3) the same,
4) a little more, or
5) a lot more

of a specific type of burden.

The modified Caregiver Burden Scale (Montgomery, n.d.) is a derivative of an earlier Caregiver Burden Scale developed by Montgomery et al. (1985). The earlier version employed 20 questions that assess subjective burden and objective burden. It was used in a pilot study by Hollander et al. (2001) to examine outcomes of home care services. These researchers rated the Caregiver Burden Scale as an excellent instrument for assessing burden among caregivers of home care patients.

The modified version is relatively short (14 items) compared to other scales:

- Appraisal of Caregiving Scale – 53 items;
- Caregiver Reaction Assessment scale – 24 items;

- Modified Caregiver Appraisal Scale – 28 items).

It also had the added benefit of being multidimensional (Caregiver Tasks, Caregiver Load Scale, Caregiver Burden Tool). The length of the instrument was of particular importance so that it is less intrusive and cumbersome to the caregiver already suffering time restrictions because of tasks related to the provision of informal home care. Because this section was dependent on voluntary responses by caregivers, the relatively short length of the Caregiver Burden Scale may have increased response rates.

A later study by Montgomery (n.d.) found 3 domains in the Caregiver Burden Scale. They (objective burden, subjective stress burden, and subjective demand burden) are statistically and conceptually distinct. This suggests that caregivers who report feelings of objective burden may not necessarily report subjective stress burden or subjective demand burden. Montgomery stated "it is important to distinguish the workload from the impact of that workload on caregivers (p. 2). If the caregiver burden items are able to distinguish between the domains of burden, assessors may be able to intervene by directing care towards those specific types of burden. Specifically, Montgomery stated that:

> "It is also useful to distinguish among the different types of burden because the interventions that are most appropriate to address one type of burden may not be useful to address a different type of burden. When working with family caregivers it is important for providers to know exactly which type of burden or stress is most salient at a given point in time. This knowledge should help providers identify support strategies that are appropriately matched to the source of stress. For example, an individual who is stressed or burdened because of the infringement of care responsibilities on other life activities of the caregiver (objective burden) is likely to benefit from help that will alleviate tasks or care responsibilities, such as in-home services. In contrast, a caregiver who is most stressed because he or she believes the demands made by the care recipient are inappropriate or excessive, may best be helped by an opportunity to learn more about the disease process, a care recipients true level of dependency and appropriate levels of support. Similarly, a caregiver who is emotionally stressed (subjective stress burden) may benefit from a support group or individual counselling" (n.p.).

Earlier research traditionally examined the general concept of burden without taking into account these differences. Clearly, the implications for each burden domain are different. It is important to distinguish between the domains when identifying ways to reduce burden.

The Caregiver Burden Scale began by asking the caregiver “Since you began caregiving, how has assisting or having contact with him/her affected the following aspects of your life?” Because this study’s main concern revolved around caregiving and assisting the patient, the question was rephrased to reflect that concern. In addition, the question referred to the patient as “him/her”; this was rephrased to “your loved one”. The question asked, “Since you began caregiving, how has assisting your loved one affected the following aspects of your life?”

The operational definition of objective burden, subjective stress burden, and subjective demand burden given by Montgomery (n.d.) are as follows:

The definition of objective burden is the “perceived infringement or disruption of tangible aspects of a caregiver's life” (Montgomery, n.d., n.p.). Montgomery’s Caregiver Burden Scale measures objective burden using six items:

a) amount of time one has for one's self,
b) amount of personal privacy one retains,
c) time available for recreational activities,
d) restrictions on vacations and trips,
e) amount of time available to do one's own work and daily chores, and
f) amount of time for friends and relatives.

Caregivers who report objective burden are likely to score high on these measures because the caregiving tasks infringe upon their personal time. Montgomery has shown the internal consistency (Cronbach's Alpha) to range from .87 to .90. Cumulative scores range from 6 to 30. Earlier research suggests that a score above 23[3] is indicative of high objective burden.

The Caregiver Burden Scale defines subjective stress burden as "the emotional impact of caregiving responsibilities on the caregiver" (Montgomery, n.d., no page). The four item that measure subjective burden are:

a) stress in the relationship with the dependent relative,
b) tension in the caregiver's life,
c) nervousness and depression related to the relationship with the dependent relative and,
d) anxiety about things.

Scores from the subjective stress burden domain range from 4 to 20 and have an internal consistency (Cronbach's Alpha) ranging from .68 to .82. Earlier research suggests that a score at or above 15 should be viewed as high.

Finally, Montgomery (n.d) defines subjective demand burden as "the extent to which the caregiver perceives care responsibilities to be overly demanding" (no page). Items measuring subjective demand burden include:

a) attempts by the dependent relative to manipulate the caregiver,
b) unreasonable requests of the caregiver,
c) feelings by the caregiver of being taken advantage of by the dependent elder, and
d) demands made by the dependent relative that are over and above what is needed.

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[3] Although the suggested scores for high caregiver burden within each domain are clearly stated, norms for different populations are not yet clearly established.

Scores for the subjective demand burden domain range from 4 to 20 and have an internal consistency (Cronbach's Alpha) ranging between .81 and .88. Earlier research suggests that scores above 13.5 should be viewed as high.

Burden Interview. Burden Interview (Zarit et al., 1985) uses 22 questions to examine subjective strain for caregivers of persons suffering from dementia. Each item is measured on a 5-point Likert scale:

a) never,
b) rarely,
c) sometimes,
d) quit frequently,
e) nearly always.

Scores on the Burden Interview range from 0 to 88, with higher totals reflecting greater burden. Research identified three underlying factors that include Caregiver Anger, Patient Dependency, and Caregiver Lack of Privacy. Subsequent research has found that 14 of the 21 items tap three underlying factors that represent Embarrassment/Anger, Patient Dependency, and Self-criticism (Knight, Fox, & Chou, 2000).

Short scales to measure burden are important and may measure burden more consistently when reliability and validity can be maintained (Knight et al., 2000). A more recent version of the ZBI has been developed (Bédard et al., 2001). The short version includes a short version (12-item) and a screening version (4-item) of the ZBI. The short version is highly correlated with the full version, with correlations rating from 0.92 to 0.97 with high internal consistency ($\alpha = .88$). The psychometric properties were supported by O'Rourke and Tuokko (2003).

Satisfaction with Life Scale. The Satisfaction with Life Scale is a 5-item survey that measures global cognitive judgments of satisfaction with one's life (Diener et al., 1985).

Additional Questions. In addition to the Caregiver Burden Scale and interRAI PC, 5 supplementary questions were included. Additional questions identified the relationship (spouse, child, friend, or neighbour) to the patient, their resident status (non-resident, co-resident), the caregiver's age, the caregiver's sex (male, female), and the length of time the caregiver has been providing care to his/her loved one.

Frias et al. (2005) found that caregivers who report poor health are at greater risk of caregiver burden. Therefore, three additional questions determined, in a broad sense, the overall health status of the caregiver. These questions ask the caregiver about his/her (a) current self-perceived health, (b) change in health status since any caregiving activity began, and (c) length of time the caregiver has provided care to their loved one.

Three questions examined self-reported mood among caregivers. Reasons for including self-reported mood are cited by B. Given et al. (2004) who found a relationship between burden and depression. This seeks to examine the relationship between self-reported mood and caregiver burden. Questions measure (a) anhedonia (little interest or pleasure in things your normally enjoy), (b) anxiety (anxious, restless, or uneasy), and (c) depression (sad, depressed, or hopeless)[4]. The questions will measure the frequency of occurrence over the previous 3 days 1=none, 2=1-2 days, 3=all 3 days, and 4=no response).

Focus Group. The Caregiver Survey and concordant materials (consent form, information letter) were validated by a focus group. The purpose of the focus group was to

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[4] These items are listed in the interRAI PC and measures the client's self-reported mood. The mood items were remain consistent with the interRAI PC, measured on a 4 point scale, 0 = not in last 3 days to 3 = daily in the last 3 days.

check for clarity and readability. Participants for the focus group included a group of individuals over the age of 50.

The recruitment procedure for the focus group involved a discussion with the local Ontario Network for the Prevention of Elder Abuse (ONPEA) representative. The representative asked the local Elder Fraud Stoppers, a group of 6 to 8 elderly persons aged 60 to 80, to participate in the focus group. The Fraud Stoppers are local to Thunder Bay, Ontario, Canada.

The focus group was held at the Pottery House located on Lakehead University's campus in Thunder Bay, Ontario. The focus group took place on March 29, 2007. The total sample consisted of 6 persons aged 59 to 80, all of whom were female. The consent forms were signed and returned to the researcher after a brief introduction. The meeting lasted 1.5 hours.

The meeting began with an examination of the CCAC case manager script and information letters (see Appendix B). The participants acknowledged the importance of the script for both the patient and the caregiver. They discussed the fact that, because of the patient's illness, they may not be willing to read the entire information letter. Caregivers may not read the information letter because they are stressed and/or pressed for time. The participants had noted how important it is to keep the script clear and easy to understand by avoiding big words and keeping sentences short. They had all made recommendations to improving the script and information letters.

The caregiver survey was well received. The participants all stated that they like the size of the font and the colours. They had also liked the use of blocks to delineate the different sections of the Caregiver Burden Survey. However, the participants also noted some inconsistencies in the survey and made suggestions to improve it. Those suggestions included using a consistent font in the headers and switching to a paper with mat finish rather than a gloss finish.

After a lengthy discussion, the participants also suggested including an additional question asking caregivers whether they are caring for someone else in addition to the home care recipient. They cited cases where many older caregivers are not only caring for spouses and siblings but may also be caring for other family members such as children and/or grandchildren. This question was incorporated into the caregiver survey.

The necessary changes were made to the scripts, information letters, and caregiver survey. Those changes were then submitted to the University of Waterloo Office of Research Ethics for final approval, which was granted on May 19, 2007.

Analyses

Analyses were performed using the Statistical Analysis Software (SAS) version 9 and SPSS version 9. Analyses used to examine the relationship between the interRAI PC caregiver burden items and the Caregiver Burden Scale domains included means, crosstabs, and correlation analysis. Appropriate corrections for ordinal and dichotomous variables were made where suitable.

Participants

Two CCACs were asked to participate in this study. Participating CCAC's administrators read the information letter and signed the consent forms after an introduction to the project (see Appendix C).

Preliminary Results

Two CCACs were asked to participate in this study. After a brief introduction, the CCAC's administrators read the information letter and signed the consent forms (see Appendix C). A total of 476 home care assessments were completed between June 2007 and November 2007. Of the patients who were assessed by a CCAC case manager, 37% (178/476) were approached about participating in the study using the study materials (see Appendix D & E) and 40% (71/178) subsequently completed the survey. Table 1 shows the characteristics of patient/caregiver dyads who were not approached, approached but did not participate, and those who agreed to participate and completed the survey.

Table 1. Patient differences between participants and non-participants

Variable	Response	Not approached		Approached		Completed	
		N	%	N	%	N	%
Sex	Male	140	48%	52	49%	33	47%
	Female	151	52%	55	51%	37	53%
	Total	291	100%	107	100%	70	100%
Marital status	Never married	17	6%	4	4%	1	1%
	Married/spouse	169	58%	75	71%	51	72%
	Widowed	76	26%	18	17%	17	24%
	Separated/divorced	27	9%	9	8%	2	3%
	Total	289	100%	106	100%	71	100%
Residential status	Live alone	63	24%	18	18%	9	13%
	Spouse/partner	113	43%	41	42%	42	63%
	Spouse/partner & others	29	11%	20	20%	4	6%
	Child(ren)	36	14%	15	15%	9	13%
	Parents	2	1%	1	1%	0	0%
	Siblings	3	1%	1	1%	0	0%
	Relatives	9	3%	1	1%	0	0%
	Non-relatives	8	3%	1	1%	3	4%
	Total	263	100%	98	100%	67	100%

The study compared patient/caregiver dyads that were approached about the study to patient/caregiver dyads that were not approached. A number of variables were examined; they include age, sex, Chess Scale, CPS, Pain Scale, ADL Hierarchy Scale, and IADL. Patients who were approached about the study experienced higher levels of ADL impairment compared to those who were not approached (Table 2; ADL, mean = 0.91, mean = 1.53, respectively; t-test df = 426, t-value = 3.33, p-value < 0.001).

Table 2. Description of potential patients of caregivers that received care during the study as a function of participation in the study

	Approached to participate									
	No (N=298)				Yes (N=178)					
Variable	Mean	LCI	UCI	N	Mean	LCI	UCI	N	t-value	p-value
Age	70.39	68.79	72.00	293	71.15	69.30	73.01	176	-0.59	0.55
Cognition	0.89	0.71	1.06	279	0.64	0.44	0.85	154	1.68	0.09
IADL	12.07	11.40	12.73	283	12.37	11.54	13.19	166	-0.55	0.58
ADL	1.53	1.30	1.77	273	0.91	0.63	1.18	153	3.33	0.00
Chess	2.65	2.48	2.82	260	2.48	2.30	2.67	161	1.22	0.22
DRS	0.74	0.56	0.91	273	0.64	0.43	0.85	146	0.69	0.49
Pain scale	1.50	1.37	1.64	269	1.56	1.37	1.75	144	-0.52	0.61

It is important to note that case managers were instructed, at their own discretion, to not to approach patient/caregiver dyads about the study if it was deemed inappropriate. It appears that a defining factor associated with patient/caregiver dyads that were and were not appropriate was a high level of ADL impairment.

The focus then turned to the responders of the survey and compared patient/caregiver dyads who had responded to the survey to those who did not. The same variables were examined. Table 3 examines differences between patient/caregiver dyads who consented (n=178) to participate but did (n=71) or did not (n=107) complete the survey. T-tests were again used to examine patient characteristics of patient/caregiver dyads who had completed the survey. Analyses show that patients of patient/caregiver dyads who completed the survey were older than those who did not (M=73.5, SD=11.9, M=69.5, SD=12.7 respectively; t-value = -2.11, df=174, 0.04.

Table 3. Comparing patient characteristics of caregivers who were approach and declined to those who participated

	Completed survey									
	No (N=107)				Yes (N=71)					
Variable	Mean	LCI	UCI	N	Mean	LCI	UCI	N	t-value	p-value
Age	69.32	66.88	71.77	106	73.93	71.15	76.71	70	-2.43	0.02
Cognition	0.77	0.47	1.07	91	0.46	0.21	0.71	63	1.46	0.15
IADL	12.27	11.14	13.40	100	12.52	11.31	13.72	66	-0.29	0.77
ADL	0.93	0.57	1.30	91	0.87	0.44	1.30	62	0.22	0.82
Chess	2.55	2.31	2.79	98	2.38	2.09	2.68	63	0.89	0.38
DRS	0.79	0.48	1.09	84	0.44	0.16	0.71	62	1.64	0.10
Pain Scale	1.66	1.41	1.92	83	1.43	1.14	1.72	61	1.21	0.23

Table 4 shows the differences between patient and caregiver characteristics among those who completed the Caregiver survey. The majority of caregivers were female even though the proportion of sex for patients was evenly distributed. On average, patients appear considerably older than caregivers. The relationship status of the patient/caregiver dyads remained consistent, with the majority of caregivers being the spouse. Consistent with this is that the average patient was married and lived with his/her spouse. Caregivers were caring for the patient for an average of 21 months (SD= 3.4). The majority of caregiver cared for only one person (90%, 63.71). Only 10% of caregivers provided care to other family members or friends.

Table 4. Differences between the patient and the caregiver

		Caregiver		Patient	
		N	%	N	%
Sex	Female	48	70%	37	53%
	Male	21	30%	33	47%
		69	100%	70	100%
Age	(Mean, SD)	60.7	1.4	73.9	1.4
Relationship	Child	25	35%	20	31%
	Spouse	37	52%	39	61%
	Other	9	13%	5	8%
		71	100%	64	100%
Marital status	Married/partner	-	-	51	72%
	Widowed	-	-	17	24%
	Other	-	-	3	4%
				71	100%
Residential status					
	Alone	-	-	9	13%
	Spouse	-	-	42	63%
	Spouse & other	-	-	4	6%
	Child	-	-	9	13%
	Other	-	-	3	4%
				67	100%
Duration of care: Months					
	(Mean, SD)	21.4	3.4	-	-
Additional caregivers					
	(Mean, SD)	2.6	0.2	-	-
Additional care to others					
	No	63	90%	-	-
	Yes	7	10%	-	-
		70	100%		

Factor Analysis of the Caregiver Burden Scale

This study used confirmatory factor analysis to validate the presence of the three Caregiver Burden Scale domains (see appendix A). This is the first time that the Caregiver Burden Scale has been administered to a sample of palliative home care patients. In addition, this step was made even more essential because these items have never been administered via self-report.

Methods

Analyses

The minimum sample size was determined by the 4:1 rule (MacCallum, Widaman, Preacher, & Hong, 2001). At least four assessments were obtained for each variable in the Caregiver Burden Scale and Burden Inventory. Because the Caregiver Burden Scale includes 14 variables to measure three domains of caregiver burden (objective burden, subjective stress burden, and subjective demand burden), a minimum sample size of 56 was necessary (14*4=56) to use factor analysis. Taking into account the low response rate of mail-in surveys (estimate 40% response rate), assessors needed to distribute a minimum of 350 postal surveys to informal caregivers.

Results

The average score for subjective stress burden scale (see Figure 2) was 15.40 (SD = 2.74, Min = 8, Max = 20, n = 72) and had a moderate level of reliability (Cronbach's Alpha = 0.71). Earlier research shows that 74% (53/72) of the palliative home care patients were considered high on the subjective stress scale.

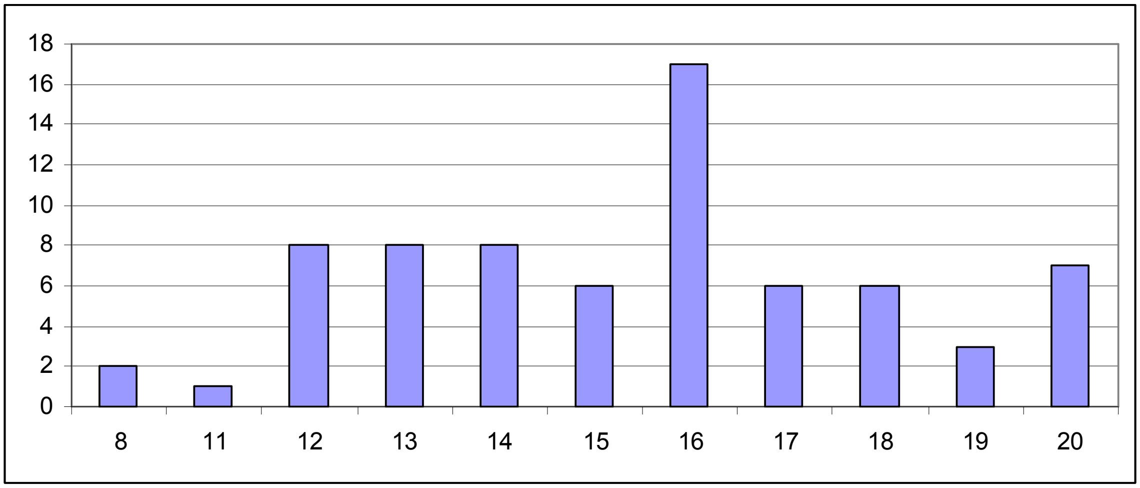

Figure 4. Distribution of the subjective stress burden scale.

The average score for the subjective demand burden scale was 12.74 (SD = 3.67, Min = 4, Max = 20) and had a high level of reliability (Cronbach's Alpha = 0.89). Earlier research shows that 28% (19/68) of the palliative home care patients were considered high on the subjective demand scale.

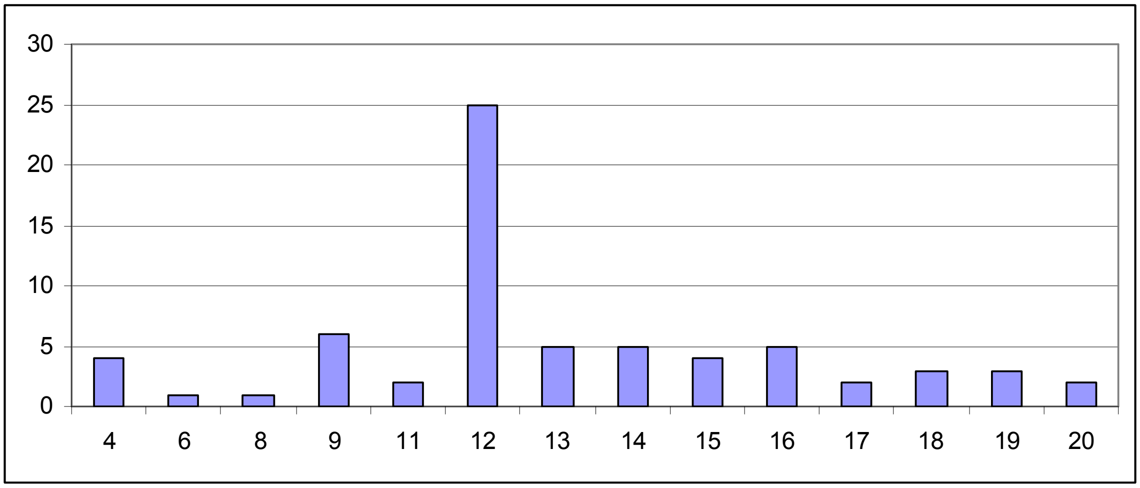

Figure 5. Distribution of the subjective demand scale

Scores on the objective burden scale averaged 17.65 (SD = 2.35, Min = 11, Max = 20) and displayed a moderate/high level of reliability (Cronbach's Alpha = 0.77). Earlier research shows that 0% (0/72) of the palliative home care patients were considered high on the objective burden scale.

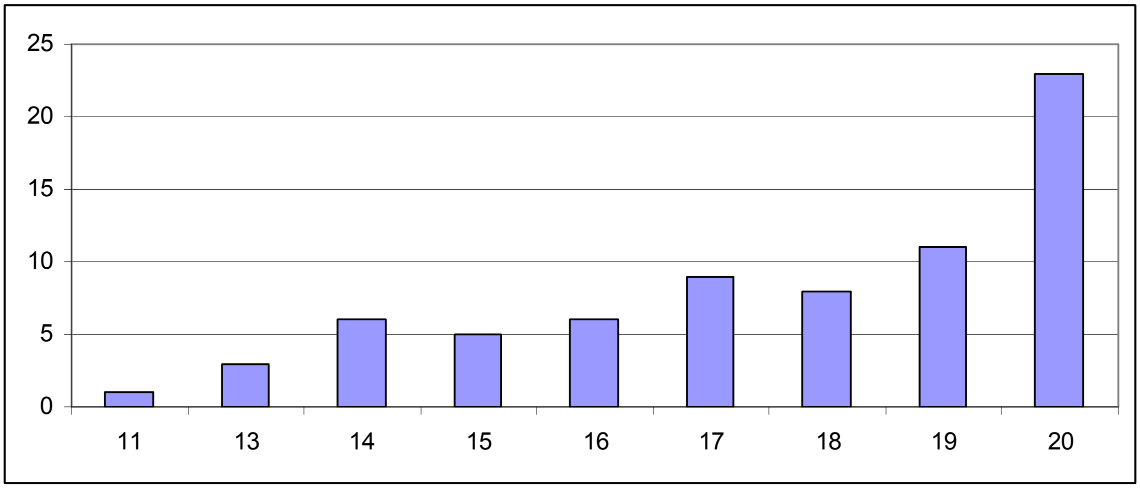

Figure 6. Distribution of the objective burden scale

The two scales that measured caregiver burden were analyzed to confirm the hypothesized factor structure of the underlying domains. Because many of the domains measuring caregiver burden are correlated, any factor analyses must incorporate this correlation into the results. For that reason, an oblique rotation was performed using SAS by employing the promax technique. This technique allows for an orthogonal rotation that accounts for correlations among the factors. The loadings are raised to the power of 2, 4, or 6 to drive small correlations to zero and to reduce large correlations. Factors often remain correlated but the underlying factors are maximized and correlations are minimized.

The 14 items from the Caregiver Burden Scale (Montgomery, n.d.) were entered into a factor analysis using SAS Factor. The sample included 71 caregivers who completed the Caregiver Survey. Eigenvalues equal to or greater than 1 were used to identify factors (see Figure 1.). Results are consistent with earlier research indicating the presence of 3 factors that accounted for 64% of the variance. Analyses show that most of the items loaded on only one of the three factors and many of the factor loadings were greater than 0.60.

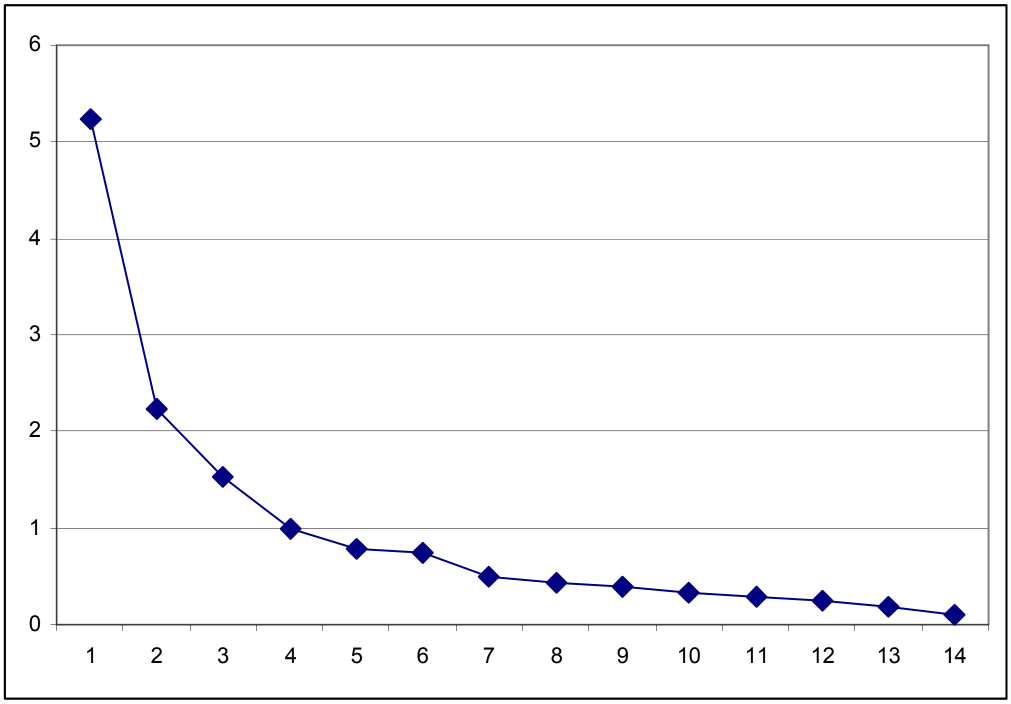

Figure 7. Scree plot for Caregiver Burden Scale

Loadings of variables on factors, communalities, and percents of variance and percents of covariance are shown in Table 5. The variables are grouped by their corresponding factor loadings to simplify interpretation of the factors. Factor loadings are grouped by descending factor loadings within each group. Factor loadings ≤ 0.40 were deleted to improve interpretability.

In subsequent analyses, variables D3 (personal privacy) and D11 (time to do your own work and daily chores) were not included in the cumulative scales.

Table 5. Factor analysis of the Montgomery Caregiver Burden Scale, factor structure correlations

F1	F2	F3	Communalities	Item
Subjective Demand Burden				
0.94	-	-	0.91	feelings that you are being taken advantage of by your relative/friend?
0.93	-	-	0.94	unreasonable requests made of you by your relative/friend?
0.84	-	-	0.89	demands made by your relative/friend that are over and above what s/he needs?
0.77	-	-	0.61	attempts by your relative to manipulate you?
0.63	-	0.60	0.78	time to do your own work and daily chores?
Subjective Stress Burden				
-	0.79	-	0.69	nervousness and depression concerning your relationship with your relative/friend?
-	0.81	-	0.82	anxiety about things?
-	0.75	-	0.78	tension in your life?
-	0.49	-	0.24	stress in your relationship with your relative/friend?
Objective Burden				
-	-	-	0.36	personal privacy?
-	-	0.84	0.92	time for friends and other relatives?
-	-	0.69	0.57	time to spend in recreational activities?
-	-	0.58	0.41	vacation activities and trips?
-	-	0.68	0.76	time to yourself?
3.93	2.88	2.89	9.70	
0.28	0.21	0.21	0.69	Proportion of variance
0.48	0.35	0.35		Proportion of covariance

Discussion

The majority of the items on the Caregiver Burden Scale (Montgomery, n.d.) loaded on their hypothesized factors, Factor 1 represents Subjective Demand Burden, Factor 2 represents Subjective Stress Burden, and Factor 3 represents Objective Burden. With the exception of two items (item 3, personal privacy and item 11, time to do your own work and daily chores), these factors are consistent with the original research (Montgomery, N.D.). These items were originally intended to be part of Factor 2, Objective Burden. Original research placed item 11 with Factor 1 (Subjective Demand Burden), this study found that item 11 did not load on any particular factor.

Although the Caregiver Burden Scale is not well validated, it remains one of the few scales developed to measure caregiver burden among caregivers of terminally ill persons. Factor analyses of the Caregiver Burden Scale showed the results to be consistent with earlier research. For this reason, it appeared to be a valid measure of caregiver burden among terminally ill home care patients. This finding is important because it supports the validity of the Caregiver Burden Scale. The next step was to compare these results with that of another burden scale (Burden Interview; Zarit et al., 1985).

Factor analysis of the Burden Interview

Methods

Analyses

Refer to page 69.

Results

The 12 items from the Burden Interview (Zarit et al., 1985) were entered into a factor analysis using SAS Factor. The sample included 71 caregivers caring for terminally ill home care patients. These caregivers were identified by the case manager as the primary caregiver to the CCAC home care patient. To be included in the analyses, the primary caregiver had to have been present during the case manager's assessment of the patient.

Similar to the aforementioned factor analysis, a promax rotation technique was employed. Eigenvalues equal to or greater than 1 were used to identify the underlying factor structure (see Figure 2.). Factor analysis identified the presence of two factors. Analyses show that the items loaded on either one of the two originally hypothesized factors. Many of these factor loadings were greater than 0.60. These 2 factors were shown to account for 51% of the variance, Factor 1 accounted for 34% of the variance and Factor 2 accounted for 17% of the variance. These results are consistent with earlier research (Bédard et al., 2001).

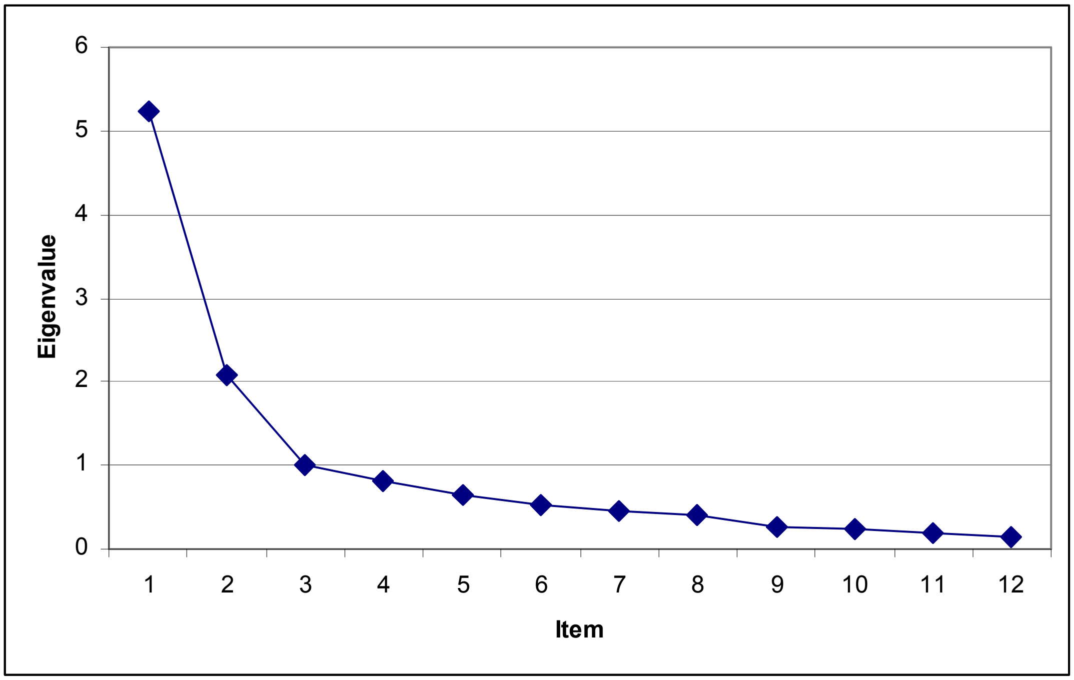

Figure 8 Scree plot for Zarit Burden Scale

Loadings of variables on factors, communalities, and percents of variance and covariance are shown in Table 6. The variables are grouped by their corresponding factor loadings to simplify interpretation of the factors. Factor loadings are grouped by descending factor loadings within each group. Factor loading ≤ 0.40 were deleted to aid interpretability.

Table 6. Factor analysis of the Burden Inventory, factor structure correlations

F1	F2	Communalities	Item
Personal Strain			
0.84	-	0.72	that your social life has suffered because you are caring for your relative/friend?
0.84	-	0.71	that you have lost control of your life since your relative/friend's illness?
0.85	-	0.77	that because of the time you spend with your relative/friend that you don't have enough time for yourself?
0.72	-	0.54	that you don't have as much privacy as you would like because of your relative/friend?
0.71	-	0.62	stressed between caring for your relative/friend and trying to meet other responsibilities (work/family)?
0.66	-	0.48	that your health has suffered because of your involvement with your relative/friend?
0.67	-	0.58	angry when you are around your relative/friend?
0.59	-	0.35	that your relative/friend currently affects your relationship with family members or friends in a negative way?
0.64	-	0.73	strained when you are around your relative/friend?
Role Strain			
-	0.88	0.77	you could do a better job in caring for your relative/friend?
-	0.82	0.68	you should be doing more for your relative/friend?
-	0.72	0.66	uncertain about what to do about your relative/friend?
4.78	2.40	7.18	
0.34	0.17	0.51	Proportion of variance
0.67	0.33		Proportion of covariance

The factor analysis of the Burden Interview accounted for 51% of the variance. The first factor was larger and accounted for 34% of the variance. No cross loadings ≤ 0.40 were observed between the two factors.

Finding show that the average score for personal strain was 23.94 (SD=7.92, Min = 9, Max = 40 with a high level of reliability (Cronbach's Alpha = 0.90). Scores for role strain averaged 7.95 (SD = 2.88, Min = 3, Max = 15) with a moderate level of reliability (Cronbach's Alpha = 0.76).

Discussion

The purpose of this section was to examine the factor structure of the Burden Interview (Zarit et al., 1985). This was a necessary step to validating the Caregiver Burden Scale

(Montgomery et al., ND). Results show that each of the items load on its hypothesized factor. The first 9 items represent Personal Strain and the last three items represent Role Strain. These results are consistent with earlier research by Bédard et al. (2001).

To the author’s knowledge, even though research on the Burden Interview is extensive, spanning many different populations, this is the first time the Burden Interview has been used to examine caregiver burden among palliative home care patients. Because results are consistent with earlier research, it is reasonable to conclude that the Caregiver Interview is appropriate for use in this study population.

Correlations between the Caregiver Burden Scales

Pearson correlations were used to examine the relationship between the Caregiver Burden Survey and the Burden Interview. These relationships were examined using the study's Caregiver Burden Survey described earlier. Characteristics of caregivers who completed the survey are reported earlier in this section.

Results

Results show that subjective stress burden correlates highly with personal strain and role strain. However, subjective demand burden and objective burden only correlate with personal strain (see Table 7).

Table 7. Pearson correlation between domains from the Caregiver Burden Scale and the Burden Interview

Caregiver Burden Scale		Burden Inventory	
		Personal strain	Role strain
Subjective stress burden			
	r	0.54	0.26
	p	<0.01	0.04
	n	61	64
Subjective demand burden			
	r	0.63	-0.07
	p	<0.01	0.57
	n	59	60
Objective burden			
	r	0.63	0.11
	p	<0.01	0.40
	n	62	63

Discussion

Results of this study suggest that the Caregiver Burden Scale is an adequate measure of caregiver burden among caregivers of terminally ill home care patients. Correlations between the two scales and among the domains of the two scales indicate that subjective stress burden correlates with personal strain and role strain, suggesting that caregivers who feel the emotional impact of providing care to a terminally ill family member or friend are also stressed due to conflict or overload. This correlation likely represents the fact that caregivers experiencing conflict or overload are also experiencing stress associated with care. However, the role strain is not necessarily related to the disruption associated with caregiving (objective burden) or how the caregiver perceives his or her responsibility as demanding (subjective demand burden). Caregivers who experience role strain may not perceive that role as overly demanding or disruptive to their schedule. Results of these analyses also suggest that the subjective stress domain provides an accurate representation of the Burden Interview.

The correlations found in Table 7 are moderate; this likely reflects differences in how the interRAI PC tool and the two scales found in the caregiver survey were measured. While the interRAI PC is an informant rating scale, completed on behalf of the patient and caregiver by the case manager, the two scales found in the caregiver survey were set up to be self-report. Therefore, because of the sensitivity of the questions being asked by the self-report scales, some discrepancy is likely to occur.

To conclude, the Caregiver Burden Scale is a valid measure of caregiver burden among caregivers caring for terminally ill family members or friends. This conclusion is supported by the original research to develop this scale. The next step is to examine the items in the interRAI PC as they relate to the Caregiver Burden Scale. This step is necessary in validating those items as they relate to caregiver burden so that they may identify determinants of caregiver burden in this population.

interRAI PC Caregiver Burden Items

Methods

Participants

Participants are described above. Characteristics of caregivers who completed the survey are reported earlier in this section.

Materials

Factors associated with the 4 caregiver burden items were examined using point-bi-serial correlation. This form of correlation is computed using the formula for the Pearson Product Moment Correlation. It is a correlation coefficient that is used when one variable is dichotomous. The correlation coefficient can range from -1 to +1.

The sample included patient/caregiver dyads who completed the Caregiver Survey (n=71). The dependent variables comprised each of the interRAI PC items hypothesized to measure caregiver burden. Scores for these items were determined by the case manager and were measured dichotomously (0=No, and 1=Yes). Caregiver burden is measured under the heading of "Informal Helper Status" and measures:

a) strong relationship with family
b) the primary caregiver's ability to continue providing care,
c) the primary caregivers feelings of distress or depression, and
d) whether the family expresses feeling overwhelmed by the patients illness.

Case managers were instructed to interview the caregiver and the patient separately. Questions should address the caregiver's ability to provide care and should address both the current and future needs of the patient.

The independent variables examined include anhedonia, anxiety, depression, subjective stress burden, demand stress burden, objective burden, personal strain, role strain, life satisfaction, current health of the caregiver, and declining health of the caregiver. These items are self-report. Scores are outlined subsequently.

Measures of anhedonia, depression, and anxiety were scored on a 4-point scale. The anhedonia construct measured the level of interest or pleasure in things he or she would normally enjoy. Measures of depression referred to the patient's self-reported level of depression, sadness, or hopelessness. The anxiety measure examined self-reported levels of anxiety, restlessness, or uneasiness. Scores on each of these measures are recorded on a scale ranging from 0 to 4 and measure the number of days – over the previous 3 days - he or she felt: (a) anxiety, (b) depression, and (c) anhedonia:

1) = none,

2) = 1-2 days,

3) = all 3 days, and

4) = no response.

Subjective stress burden, demand stress burden, and objective burden are subscales derived from the Caregiver Burden Scale. Personal Strain and Role Strain are subscales derived from the Burden Inventory. These subscales are the cumulative scores of items found in the Caregiver Burden Scale and Burden Inventory. These scores are described in an earlier section examining the factor analysis of the Caregiver Burden Scale and Burden Inventory, respectively.

Additional questions on health were included. Health conditions refer to the caregiver's current state of health and the decline in the caregiver's health since caregiver began providing care. Scores range from 1 to 5:

1) = Very poor,

2) = Poor,

3) = Okay,

4) = Good, and

5) = Very good.

These items represent very broad measures of health.

Results

Table 8 shows the variables that were associated with the 4 interRAI PC caregiver burden items. It shows that subjective stress burden was related to the caregiver being unable to continue, caregiver anger, distress, and/or depression, and reports of the family being overwhelmed by the patients illness. Self-reported mood was related to having a helper that was unable to continue and reports of family members being overwhelmed by the patient's illness. Items from the Burden Interview failed to correlate with any of the interRAI PC caregiver burden items. No relationship was found between the Satisfaction with Life Scale and the interRAI PC caregiver burden items.

Table 8. Associations with the interRAI caregiver burden items

Variable		Strong relationship with family *(O4a)*	Helper unable to continue *(O4b)*	Caregiver anger, distress, depression *(O4c)*	Family overwhelmed *(O4d)*
Caregiver burden scale					
Subjective demand	r	-0.17	0.19	0.08	-0.13
Subjective stress	r	0.07	**0.35***	**0.25***	**0.26***
Objective burden	r	0.05	0.13	-0.01	0.05
Burden inventory					
Personal strain	r	-0.11	0.14	0.04	-0.02
Role strain	r	-0.08	0.03	-0.06	0.17
Happiness scale	r	0.00	0.04	-0.13	-0.22
Self-reported distress	r	-0.02	**0.26***	0.17	**0.29***

** Significant at the 0.05 level*

Discussion

Analyses show subjective stress burden was related to (a) caregivers who are unable to continue providing care, (b) report feelings of distress, anger, or depression, and (c) who are overwhelmed with the patient's illness. Self-reported distress, a measure that includes anxiety, depression, and anhedonia, was related to caregivers who were unable to continue and who were overwhelmed with the patient's illness. These relationships are evidence that the three interRAI PC items largely reflect the psychological distress associated with caring for a terminally ill family member or friend. Subjective stress burden reflects the emotional impact of providing care to terminally ill family members of friends.

Face validity indicates that these three items do represent the physical, emotional, and psychological aspects of care. What these items do not examine is objective burden or subjective demand burden. Perhaps additional questions need to be included in the interRAI PC dossier that would make it more comprehensive. However, the original hypothesis of this dissertation states that it the subjective stress precipitated by providing care to a terminally ill family member or friend that can influence place of death, rather than objective burden or subjective demand burden.

Development of the Caregiver Burden Scale

Development of an *interRAI PC Caregiver Burden Scale* is important for both the patient and the caregiver. For example, patients who are cared for by a caregiver who is distressed may be at risk of poor care. Caregivers who are distressed are at risk of poor health.

Methods

Participants

The sample included 1,130 home care patients receiving palliative care services from one CCAC in Ontario (see Table 9).

Analyses

The relationships among the 4 interRAI PC caregiver burden items were examined using correlational analyses. The tetrachoric technique was employed because the binary items (yes, no) reflect a latent continuous variable.

Results

The proportion of males to females was similar, 49% and 51%, respectively. The majority of the patients were widowed (26%) or married (60%) and lived with a spouse and/or one or more children (56%). Few patients lived with parent(s), siblings, relatives, or non-relatives. Patients were on average 71 years of age.

Table 9. Demographics of patient characteristics

Patient characteristics		N	%
Sex	Male	552	49%
	Female	574	51%
	Total	1,126	100%
Age	Mean (SD; Min; Max; N)	71.0 (13.65; 19-101; 1119)	
Marital status	Never married	72	6%
	Married/partner	669	60%
	Widowed	295	26%
	Separated/divorced	85	8%
	Total	1,121	100%
Living arrangement	Alone	198	19%
	Spouse	436	42%
	Spouse & others	148	14%
	Child(ren)	156	15%
	Parents	21	2%
	Siblings	17	2%
	Other relatives	19	2%
	Non-relatives	43	4%
	Total	1,038	100%

The tetrachoric correlation shows that caregiver distress/depression is related to the caregiver's ability to continue providing care and the family's feelings of being overwhelmed by the patient's illness (see Table 10). The caregiver's ability to continue providing care also correlates highly with the family's feeling of being overwhelmed by the patient's illness. Having a supportive family failed to correlate with any of the other items.

Table 10. Tetrachoric correlation examining the interRAI PC caregiver items

		Supportive family *(O4a)*	Caregiver unable to continue *(O4b)*	Caregiver depressed/distressed *(O4c)*
Caregiver unable to continue			-	
(O4b)	r	-0.24	-	-
	p	0.10	-	-
	n	1,041	-	
Caregiver depressed, stressed				
(O4c)	r	-0.06	0.64	-
	p	0.09	*0.05	-
	n	1,038	1,023	-
Family overwhelmed				
(O4d)	r	0.03	0.75	0.86
	p	0.09	*0.04	*0.03
	n	1,020	1,002	1,010

* p-value ≤ 0.05

The later 3 caregiver burden items were summed to create the interRAI PC Caregiver Burden Scale. Scores on this scale range from 0 to 3. The distribution of the interRAI PC Caregiver Burden Scale scores are provided in Table 11. It shows that 23% (228/1,001) of caregivers were rated by case managers as having some measure of caregiver burden. The majority of caregivers who scored on the interRAI PC Caregiver Burden Scale had a score of 1 (46%, 105/228) whereas only 4% experience all three. The 3 interRAI PC caregiver burden items that were shown to be highly correlated using tetrachoric correlations were entered into a reliability analysis.

Table 11. Distribution of the interRAI PC Caregiver Burden Scale scores

Score	N	%
0	773	77%
1	105	11%
2	82	8%
3	41	4%
Total	1,001	100%

Table 12 shows the distribution of interRAI PC caregiver burden scores as they relate to the individual items used to calculate the scale. It suggested that the two variables that contribute the most to the interRAI PC Caregiver Burden Scale are:

A) Caregiver distress/depression and

B) Family overwhelmed with patient's illness.

Caregivers with a score of two were more likely to score on these two items simultaneously. Only 16% of caregivers who scored 1 were unable to continue and only 20% of caregivers who had a score of 2 were unable to continue. It is possible that caregivers who were unable to continue eventually cease providing care. This accounts for the low percentage of scores on that item.

Table 12. Distribution of burden scores related to the interRAI PC Caregiver Burden Scale

	Score			
	1		2	
	N	%	*N*	%
Caregiver unable to continue *(o4b)*	*17*	16%	*16*	20%
Caregiver distress/depression *(o4c)*	*37*	35%	*68*	83%
Family overwhelmed with illness *(o4d)*	*51*	49%	*80*	98%

Note: Caregiver Burden Scale ranges from 0 to 3; Scores 0 and 3 are not included in the table; sample size = 1,001

As stated earlier, the results of these analyses suggest that the later 3 interRAI PC caregiver burden items could be summed to create an interRAI Caregiver Burden Scale. This scale ranges from 0 to 3.

The following analyses examines the reliability of this proposed scale. The 3 interRAI PC items that reflect caregiver burden were entered into a Reliability Analysis. The subsample included 1,001 patient/caregiver dyads with scores only on the interRAI PC instrument.

The reliability analysis (see Table 13) shows good reliability (Alpha = 0.72), the deletion of “caregiver unable to continue providing care” (O4b) increased reliability by 0.04 (Alpha = 0.76), however, for theoretical reasons this items reflects an important part of caregiver burden so it will be included in the scale.

Table 13. Reliability analysis of interRAI PC caregiver burden items

Mean	SD	n	
0.07	0.26	1,001	Caregiver unable to continue *(O4b)*
0.15	0.35	1,001	Caregiver distress, depression *(O4c)*
0.17	0.38	1,001	Family overwhelmed with illness *(O4d)*

Scale	Variance	SD	n
0.39	0.65	0.81	3

$\alpha = 0.72$

The next step was to correlate the interRAI PC Caregiver Burden Scale against each of the domains in the Montgomery Caregiver Burden Scale and Zarit Burden Interview, along with the Satisfaction With Life Scale and self-reported mood items (anhedonia, depression, and anxiety).

Results show that higher scores on the interRAI PC Caregiver Burden Scale were correlated with higher subjective stress burden scores and higher self-reported mood scores (Table 14; anxiety, depression, and anhedonia). Because subjective stress burden and self-reported mood (i.e., depression, anxiety, and anhedonia) represent emotional disturbances, it is likely that the interRAI PC Caregiver Burden Scale reflects the emotional impact associated with providing care to a terminally ill family member or friend. As stated earlier, the 3 caregiver burden items include:

a) the caregiver is unable to continue,

b) caregiver is distressed or depressed, and

c) the family is overwhelmed with the patients illness.

Results show that the interRAI PC Caregiver Burden Scale, the summation of the 3 caregiver burden items, represents the emotional impact of caregiving (subjective stress burden) and psychological distress.

Table 14. Factors correlated with the interRAI PC Caregiver Burden Scale

Variable		Value
Montgomery caregiver burden scale		
Subjective demand burden	r	-0.04
(Subdemand_o)	p	0.78
	n	61
Subjective stress burden	r	0.31
(Substress_o)	p	*0.01
	n	61
Objective burden	r	0.09
(obburden_o)	p	0.47
	n	61
Zarit burden scale		
Personal strain	r	0.05
(p_strain)	p	0.69
	n	58
Role strain	r	0.07
(r_strain)	p	0.61
	n	61
Miscellaneous		
Life satisfaction index	r	-0.14
(pwb1)	p	0.29
	n	57
Self-report psychological well-being	r	0.28
(psycho)	p	*0.03
	n	60

* $p < 0.05$

Discussion

This sub-study was able to examine the four interRAI PC items that are hypothesized to reflect caregiver burden. They include:

A) the presence of supportive family (o4a),

B) caregiver's ability to continue providing care (o4b),

C) caregiver distress and/or depression (o4c), and

D) family member's feelings of being overwhelmed by the patient's illness (o4d).

Results show high correlations between the 2nd, 3rd, and 4th items in the interRAI PC. These correlations indicate that caregivers who are unable to continue providing care are also more likely to be distressed and/or depressed and family members are also more likely to be overwhelmed by the patient's illness. Correlations between the 1st and the 2nd, 3rd, and 4th items were not significant.

Because tetrachoric correlations support a relationship between the 2nd, 3rd, and 4th items, only those 3 items were entered into the reliability analysis. The reliability analysis show a moderate level of reliability among the three caregiver burden items (alpha = 0.72). A small increase in reliability could be achieved by deleting the variable "caregiver is unable to continue," however, that variable was included in the final scale for theoretical reasons.

It is possible that the reason why so few caregivers were unable to continue is that caregivers who are unable to continue are also more likely to have discontinued home care for institutional care (hospice or hospital). From a theoretical perspective, this item may be particularly important as a risk factor for hospital or hospice death among patients who wish to die at home.

Results suggest that caregivers who scored a 2 on the interRAI PC Caregiver Burden Scale were also more likely to be distressed or depressed and have family members who were overwhelmed with the patient's illness. This may also represent a significant risk factor for home death whereby caregivers who were distressed or depressed or overwhelmed by the patient's illness may be unable to continue providing care. Caregivers who trigger any of these items may reduce the patient’s likelihood of home death, especially among patients who wish to die at home.

Taken together, the proposed interRAI PC Caregiver Burden Scale appears to provide a sufficient measure of caregiver burden. This scale is related to the emotional impact and distress associated with caring for a terminally ill family member or friend.

Although it is considered a satisfactory score, an alpha of 0.72 may reflect the multifactorial nature of caregiver burden, which a single scale cannot sufficiently measure. Conversely, it may also reflect the underlying manner in which the interRAI PC measures caregiver burden (in a dichotomous fashion: yes vs. no). Perhaps the scale in which it is measured should be reconsidered, one example is to mimic that of the self-reported mood items that measure affective disturbance over the previous 3 days (e.g., not at all, once, twice, or on all three days). This would provide a greater degree of variance and the ability to assign a threshold determining when burden becomes problematic.

Study II – Determinants of Caregiver Burden

This section identifies determinants of caregiver burden. Potential factors include the characteristics of the patient and the caregiver. Earlier research suggests that caregiver burden is associated with tasks related to everyday caregiving, to the caregiver's levels of depression and emotion, to the care that is beyond the limits of the caregiver's skill level, and to the impact that it has on the caregiver's instrumental activities of daily living (Montgomery et al., 1985).

Home care patients who are palliative often require high levels of care before and after their ability to perform everyday activities become impaired. Patients may experience reduced functioning and/or symptoms that are difficult to manage. The health of the caregiver may decline because of the stressors associated with caregiving. Informal caregivers can comprise family, friends, neighbours, or others. They are often called upon to provide additional assistance not typically provided by home care agencies. This may place a burden on informal caregivers. This section will examine the determinants of caregiver burden in palliative home care.

Methods

Sample

Participants included all palliative home care patients from one CCAC in Ontario. Palliative home care patients were either transferred from general home care to palliative home care or were referred to palliative home care from outside agencies (acute care, complex continuing care, etc.). Methods to assess the needs of patients receiving palliative home care are addressed earlier.

Eligible patients were in various stages of terminal illness. Inclusion criteria comprised any adult equal to or greater than 18 years of age that was English speaking and received home health care. Ontario home health care is provided by CCACs. Services that are provided are paid for by the provincial government through the Ministry of Health and Long-Term Care. Referral to palliative home care can be provided by anyone; however, the patient must meet the pre-existing eligibility criteria to receive services.

Materials

CCACs direct home support in Ontario. The responsibility of the case manager is to assess each new or existing patient and determine his or her eligibility for services and the variety and quantity of assistance necessary to maintain home support. The maximum amount of care time allocated by professional home care providers is 80 hours in the first month and 60 hours for each additional month thereafter. Additional care can be provided under certain extraneous circumstances. Care provided by professional home care providers includes, but is not limited to, home health aids, home nursing, homemaking services, and meals. Measures on health are captured using the interRAI PC. Version 9 of the interRAI PC was introduced in August 2006.

A number of variables were used in these analysis, including patient characteristics, patient health conditions, and caregiver characteristics. The interRAI PC measures fatigue on a 5 point scale: 0) none, 1) minimal, 2) moderate, 3) severe, and 4) unable to commence any normal day-to-day activities. This was collapsed to aid interpretation: none to moderate (0-2), and severe to unable to commence day-to-day activities (3-4).

Health conditions (see Table 15, page 98) are defined on a 5-point scale, where 0=not present, 1=present but not exhibited on last 3 days, 2=exhibited on 1 of last 3 days, 3=exhibited on 2 of last 3 days, and 4=exhibited daily in last 3 days. These variables were collapsed to indicate the occurrence of a problem within the last 3 days: not present to present but not exhibited on last 3 days (0 to 1) and exhibited in one of last 3 days to present days in last 3 days (2 to 4).

Marital status is measured using 6 categories: never married, married, partner/significant other, widowed, separated, and divorced. Marital status was collapsed into 4 categories: 1, never married, 2, married/significant other, 3, widowed, and 4, separated/divorced. Marital status was also dummy coded to compare each group to everyone else (never married vs. everyone else, married/significant other vs. everyone else, widowed vs. everyone else, and separated/divorced vs. everyone else).

Estimated prognosis, which is the case manager's appraisal of the persons length of life, and is determined using his or her judgment, physician appraisal, and patient charts, is measured on the interRAI PC as 1, death is imminent; 2, less than 6 weeks; 3, 6 weeks or longer, but less than 6 months; 4, 6 months or longer. This variable was collapsed to compare patients with 6 weeks or less to live to those whose prognosis was estimated to be greater than 6 weeks.

Self-reported mood captures 3 domains, anhedonia (little interest or pleasures in things you normally enjoy), anxiety (anxious, restless, or uneasy), and depression (sad, depressed, or hopeless). These three domains are measured on a 5-point scale: 0, not at all in last 3 days, 1, not in last 3 days but often feels that way, 2, in 1-2 of last 3 days, 3, daily in last 3 days, and 4, person could not (would not) respond. Patients who scored 8 were recoded to 0 and all three domains were summed to create a new variable reflecting self-reported mood ranging from 0 to 9.

The interRAI PC defines urinary incontinence on 7 categories: 0=continent, 1=control with catheter or ostomy over last 3 days, 2=infrequent incontinent, 3=occasionally incontinent, 4=frequently incontinent, 5=incontinent, and 8=did not occur. Scores of 8 were recoded to 0. scores were then collapsed into two categories, continent to infrequent incontinent (0 to 2) and occasionally incontinent to incontinent (3 to 5).

Advanced directives measured by the interRAI PC and focused on in the analyses include do-not-resuscitate, do-not-intubate, do-not-hospitalize, and do-not-send-to-emergency. These variables are measured dichotomously, (0=not in place, 1=in place).

Table 15. Health conditions measured by the interRAI PC

Category	Variable
Pulmonary	
	Difficulty clearing airway secretions
GI status	
	Acid reflux – regurgitation of acid from stomach to throat
	Bloating – e.g., distended abdomen; feels unusually full
	Constipation – no bowel movement in 3 days
	Diarrhea
	Fecal impaction
	Nausea
	Vomiting
Sleep problems	
	Difficulty falling asleep or staying asleep
	Too much sleep – excessive amounts of sleep that interferes with person's functioning
Other	
	Dizziness
	Dry mouth
	Excessive sweating
	Fever
	Hallucinations
	Hiccups
	Jaundice
	Muscle cramps
	Peripheral edema
	Seizures
	Stroke
	Twitching

The section on responsibilities and directives records the patient's final wishes. This section includes the wish to die at home and the wish for hastened death. These two items are measured on a 3-point scale:

a) 0 = No,

b) 1 = Yes, and

c) 8 = Unable to determine.

For the purposes of these analyses, patients whose wishes were unable to determine were recoded to 0 to compare patients who wished to die at home to everyone else and patients who wished for hastened death to everyone else.

Key informal helpers were categorized into one of 8 categories:

a) child or child-in-law,
b) spouse,
c) partner/significant other,
d) parent,
e) sibling,
f) other relative,
g) Friend or neighbour, and
h) no informal helper.

This variable was collapsed into 3 groups: 1) child or child-in-law, 2) spouse/significant other, and 3) other. Patients who did not have a caregiver were removed from any further analyses.

The interRAI PC records the characteristics of the caregiver. The characteristics of the informal caregiver were identified using Section M of the interRAI PC version 9. This section records such characteristics as the caregiver's relationship to the patient (child, spouse, partner/significant other, parent, other relative, friend or neighbour), residential status (more than 6 months, less than 6 months, non-resident), level of daily contact (in person or by phone/email), type of care provided (ADL care and IADL care), and the hours of informal care provision and active monitoring provided (in the last 3 days).

Hours of informal care are recorded by the number of hours of care provided to the patient over the prior 3 days. Hours reflect help with instrumental and activities of daily living and are the cumulative number of hours provided by family, friends, and neighbours. This variable was positively skewed and underwent a subsequent transformation using a log transformation.

Analyses

The focus of the analyses was on the relationship of caregiver burden to the patient's physical status and caregiver traits. Because earlier versions of the interRAI PC did not assess caregiver burden, the sample was restricted to those patients who were assessed with the interRAI PC version 9. Patients could have been assessed on more than one occasion; whereby a subsample may have had more than one assessment. Because the intent of these analyses was to examine the associations of caregiver burden, all assessments were included in the analyses.

Descriptive statistics are presented first. Bivariate statistics that examine the relationship between each independent variables and the dependent variable (interRAI PC Caregiver Burden Scale) are presented second. Each set of statistics are presented with the appropriate chi square or t-test statistics. Multivaraite analysis employ logistic regression to determine which of the independent variables identified caregiver burden. The potential of interaction effects were also examined.

The dependent variable is the interRAI PC Caregiver Burden Scale. This scale is the sum of the 3 caregiver burden items located in the interRAI PC that are found to represent caregiver burden. They include: (a) caregiver is unable to continue caring activities; (b) caregiver expresses feelings of distress, anger, or depression; and (c) family or close friends report feeling overwhelmed by person's illness. As stated earlier, this scale ranges from 0 to 3.

Logistic Regression. Logistic regression is a technique used to predict a variable with only two levels (discrete outcome like group membership) with the presence or absence of caregiver burden by one or more variables that are categorical, continuous, or a mix. The difference between logistic regression and other non-parametric techniques (i.e., multiple regression) is that many of the conventional assumptions are relaxed. For example, independent variable(s) do not require equal variance within each group, to be normally distributed, or linearly related. However, appropriate cell sizes are necessary to achieve meaningful confidence intervals.

Logistic regression estimates the regression coefficients (maximum likelihood ratios) using an iterative procedure. It is based on the best linear combination of predictors.
Equation 1. The equation for logistic regression is:

$$\gamma = \frac{e^{u}}{1 + e^{u}}$$

Where γ is the probability that i hold a specific group membership and u is the linear regression equation.

$$\text{Where: } u = a+B_1X_1+B_2X_2+\ldots+B_kX_k$$

The regression coefficient in logistic regression is an odds ratio (OR). An odds ratio equal to 1 with a confidence interval that includes 1 yield no predictive value and is considered not significant. An odds ratio greater or less than 1 with confidence interval that does not include 1 is considered significant. A 95% confidence interval was used and all corresponding p-values were examined.

Variables associated with caregiver burden ($p \leq 0.10$) were entered into a logistic regression equation. Criteria for selection and elimination is a p-value of .10 or greater. The stepwise procedure was run until there was no further benefit to adding another variable into the equation.

Models were developed using the reverse selection procedure. Firstly, univariate analyses determined which variables were associated with the dependent variable. All variables that were significantly associated with the dependent variable were entered into the logistic regression simultaneously. One variable was removed at each step; the removed variable was identified to be the least significant. This was repeated until only significant variables were left in the model. The rationale for this process was to develop a succinct model of variables associated with the dependent variable.

Results

The sample included 1,130 terminally home care patients from one CCAC in Ontario. (refer to Table 9 on page 87). The proportion of males to females was similar, 49% and 51% for males and females, respectively. The majority of patients were married (60%) or widowed (26%) and lived with a spouse and/or one or more children. Patients were on average 71 years of age.

Missing cases

A problem with using administrative databases is the potential for missing data. Table 16 provides the rate of missing information for each variable. Rates of missing information range from 63% for prognosis to 3% for bloating.

Table 16. Missing cases in the administrative database.

Variable Description	Variable	# Missing N = 1,130	% Missing
Health conditions			
Prognosis	(a4a)	670	63%
Difficulty clearing airways	(C5AA)	53	5%
Acid reflux	(C5BB)	49	4%
Bloating	(C5CC)	40	4%
Constipation	(C5DD)	52	5%
Diarrhea	(C5EE)	52	5%
Fecal impaction	(C5FF)	76	7%
Nausea	(C5GG)	56	5%
Vomiting	(C5HH)	60	5%
Difficulty sleeping	(C5II)	84	7%
Excessive sleep	(C5JJ)	104	9%
Dizziness	(C5KK)	42	4%
Dry mouth	(C5LL)	50	4%
Excessive sweating	(C5MM)	44	4%
Fever	(C5NN)	41	4%
Hallucinations	(C5OO)	48	4%
Hiccups	(C5PP)	49	4%
Jaundice	(C5QQ)	47	4%
Muscle craps	(C5RR)	53	5%
Peripheral edema	(C5SS)	54	5%
Seizures	(C5TT)	57	5%
Stroke	(C5UU)	43	4%
Twitching	(C5VV)	53	5%
Fatigue	(c3a)	53	5%
Urinary incontinence	(incont)	51	4%
Patient preferences			
DNR	(n2a)	132	12%
DNI	(n2b)	172	15%
DNH	(n2c)	189	17%
DNER	(n2d)	191	17%
Living will	(n1a)	187	17%
Wants to die now	(n3c)	241	21%
Prefer home death	(prefplace)	217	19%
Patient characteristics			
Marital status	(A12)	238	21%
Caregiver characteristics			
Child caregiver	(child)	64	6%
Spousal caregiver	(spouse)	64	6%
Other caregiver	(other)	64	6%
Live with caregiver	(livewith)	53	5%
Contact with caregiver	(contactwith)	67	6%
Provides ADL Help	(adlhelp)	61	5%
Provides IADL Help	(iadlhelp)	73	6%
Caregiver Burden	(burdenn)	142	13%

Analyses

Univariate determinants of caregiver burden were examined using the interRAI PC Caregiver Burden Scale (dependent variable). Scores on the interRAI PC Caregiver Burden Scale were collapsed to aid in interpretation: 0=0, 1= 1 to 3. Health conditions that were associated with reports of caregiver burden include pulmonary issues (difficulty clearing airway), acid reflux, constipation, problems sleeping, fatigue, and urinary incontinence.

An examination of Advanced Directives showed that caregivers who experienced caregiver burden were more likely to care for patients who have not completed his or her advanced directives (Table 17; do-not-resuscitate, do-not-hospitalize, and do-not-send-to-emergency department). In addition, caregivers of patients who stated that he or she wished for hastened death were more likely to report caregiver burden.

An examination of the social aspects of caring showed that patients who were married were more likely to have a caregiver that was experiencing caregiver burden; whereas patients whose primary caregiver was not a child or spouse were less likely.

Table 17. Determinants of caregiver burden using the Caregiver Burden Scale (binary)

Variable		No		Yes					
		N	%	N	%	Total	DF	χ^2	p-value
Health conditions									
Pulmonary	No	604	78%	168	22%	772	1	6.50	0.01
	Yes	116	69%	52	31%	168			
Acid reflux	No	645	78%	183	22%	828	1	3.29	0.07
	Yes	86	70%	36	30%	122			
Constipation	No	561	79%	145	21%	706	1	8.92	0.00
	Yes	166	70%	71	30%	237			
Difficulty sleeping	No	452	81%	104	19%	556	1	13.37	0.00
	Yes	259	71%	106	29%	365			
Fatigue	No	356	83%	71	17%	427	1	19.45	<0.01
	Yes	368	71%	149	29%	517			
Urinary incontinence	No	605	78%	171	22%	776	1	3.12	0.08
	Yes	127	72%	50	28%	177			
Advanced directives									
Do-not-resuscitate	No	344	74%	118	26%	462	1	5.63	0.02
	Yes	332	81%	77	19%	409			
Do-not-hospitalize	No	522	75%	171	25%	693	1	6.32	0.01
	Yes	141	84%	26	16%	167			
Do-not-send-to-emergency	No	517	75%	168	25%	685	1	5.30	0.02
	Yes	144	84%	28	16%	172			
Wish to die now	No	610	79%	166	21%	776	1	11.32	0.00
	Yes	25	57%	19	43%	44			
Residential status									
Live alone	No	699	77%	210	23%	909	1	0.38	0.54
	Yes	49	80%	12	20%	61			
Married/common law	No	324	80%	79	20%	403	1	4.21	0.04
	Yes	424	75%	143	25%	567			
Widowed	No	532	76%	172	24%	704	1	3.47	0.06
	Yes	216	81%	50	19%	266			
Divorced	No	689	77%	205	23%	894	1	0.01	0.91
	Yes	59	78%	17	22%	76			
Caregiver status									
Child caregiver	No	506	77%	149	23%	655	1	0.23	0.63
	Yes	242	76%	77	24%	319			
Spousal caregiver	No	352	78%	99	22%	451	1	0.74	0.39
	Yes	396	76%	127	24%	523			
Other caregiver	No	638	76%	204	24%	842	1	3.66	0.06
	Yes	110	83%	22	17%	132			
Provides IADL help	No	155	82%	35	18%	190	1	2.77	0.10
	Yes	583	76%	185	24%	768			

Continuous variables were examined using t-tests with the collapsed interRAI PC Caregiver Burden Scale as the independent variable and health conditions rated on a continuous scale as the dependent variables (see Table 18). Results show that higher levels of caregiver burden were associated with higher levels of ADL, IADL, and cognitive impairment.

Higher Chess scores were also associated with higher levels of caregiver burden. Patients who reported higher levels of mood, as indicated by the Depression Rating Scale and self-reported mood, where higher scores indicate higher levels of depressive symptoms, were also more likely to have caregivers reporting caregiver burden. Differences between levels of pain among patients whose caregivers experienced caregiver burden approached significance.

Table 18. Determinants of caregiver burden using the Caregiver Burden Scale (continuous)

	Caregiver burden scale							
	No			Yes				
Variable	N	Mean	SD	N	Mean	SD	t-value	p-value
IADL[1]	730	12.70	0.21	214	14.31	0.31	-3.84	0.00
ADL[2]	680	1.50	0.08	195	2.18	0.16	-4.07	<0.01
Chess scale	655	2.62	0.05	209	3.32	0.08	-6.74	<0.01
Depression rating scale	659	0.44	0.04	173	1.00	0.11	-5.53	<0.01
CPS[3]	681	0.93	0.06	197	1.21	0.11	-2.20	0.03
Pain scale	752	1.34	0.04	226	1.49	0.08	-1.73	0.08
Self-rated mood	695	1.00	0.07	190	2.52	0.20	-8.53	<0.01

[1] interRAI IADL Scale; [2] ADL Hierarchy Scale; [3] Cognitive Performance Scale

Each of the variables from the univariate analyses examining caregiver distress or depression with a significance level or at least 0.10 were entered into a multivariate model (Table 19). The depression rating scale was removed in favour of the self-reported mood item to avoid problems of multicoliniarity. A reason for choosing self-reported mood items over the Depression Rating Scale was the higher level of association between it and the measure of caregiver burden.

Data from 70% (781/1,119) of the home care patients were entered into the model, 23% (176/781) had a score of one or more on the interRAI PC caregiver burden survey. The remaining assessments were deleted due to missing information on the interRAI PC assessment instrument. The full model against a constant-only model was statistically reliable, χ^2(2, N=

781) = 83.80, $p < 0.01$, indicating that the combined determinants reliably distinguished between patients who experienced caregiver distress, depression and those who did not.

Regression coefficients, standard errors, Wald statistics, p-values, odds ratios, and 95% confidence intervals were included in Table 19. The final model showed that higher levels on the Chess Scale were associated with caregiver burden. Initial analyses found that higher levels of self-reported mood and a wish for hastened death were associated with caregiver burden.

Table 19. Multivariate model showing only significant determinants of caregiver burden

Variable	DF	β	SE	χ^2	p-value	OR	LCI	UCI
Intercept	1	-3.07	0.27	127.49	<0.01			
Chess scale	1	0.47	0.08	37.91	<0.01	1.60	1.38	1.86
Self-reported mood	1	0.27	0.04	53.55	<0.01	1.31	1.22	1.40

Discussion

This section examined factors associated with caregiver burden among palliative home care patients. It shows that when individual variables were examined, there were a large number of determinants associated with caregiver burden. For example, health conditions, advanced directives, and social factors were determinants of caregiver burden, whereas multivariate analysis found two main determinants of caregiver burden: higher scores on the Chess scale and higher scores on the self-rated mood scale (depression, anhedonia, and anxiety). Higher scores on the Chess Scale resulted in a 60% higher risk of caregiver burden, whereas higher scores on self-rated mood was associated with a 31% increased risk of caregiver burden.

Many of the determinants found to be significant to caregiver burden in earlier research were not significant in this study. This may be due to the nature of the study population. Earlier studies typically examined determinants of caregiver burden among caregivers of terminally ill patients receiving hospice or hospital care. These patients are often in extremely poor health, more so than the population in the present study. In fact, the current study population appears to be suffering from fewer health conditions than typically found among patients whose prognosis is very short.

Study III – Preferred and Actual Place-of-death

Preferred place of death, whether at home or otherwise is an important determinant of home death. It is often a central theme of CCACs to realize the goal of terminally ill home care patients, one of these goals includes enabling the patient to achieve a good death in his or her preferred location. Many of the issues related to determinants of preferred place of death are addressed earlier. Suffice to say, this section examines factors associated with a preference for home death.

Methods

The materials for this study are the same as that of section II. Unlike section II, the CCAC tracked the patient's place of death. In addition to monitoring the health of patients who died while receiving home care, the CCAC also followed patients discharged from service to alternate health care settings. The CCAC collected this information as part of normal practice.

The interRAI PC includes questions that determined the patients preferred place of death at the time of assessment. The interRAI PC records the patient's wishes dichotomously (0=No, 1=Yes). Congruency between preferred vs. actual place of death was assessed by using information on place of death provided by the CCAC and the interRAI PC assessments. Only patients who indicated a preferred place of death were included in these analyses. They were placed into 2 groups, congruent home death or incongruent home death.

Analyses

Analyses are similar to that of section II, with the exception that the dependent variable was the patient's preferred place of death (home vs. other). In addition, this section examined the level of agreement between the patient's preferred place of death versus their actual place of death. Level of agreement was assessed using a kappa coefficient (Cohen, 1960; Feinstein & Cicchetti, 1990).

Analyses first examined the univariate determinants of home death (with institutional death as the reference category). It then proceeded with multivariate determinants by entering all significant associations into a logistic regression model. Level of agreement between preferred versus actual place of death, and factors associated with congruent death (preferred versus actual place of death) were examined using kappa.

The rationale for this section is the fact that existing literature finds some patients who wish to die at home do not achieve that goal. Basic research has examined congruence between preferred versus actual place of death. However, this proposed study is the first to employ a comprehensive instrument like the interRAI PC, an instrument designed to measure health conditions, cognitive and physical functioning, psychosocial well-being, informal support, and more.

Kappa coefficient. Level of agreement between preferred vs. actual place of death was determined using kappa coefficient. The purpose of using kappa was to test whether the level of agreement exceeds chance levels. A kappa coefficient can range from -1 to +1. Coefficients close to 1 equal higher levels of agreement. Kappa can be calculated using SAS using the Proc Freq procedure and specifying the AGREE option.

Equation 2. The equation for kappa, developed by Cohen (1960) is as follows:

$$\hat{k} = \frac{P_o - P_e}{1 - P_e}$$

Where $P_o = \sum ipii$ and $P_e = \sum ipi.p.1$.

The two response variables, preferred place of death and actual place of death, are viewed as independent scores from each participant.

Results

The sample included 1,126 terminally home care patients from one CCAC in Ontario. Characteristics of the home care patients are found on Table 9, page 87.

Identifying the patient's preference for home death is important when examining where palliative home care patients actually die Therefore it is important to fully examine this relationship and how it may be dependent on the patient characteristics, patient health, and caregiver characteristics. Table 22 shows the univariate binary factors associated with a stated preference for home death. Table 23 shows the univariate continuous variables associated with a stated preference for home death.

Analyses show that a preference for home death was strongly related to advanced directives, indicating that patients who completed advanced directives (do-not-resuscitate, do-not-intubate, do-not-hospitalize, and do-not-sent-to-emergency) were more likely to prefer home death. Patient characteristics associated with preferred home death also included a wish for hastened death where patients who desire home death wish for death to occur sooner. Marital status was also examined and showed that married patients were more likely to state a preference for home death while never married or divorced patients were less likely to prefer home death. Patients who had a co-resident caregiver or a caregiver who provided assistance with IADLs were more likely to prefer home death. Patients whose primary caregiver was not a spouse or child were less likely to prefer to die at home. The patient's health conditions that were associated with a reduced likelihood of wanting to die at home were (a) difficulty sleeping, (b) dry mouth, and (c) peripheral edema. Conversely, patients who experienced urinary incontinence on a daily basis were more likely to prefer home death. Other variables that were not significant with a preference for home death are listed in Tables 20 and 21 because the p-value is < 0.10. These variables were retained and included in the multivariate analysis examining factors associated with a preference for home death.

Table 20. Factors associated with a preference to die at home (binary)

		No		Yes					
Variable		N	%	N	%	Total	DF	χ^2	p-value
Health conditions									
Bloating	No	215	37%	373	63%	588	1	6.71	0.01
	Yes	63	49%	66	51%	129			
Nausea	No	187	36%	326	64%	513	1	4.09	0.04
	Yes	86	45%	106	55%	192			
Difficulty sleeping	No	148	34%	284	66%	432	1	10.66	0.00
	Yes	122	47%	139	53%	261			
Excessive sleep	No	220	42%	310	58%	530	1	7.32	0.01
	Yes	45	29%	108	71%	153			
Dizziness	No	191	36%	338	64%	529	1	4.77	0.03
	Yes	84	45%	102	55%	186			
Advanced directives									
Do-not-resuscitate	No	163	61%	104	39%	267	1	90.19	0.00
	Yes	113	25%	334	75%	447			
Do-not-intubate	No	191	55%	155	45%	346	1	70.88	0.00
	Yes	84	24%	266	76%	350			
Do-not-hospitalize	No	251	48%	276	52%	527	1	65.38	0.00
	Yes	21	13%	146	87%	167			
Do-not-sent-to-emergency	No	251	48%	272	52%	523	1	71.95	0.00
	Yes	20	12%	152	88%	172			
Estimated prognosis	No	17	22%	59	78%	76	1	12.42	0.00
	Yes	224	44%	289	56%	513			
Patient characteristics									
Live alone	No	253	37%	423	63%	676	1	7.48	0.01
	Yes	28	57%	21	43%	49			
Married	No	139	46%	162	54%	301	1	11.94	0.00
	Yes	142	33%	282	67%	424			
Widowed	No	207	39%	322	61%	529	1	0.11	0.74
	Yes	74	38%	122	62%	196			
Divorced	No	244	36%	425	64%	669	1	19.07	0.00
	Yes	37	66%	19	34%	56			
Caregiver characteristics									
Child caregiver	No	189	39%	293	61%	482	1	0.10	0.76
	Yes	92	38%	150	62%	242			
Spouse caregiver	No	152	43%	198	57%	350	1	6.08	0.01
	Yes	129	34%	245	66%	374			
Other caregiver	No	221	36%	395	64%	616	1	14.98	0.00
	Yes	60	56%	48	44%	108			
Live with caregiver	No	110	59%	78	41%	188	1	41.27	0.00
	Yes	171	32%	364	68%	535			
Provides IADL assistance	No	85	62%	52	38%	137	1	39.82	0.00
	Yes	190	33%	388	67%	578			
Strong supportive family	No	29	63%	17	37%	46	1	12.06	0.00
	Yes	251	37%	423	63%	674			

Continuous variables (see Table 21) were examined. Patients who preferred to die at home had tended to be older, were more likely to suffer from higher levels of ADL, IADL, and cognitive impairment, and typically scored higher on the Chess Scale. Higher scores on any of these scales are associated with a poor or worsening condition. Patient affect was examined and showed that patients who preferred to die at home scored higher on the self-reported mood items measuring depression, anxiety, and anhedonia.

Table 21. Factors associated with a preference to die at home (continuous)

	Preference for home death							
	No			Yes				
Variable	N	Mean	SD	N	Mean	SD	t-value	p-value
Age	283	69.14	14.03	447	73.09	13.01	-3.88	0.00
ADL[1]	269	1.06	1.79	405	2.22	2.19	-7.20	<0.01
IADL[2]	278	11.60	6.05	436	14.25	4.75	-6.51	<0.01
Chess scale	261	2.53	1.30	382	3.05	1.33	-4.90	<0.01
Pain scale	283	1.60	1.11	447	1.40	1.15	2.37	0.02
CPS[3]	267	0.75	1.30	413	1.14	1.72	-3.20	0.00
Self-reported mood	271	1.70	2.50	410	1.09	2.14	3.45	0.00

[1] ADL Hierarchy Scale; [2] interRAI ADL Scale; [3] Cognitive Performance Scale

Significant variables associated with preferred home death were then entered into a logistic regression equation. Data from 57% (632/1,115) of the home care patients were entered into the model, 61% (383/632) of the patients stated a preference to die at home. The remaining assessments were deleted due to missing information on the interRAI PC assessment instrument. The full model against a constant-only model was statistically reliable, $\chi^2(7, N= 632) = 176.43$, $p < 0.01$, indicating that the combined determinants reliably distinguished between patients who stated a preference to die at home from those who did not. The final model accounted for 24% of the variance ($r^2 = 0.24$) and a C-statistic of 0.80.

Table 22. Multivariate model showing factors associated with preferred place of death

Variable	DF	β	SE	χ^2	p-value	OR	LCI	UCI
Intercept	1	-3.58	0.61	34.25	<0.01			
Advanced directives								
Do-not-resuscitate (N2a)	1	1.59	0.26	38.44	<0.01			
Do-not-send-to-emergency (N2d)	1	1.09	0.29	14.22	0.00	2.96	1.68	5.21
Caregiver characteristics								
Caregiver provides IADL help	1	0.60	0.27	4.85	0.03	1.83	1.07	3.13
Live with caregiver	1	0.95	0.25	14.67	0.00	2.57	1.59	4.18
Home health aid	1	-0.15	0.07	5.02	0.03	0.86	0.76	0.98
Patient characteristics								
Age	1	0.02	0.01	9.00	0.00	1.02	1.01	1.04
ADL[1]	1	0.29	0.08	12.94	0.00			
Interaction								
Do-not-resuscitate by ADL impairment	1	-0.22	0.10	5.00	0.03			

[1]interRAI PC IADL Scale; ‡ reference group

The final model (Table 22) shows seven items associated with preferred home death. Patients whose primary caregiver was a co-resident or whose caregiver provided assistance with IADL to them were more likely to prefer to die at home. However, patients who received homemaking services from the CCAC were less likely to prefer home death. Also, patients who had completed advanced directives that included do-not-hospitalize orders or do-not-resuscitate orders were also more likely to have stated a preference to die at home. Patients who completed a do-not-resuscitate order were almost 3-times more likely to prefer home death. The presence of a do-not-send-to-emergency order was associated with a preference for home death however there was also an interaction between that variable and the measure of ADL impairment. A significant interaction was found between the completion of a do-not-resuscitate order and level of ADL impairment. Closer examination of this interaction shows that as ADL impairment increases, the likelihood that the patient will prefer home death decreases.

The final analysis examined preferred vs. actual place of death among terminally ill home care patients who had died. Just over 56% (249/442) of patients preferred to die at home. Patients who wished to die at home were more likely to do so (Table 23), whereas patients who did not wish to do so were less likely to die at home. There was significant agreement between preferred place of death and actual place of death (Kappa = 0.22, p = 0.05) among patients who stated a preferred place.

Table 23. Preferred vs. actual place of death

		Place of death							
		Other		Home					
Variable		N	%	N	%	Total	DF	χ^2	p-value
Prefer home death	No	79	62%	48	38%	127	2	31.17	<0.01
	Yes	80	32%	169	68%	249			
	Unknown	28	42%	38	57%	66			

Discussion

The wish to die at home has many factors associated with it. Similar to results reported by Stajduhar et al. (2008), just over half of patients preferred to die at home. Multivariate analysis shows that patients who are older and suffer higher levels of ADL impaired were more likely to prefer home death. Patients who complete advanced directives (e.g., do-not-resuscitate and do-not-send-to-emergency) were also more likely to prefer home death.

Patients who were more likely to prefer home death were more likely to have a caregiver who lived with the patient. Patients whose caregiver provided IADL care were more likely to prefer home death. This says volumes about the importance of the relationship between the patient and the caregiver and whether or not home death is preferred. It also shows that the preference for home death is largely dependent upon the patient's current situation and/or health. For example, some patients may wish to die at home but, for social or health related reasons, may realize that it is an unattainable goal. This relationship may be supported by the finding that the presence of homemaking services reduces the odds of preferring home death. If the caregiver is not comfortable providing end-of-life care to the patient because the patient/caregiver relationship falls outside the realm of what is considered appropriate or comfortable, the patient will not verbalize his or her wishes for home death. Similarly, if the patient relies on formal care (e.g., home nursing or homemaking services) then the patient may not be comfortable with dying at home.

The interaction between the presence of a do-not-resuscitate order and level of ADL impairment is unique. It indicates that the relationship of ADL impairment and do-not-resuscitate orders on preference for home death is not entirely direct, that those two factors are dependent on each other. It shows that among patients who completed a do-not-resuscitate order, the odds of preferring home death decrease with higher levels of ADL impairment.

The patient's preferred place of death appears to play a significant role in the location of his/her final place of death. Table 25 shows preferred versus actual place of death among home care patients who had died. A high proportion of home care patients who wished to die at home achieved that goal (68%). Of patients who indicated that they did not want to die at home, a large proportion had not died at home (62%). Even though the results are significant, it is interesting to note that 38% of patients who did not wish to die at home did in fact do so, and 32% of patients who wished to die at home had later died elsewhere. Even though there is a strong relationship between preferred place of death and actual place of death, much work remains to be done to improve rates of congruency. These results indicate that other factors can influence place of death.

A limitation of these analyses is that the patients' wish for home death, whether it is "yes" or "no," can change over time. Examining this aspect of preferred place of death using cross-sectional data was beyond the scope of this study. Perhaps some of the incongruent findings between preferred versus actual place of death were due to the fact that patients do change their minds, and that this was not captured by the interRAI PC assessment instrument. If this is the case, CCACs may be achieving higher congruency rates between preferred vs. actual place of death than what is shown here.

A second limitation is that some patients may not verbally state their wishes regarding their preferred place of death. Patients may feel that home death is not in the best interest of his or her caregiver, the patient may not have an informal caregiver that is available or able to provide that level of care at home. For personal reasons, the informal caregiver may not wish for the patient to die at home. In instances such as this, the patient may simply wish to remain at his or her home as long as possible.

To conclude, the final multivariate model explaining preference for home death is not all-encompassing. The large intercept indicates that it is not complete. Also, the interaction between do-not-resuscitate order and level of ADL impairment should be treated with caution in that this is a newly identified relationship and may be an anomaly in the data.

Study IV – Determinants of Home Death

This section examined the determinants of home death. Maintaining autonomy over one's place of death is important to many terminally ill patients receiving services from CCACs. Some patients wish to remain in their homes as long as possible and only choose to die at home under ideal circumstances. Other patients clearly intend to die at home but are unable to do so when circumstance dictates that they must be transferred to institutional care. This may occur for a number of reasons. For example, informal caregivers may become unable to cope with the demands of care. Or formal caregivers operating out of CCACs may be unable to meet the needs of the patient for budgetary reasons.

Earlier research has examined determinants of home death. Much of this research has focused on hospice care and hospital care. This study is unique in that it examined home death among terminally ill home care patients. This sample represents persons living in the community who rely on services provided by CCACs. This topic is important whereby it represents the means to promote dying in place.

Methods

Materials

The materials are the same as that used in section III. In addition to monitoring the health of patients who died in CCAC's care, the CCAC also followed patients discharged from service to alternate health care settings. The CCAC collected this information as part of normal practice.

Sample

Only patients who had a date of death recorded by the CCAC were included in the following analyses.

Results

Table 24 shows the demographic characteristics of the home care patients included in these analyses (n=559) that examined determinants of home death. The average age was 71 years (SD=13). The sample included an even distribution of males and females, 52% and 48%, respectively, the majority of which were either married (62%) or widowed (26%).

Table 24. Demographics of patient characteristics

Variable	Response	N	%
Patient characteristics			
Sex	Male	286	52%
	Female	264	48%
	Total	550	100%
Age	Mean *(SD; Min- Max; N)*	71.1	*(13.3; 19-101; 551)*
Marital status	Never married	30	5%
	Married/partner	341	62%
	Widowed	140	26%
	Separated/divorced	35	6%
	Total	546	100%
Living arrangement	Alone	84	17%
	With spouse	220	44%
	With spouse & other(s)	80	16%
	With child(ren)	81	16%
	With parent(s)	8	2%
	With sibling(s)	7	1%
	With other relative(s)	6	1%
	With non-relative(s)	19	4%
	Total	505	100%

Just over half of the patients died at home (56%) and over one third died in hospital (see Table 25). Note that a hospice centre was opened towards the end of the study so only 6%

had recorded a death in hospice care. This accounted for the low number of patients transferred to hospice care during the time of this study. How this may have influenced the outcome of the study is difficult to determine, it is likely that many of the patients transferred to hospice care would have otherwise have been transferred to hospital care, making it likely that the new hospice care centre had little effect on rates of home death.

Table 25. Location of death for palliative home care patients

Variable	Response	N	%
Location of death	Home	308	56%
	Hospital	206	37%
	Hospice	33	6%
	Retirement home	2	1%
	Total	550	100%

Terminal disease among the patients were predominantly cancer related (86%), many of whom had more than one diagnosis of cancer, (41%, see Table 26). Almost a quarter of all patients presenting with a cancer related diagnosis had malignant neoplasm of trachea and/or bronchus. Among patients presenting with non-cancer related diagnosis, coronary heart failure and renal failure were predominant, 18% and 15%, respectively.

Table 26. Presenting diagnoses of terminally ill home care patients who died

Diagnoses	N	%
Type of disease		
Cancer diagnoses	472	86%
Non-cancer diagnoses	79	14%
Total	551	100%
Cancer diagnoses		
1 Cancer related diagnosis	277	59%
2 Cancer related diagnoses	167	35%
3 Cancer related diagnoses	23	5%
4 Cancer related diagnoses	5	1%
Total	472	100%
Cancer classification		
Malignant neoplasm of trachea, bronchus, and lung	171	24%
Secondary malignant neoplasm of other specified sites	67	10%
Secondary malignant neoplasm of respiratory and digestive systems	65	9%
Malignant neoplasm of female breast	41	6%
Malignant neoplasm of pancreas	40	6%
Malignant neoplasm of prostate	32	5%
Malignant neoplasm of colon	31	4%
Secondary malignant neoplasm of other specified sites	27	4%
Malignant neoplasm of bladder	19	3%
Malignant neoplasm of liver and intrahepatic bile ducts	19	3%
Malignant neoplasm of esophagus	13	2%
Malignant neoplasm of rectum, rectosigmoid junction, and anus	12	2%
Other	161	23%
Total	698	100%
Non-cancer diagnoses		
Coronary heart failure	14	18%
Renal failure	12	15%
Other	53	67%
Total	79	100%

This section examined patient and caregiver characteristics as determinants of home death. The variable describing place-of-death was collapsed to compare patients who died at home to those who did not (e.g., hospital, hospice, or other). The predicted category is home death and the reference category is death at an institution. Table 27 shows the univariate binary variables that were associated with home death at the 0.10 level or less. Table 28 shows the univariate continuous variables that are associated with home death at the 0.10 level or less.

Table 27. Determinants of home death (binary)

		Died at home							
		No		Yes					
Variable		N	%	N	%	Total	DF	χ^2	p
Advanced directives									
Do-not-resuscitate	No	85	51%	83	49%	168	1	6.94	0.01
	Yes	123	38%	199	62%	322			
Do-not-intubate	No	124	52%	114	48%	238	1	14.11	< 0.01
	Yes	81	35%	151	65%	232			
Do-not-hospitalize	No	174	49%	180	51%	354	1	14.39	< 0.01
	Yes	26	27%	69	73%	95			
Do-not-send-to-emergency	No	172	49%	180	51%	352	1	11.98	< 0.01
	Yes	29	29%	70	71%	99			
Caregiver Factors									
Unable to continue providing care	No	206	42%	280	58%	486	1	4.66	0.03
	Yes	24	60%	16	40%	40			
Caregiver distress, Depression	No	185	43%	250	57%	435	1	1.07	0.30
	Yes	45	48%	48	52%	93			
Family overwhelmed	No	173	42%	236	58%	409	1	2.63	0.10
	Yes	57	51%	55	49%	112			
Co-resident caregiver	No	57	55%	47	45%	104	1	5.96	0.01
	Yes	180	42%	253	58%	433			
IADL help (*Primary caregiver)*	No	54	58%	39	42%	93	1	9.88	< 0.01
	Yes	176	40%	261	60%	437			
Patient characteristics									
Married	No	38	57%	29	43%	67	1	5.46	0.02
	Yes	204	42%	286	58%	490			
Widowed	No	182	44%	233	56%	415	1	0.11	0.74
	Yes	60	42%	82	58%	142			
Divorced	No	218	42%	303	58%	521	1	8.45	< 0.01
	Yes	24	67%	12	33%	36			
Prefer home death	No	105	55%	85	45%	190	1	23.87	< 0.01
	Yes	79	32%	168	68%	247			
Health Conditions									
Fatigue (Daily)	No	107	49%	112	51%	219	1	3.90	0.05
	Yes	128	40%	190	60%	318			
Urinary Incontinence *(Daily)*	No	198	47%	220	53%	418	1	7.65	0.01
	Yes	39	33%	79	67%	118			
Cancer diagnosis	No	24	30%	55	70%	79	1	6.70	0.01
	Yes	222	46%	261	54%	483			
Excessive sleep	No	158	47%	180	53%	338	1	4.53	0.03
	Yes	61	37%	105	63%	166			

Univariate binary variables that were associated with home death included advanced directives, patient characteristics, patient's health conditions, and caregiver characteristics. Taken advanced directives as whole, patients who complete advanced directives were more likely to die at home compared to those who did not. In this case, advanced directives included do-not-resuscitate orders, do-not-intubate orders, do-not-hospitalize orders, and do-not-send-to-emergency orders. Patients who were married were more likely to die at home and those who were divorced were less likely. Patients who desired home death were more likely (68%) to die at home compared to those who did not (45%).

Examining continuous variables in univariate analyses showed that ADL, IADL, CPS, and the amount of informal care time were significantly associated with home death (Table 28). Patients who died at home were significantly more functionally impaired (ADL & IADL) and suffered higher levels of cognitive impairment than patients who died elsewhere have. The amount of informal care time was also higher for patients who died at home. The length of time to death, or prognosis, was not significantly associated with home death. The average length of time to death was 51 days (95% CI 46-56 days, min=0, max=532).

Table 28. Determinants of home death (continuous variables)

	Home death							
	No			Yes				
Variable	N	Mean	SD	N	Mean	SD	t-value	p-value
ADL[1]	211	1.39	1.94	266	2.27	2.24	4.51	<.001
IADL[2]	234	12.93	5.24	299	14.77	4.45	4.38	<.001
CPS[3]	213	0.75	1.35	260	1.25	1.73	3.41	0.00
Informal care time[4]	219	21.78	18.17	278	26.83	21.17	2.81	0.01
Chess scale	213	3.04	1.15	273	3.25	1.25	1.91	0.06

[1] ADL Hierarchy Scale; [2] interRAI IADL Scale; [3] Cognitive Performance Scale; [4] Informal care time measured in hours reflecting the cumulative amount of care time provided over the previous 3 days

All variables significant at the 0.10 level or less were simultaneously entered into a logistic regression (Table 29). Additional variables that may possibly be of theoretical significance included age, sex (male, female) and the number of days until death (time). To avoid oversaturation, variables that were not significant were removed at each step.

Data from 67% (372/559) of the home care patients were entered into the model, 58% (215/372) of the patients died at home, the remaining died elsewhere. The remaining assessments (187/559) were deleted due to missing information on either the interRAI PC assessment instrument or the discharge abstract.

The full model against a constant-only model was statistically reliable, χ^2 (4, N= 372) = 47.78, $p < 0.01$, indicating that the combined determinants reliably distinguish between patients who died at home from those who did not. The final model accounted for 12% of the variance ($r^2 = 0.12$) (max rescaled $r^2 = 0.16$) and a C-statistic of 0.69.

Subsequent analyses examined differences between patients whose caregivers were able to continue to caregivers who were not. Data showed that caregivers who were unable to continue were caring for patients who were more ADL impaired (yes = 2.08 vs. no = 1.59), suffered higher levels of instability (yes = 3.31 vs. no = 2.73), and experienced higher levels of self-reported depression (yes = 2.22 vs. no = 1.27).

Table 29. Multivariate model examining factors associated with home death

Variable	DF	β	SE	χ^2	p-value	OR	LCI	UCI
Intercept	1	-0.40	0.17	5.32	0.02			
Patient characteristics								
Do-not-hospitalize (n2c)	1	0.67	0.30	4.98	0.03	1.95	1.09	3.50
Preference for home death (prefplace)	1	0.87	0.23	13.94	0.00	2.40	1.51	3.79
Caregiver characteristics								
Caregiver unable to continue (o4b)	1	-1.25	0.43	8.52	0.00	0.29	0.13	0.66
Health conditions								
Excessive sleep (C5JJ)	1	1.00	0.29	11.68	0.00	2.73	1.53	4.84

[1]ADL Hierarchy Scale; [2] Dummy variable comparing patients who were divorced or separated to everyone else.

The model showed 4 main determinants of home death. Patients who had completed do-not-hospitalize orders were 95% more likely to die at home. Consistent with earlier analyses, a stated preference for home death was associated with a greater likelihood (OR: 2.40) of home death. Patients who slept excessively were 2.73 times more likely to die at home. Finally, patients whose caregiver was unable to continue were 71% less likely to die at home.

Discussion

The main effects that increased the likelihood of home death included a) the wish to die at home, b) do-not-hospitalize orders, and c) excessive amounts of sleep. The single item that decreased the likelihood of home death was having an informal caregiver who was unable to continue providing care.

Patient's who wished to die at home were more than twice as likely to do so. The patient may be more adamant about home death and/or family and friends may be more supportive of the patient's final wishes. However, the measure used in these analyses require that the patient state his or her stated preference (home death or otherwise). Patients may not always enunciate their preference, especially when he or she knows that the primary informal caregiver is not in favour of home death. This relationship requires further research. Only one study examined the interplay between the patient's wishes for home death and the caregiver's wishes (Tang et a., 2005). Examining this relationship was beyond the scope of this study because of its sensitive nature.

The presence of a caregiver that is unable to continue decreases the likelihood of home death. The caregiver may be unable to cope with the physical, psychological, or emotional demands of care. The patient's primary caregiver may not favour home death for a number of reasons. For many people, the home is often considered a sanctuary and the thought of a family member or friend dying in this sanctuary may not bode well for co-resident caregivers. Caregivers may be hesitant to keep terminally ill family members or friends at home because the equipment necessary to do so and formal care required to keep the patient comfortable may be large or noisy and may be considered intrusive to the home.

Completion of a do-not-hospitalize order increases the likelihood of home death by 95%. This may be an alternative way for home care patients to convey their wishes without directly stating their preference for home death. However, the wish to not be hospitalized does allow for alternate places of death, for example, patients may prefer to die in hospice care. In this study, the likelihood of hospice care while receiving palliative home care was low because hospice care was unavailable to many of the home care patients because it was not offered until just before data collection was completed. It is likely that the majority of home care patients preferred not to be hospitalized with the idea of remaining at home as long as possible.

An brief qualitative analysis of each patients stated goals of care, where available, showed that regardless of preferred place of death, many of the patients preferred to stay home as long as possible. However, because stated goals were qualitative and not included on every assessment, stated goals were not included in the analyses. It does indicate that the preference to die at home verses the wish to remain at home represent two distinct concepts. The later does not necessitate that the patient also prefers to die at home but that he or she prefers to remain in comfortable and familiar surroundings rather than the institutional environment of a hospital. As stated earlier, hospice care was not available to many of the home care patients until the last two months of data collection.

Patients who slept excessively were more likely to die at home. It is likely that patients who sleep excessively also required less care. They may be sedated or highly medicated, causing drowsiness. Regardless of the reasons, the level of care that they require is lower. The dying process, in and of itself, can be terrifying for both the patient and the caregiver. However, a patient who sleeps excessively may not experience death in the same way as someone who is cognizant throughout the entire process. Similarly, the caregiver's experience would also be different. The demands of care may not be as high, in fact, they may be much lower.

The hypothesis stated that caregiver burden does play a significant role on place of death. Even though caregiver burden is not the sole determinant of home death, the results of this study support the role of caregiver burden on place of death. This role is unique whereby its relationship is dependent upon the ability of the caregiver to continue providing care.

The role of caregiver can often be an intensive task. In addition to caregiver workload, caregivers may experience a great deal of psychological distress as the patient transitions though the stages of terminal disease. This study found that a significant number of informal caregivers experienced caregiver burden in the form of psychological distress and that this distress impacted place of death. However, this relationship was also dependent on the amount of informal care time the primary caregiver provided.

The role of informal support is of increasing importance to health care in Ontario and elsewhere. Rising health care costs have lead to a general shift to community based programs like that of CCACs. Informal care is most often provided by family members and close friends. The shift toward downloading health care services to the community has had a direct impact on informal caregivers. The true effects of this impact remain to be seen.

The results of this study show that the downloading of care onto family and friends can impact whether or not a terminally ill home care patient dies at home. The threshold at which this happens is when caregivers feel unable to continue, distressed or depressed, or overwhelmed by the patient’s illness. However, the effect that caregiver burden has on home death is also influenced by the patients level of care. The patient’s ability to die at home may be jeopardized when the caregiver is depended upon for care but then perceives that care as burdensome.

CHAPTER IV

DISCUSSION

Summary

The right to die at home belongs to all Canadians. Ontario's CCACs support this right, and they have worked diligently toward achieving this goal for as many palliative home care patients as possible. The purpose of this study was to examine the role of caregiver burden on home death among home care patients receiving palliative care. The study began by validating the interRAI PC caregiver burden items against two established scales: the Caregiver Burden Scale and the Burden Interview. This study next developed the interRAI PC Caregiver Burden Scale using the interRAI PC caregiver burden items. Subsequent analyses examined the determinants of caregiver burden, the preference for home death, and the place of death; it then examined the role of caregiver burden on place of death.

This study found that approximately half of palliative home care patients died at home. Evidence suggests that current programs can be improved. To do this, CCACs must aid caregivers who are unable to continue providing care and treat patients/caregivers as entire units of care, thereby addressing the needs of both the caregiver(s) and the patient.

Central Findings

The interRAI PC Caregiver Burden Scale was developed from three of the items provided by the interRAI PC. Results of this study suggested that the interRAI PC Caregiver Burden Scale is an adequate measure of caregiver burden. The primary domain focused on by the interRAI PC Caregiver Burden Scale is psychological/emotional distress. Distress may include depression, distress, or feelings of being overwhelmed. To a lesser extent, this scale also determines the ability of caregivers to continue providing care to patients. Although face validity does support all three domains, perhaps additional questions need to be included in the interRAI PC to account for the multidimensionality of caregiver burden.

Many determinants of caregiver burden were identified by using univariate analyses. Multivariate analyses showed that the main determinants of caregiver burden were higher scores on the Chess scale and an interaction effect between the wish for hastened death and self-reported mood. The Chess Scale is designed to identify patients who are at risk of a serious decline in health; it reflects the overall stability of a patient's condition. Higher scores reflect conditions that are less stable and are more likely to result in an adverse outcome. The results of this study showed that the Chess Scale and caregiver burden are associated, consistent with earlier research showing the relationship between the health conditions of the patient and levels of caregiver burden (C. Given et al., 1993; Gott et al., 2004).

A meta-analysis of caregiver burden among dementia patient carers found evidence of an association between the number of caregiver tasks and level of physical impairment associated with caregiver burden (Pinquart & Sorensen, 2003). This finding also appeared consistent with this sample. The patients who scored higher on the Chess Scale typically required higher levels of care and suffered lower levels of physical functioning, whereas the patients whose health was unstable or prone to change may have been more difficult to care for or the caregiver may have lacked the knowledge to care for someone with that condition.

The relationship between patients' self-reported mood and caregiver burden was complicated but is also supported by earlier research (Carrlsson & Rollison, 2003). The results from this study suggest that this relationship is moderated by the wish for hastened death. The odds of caregiver burden were higher for patients who reported higher levels on self-reported mood; however, this effect was only found among patients who indicated a wish for hastened death. Earlier research has shown that the wish for hastened death is closely associated with depression (Chochinov et al., 1995, 1999; Ganzini et al., 1994); feelings of dependency (Morita et al., 2004; Wilson et al., 2007); and the perception of caregiver burden (Kelly et al., 2002, 2003; Morita et al.). A full explanation of the nature of this relationship is beyond the scope of this paper; however, it does illustrate the intricate relationship between patients and caregivers. It reinforces the notion that because their needs often are co-dependent, patients and caregivers must be treated as a unit of care rather than two independent entities.

The main purpose of this manuscript was to examine the determinants of home death and the relationship of caregiver burden to home death. However, a primary determinant of place of death is the patient's preference for home death (Cantwell et al., 2000). This manuscript found that 50% of palliative home care patients prefer to die at home. This was much higher than the 37% reported by Karlsen and Addington-Hall (1998) but closer to the 47% reported by Cantwell et al. (2000). The results showed that the current study's patients who indicated a preference to die at home were often more IADL impaired, whereas ADL and cognition had little, if any, effect. Patients who complete do-not-resuscitate orders and do-not-hospitalize orders were also more likely to prefer home death. This indicates that patients who prefer to die at home may be more able to deal with their own disease and mortality.

Patients who did not prefer to die at home were more likely to be cared for by someone who was not a spouse or a child, they may be more comfortable receiving intimate care from their immediate family (Gott et al., 2004). These results were not surprising but once again illustrate the important role of caregivers in end-of-life care. The relationship between a patient and his or her spouse or child is significantly different from that of other family members or friends. The nature of caring for someone who is in need of palliative care may be demand, and the care that is required may be more intimate (e.g., feeding and bathing), often falling outside the comfort boundaries of that relationship.

Earlier research that examined the wish to die at home ranged from 80% among the general population (Romanow, 2002) to 38% among the terminally ill population (Karlsen & Addington-Hall, 1998). These results were consistent with the hypothesis that home death may be idealized among the general population. When faced with the prospect of death, many people would likely chose not to die at home. However, a high number of palliative home care patients in the current sample indicated that they would choose to die at home (50%). This may reflect the high level of home care services directed and offered by CCACs. Earlier research by McWhinney et al. (1995) reported that only 28% of the participants achieved home death. The sample investigated by the current study was considerably higher; in fact, 56% died at home, 37% died in hospital, and 6% died in hospice.

Congruency between preferred versus actual place of death was favourable among this study sample. The findings showed that 68% of patients who wished to die at home managed to do so. Earlier research by Tang and McCorkle (2003) found that only one third of the patients in their study who expressed a wish to die at home managed to do so while 55% of home care patients who did not wish to die at home did. Determining congruence is difficult because preferences can change as prognosis and health conditions fluctuate. For example, the prospects of dying at home may become less favourable if dyspnea becomes overwhelming of physical functioning becomes poor. Whether the patient remains at home or dies at home may be in the hands of the primary caregiver.

The role of excessive sleep has not been examined in earlier research. In fact, few studies have examined the role of individual health conditions on place of death. Perhaps fatigued patients sleep excessively, making them easier to care for. They may also be on more medications, including sedatives. How medication influenced place of death was not examined by this manuscript. The most likely explanation is that patients who sleep excessively are also easier to care for and subsequently may remain at home longer.

Preference for home death and do-not-hospitalize orders reflect the patients' goals of care. It is important that these goals be completed, recorded, and included in the general care plan. It is also important that these orders influence place of death. Patients who state a preference to die at home may be more inclined to complete advanced directives (e.g., do-not-resuscitate order and/or do-not-hospitalize order). These instructions, in turn, are followed to the best of the ability of the assigned case manager.

Although an earlier study found caregiver burden to influence place of death (Cameron et al., 2002), this study was the first to focus on this relationship. The relationship between these two items seems logical, given that most terminally ill home care patients cannot remain at home without the assistance of competent primary caregivers. Although the interRAI PC Caregiver Burden Scale was not related to place of death, this study did find that patients whose caregivers were unable to continue providing care were less likely to die at home. Experiencing psychological distress such as depression, anger, or feelings of being overwhelmed did not influence place of death. Subsequent analyses showed that caregivers who were unable to continue cared to patients who suffered higher levels of ADL impairment and higher levels of instability, and experienced higher levels of self-reported depression. These results may help CCACs identify patient/caregiver dyads who are at risk of incongruent place of death and focusing their efforts on helping patients complete advanced directives and ramping up home care services.

Limitations

A number of limitations were identified. For example, the first study relied on patients and caregivers volunteers. For this reason the sample may be biased. Although there is no way to determine if this is in fact the case, anecdotal evidence suggests that case managers only approached patient/caregiver dyads whose health was relatively good. However, this was the protocol set out by the ethics committee. Unfortunately this is one of the realities of researching involving vulnerable populations like terminally ill patients and their caregivers.

A second limitation was the comparison of measures. The interRAI PC relied on proxy measures of caregiver burden while the caregiver survey was self-report. This may account for the low correlation between the interRAI PC caregiver burden items and the caregiver burden survey. A review examining the reliability of proxy measures by McPherson and Addington-Hall (2003) found that high levels of accuracy can be achieved when measuring quality of services and observable symptoms. Accuracy tends to be lower when measuring pain, anxiety, or depression. Some of the questions asked by the caregiver survey were sensitive and may have been difficult to answer honestly. Proxy measures may have provided a more accurate measure of burden in those instances. For example, current health, decline in health, ability of caregiver to continue providing care may have been more suitably determined by a proxy.

A primary limitation to this manuscript was its use of administrative data. Missing data was common because they were collected as part of the patients overall care plan. Assessments with missing information were examined and compared to assessments entered into the model.

No differences were found to suggest that the findings could not be generalized beyond those included in the model. However, the use of administrative data also could be considered a positive attribute. Many researchers have experienced difficulty extracting data from this population, so the use of administrative data allowed this researcher to avoid inconveniencing this already distressed population.

Although it may be reasonable to generalize the findings to other CCACs or similar community programs, it may be difficult to generalize the findings beyond this group of home care recipients. Personal communications with palliative care nursing staff at the cancer centre estimate that 90% of cancer patients subscribe to home care services.

Implications

From the perspective of the patient, the implications of this study are important to their level of autonomy and their ability to achieve their personal goals of care, whether it be to remain at home as long as possible; to die at home; or to die in alternate settings (hospital, hospice, long-term care). Home care agencies need to determine the wishes of their patients and include those wishes in the care planning model. This can be done by completing advanced directed as soon as possible. Whether patients wish to die at home or elsewhere, caregiver burden is an important issue.

This study showed three main determinants of caregiver burden, one through main effects (Chess scale) and the other two through an interaction (self-reported mood & wish for hastened death). Higher levels on the Chess scale are related to higher levels of caregiver burden. The Chess scale is a measure for risk of decline. It is used to identify patients who may be at risk of decline or to minimize potential problems that may occur.

For caregivers, high levels of burden represent the negative aspects of providing care to terminally ill family members or friends. However, with appropriate resources, much of the psychological/emotional distress can be reduced. For example, caregivers may be uncomfortable providing certain type of care (e.g., toileting and bathing) but may take great pleasure in providing other types of care (e.g., feeding and visiting). It is up to the CCACs to ensure that the needs of patients and caregivers are being met. It is important to consider the patient/caregiver relation as a dyad of care rather than treat each independently.

Home care agencies must be able to identify caregiver burden and assign the appropriate resources necessary to reduce the potential for burden, whether this means reducing the overall level of informal care required or supporting caregivers with information about patients' illnesses and/or caregiving techniques. These are the types of services that fall under the mandate of CCACs.

CCACs will need to consider the physical, psychological, and social needs of the patients when determining the level of care required for the patients to remain at home. Because of fiscal restrictions, it is likely that not all of the dyad's needs could be met; however, by targeting specific areas that are important to patients and the caregivers, congruence between preferred versus actual place of death can be achieved.

For the patients, home death can mean achieving a "good death" that includes dying in comfortable surroundings with close family members and friends their side. It may not be ideal for everyone; for some, death may be approached under heavy sedation or surrounded by machines in an institutional setting.

From a caregiver's perspective, the death of a family member or a friend is considered one of the most difficult life events to experience. Some caregivers may not believe that home is the ideal place of death. Care time required by patients may increase dramatically in the last few days of life. Caregivers who see this exponential need for care may feel burdened and, therefore, may be less likely to favour home death.

The relationship between care time and caregiver burden requires further investigation. For example, how does the effect of burden change for caregivers who provide 16 hours of care per day or more for a long period of time compared to that of caregivers who are required to provide that level of care only in the last few days of life?

The mandate of CCACs is to help patients meet their goals of care, so improving congruency between preferred versus actual place of death is important to this concept. However, meeting these goals is not solely dependent on the use of formal care; rather, it often depends on willing and able informal caregivers.

Conclusions

The results of this paper showed that caregiver burden does influence place of death, thus supporting the notion that the needs of caregivers also should be examined when determining the needs of patients and that patients and caregivers should be considered a unit of care. The findings also suggested that the psychological/emotional needs of the patient/caregiver dyad need to be addressed.

To conclude, palliative home care serves as a substitute for institutional care, whether it is hospital, hospice, or long-term care. This substitute serves to replace formal care with informal care. Although the intentions are good, problems can arise when informal caregivers are not available or able to provide care. Home care agencies must bear in mind that caregivers’ abilities may fall short of what is needed to support terminally ill family members or friends at home. Unlike home nursing staff and personal support workers, informal caregivers do not possess the standardized skills held by those professionals. By treating the patient/caregiver dyad as a unit of care rather than considering only the patient, home care agencies may become more capable of determining the needs of patients while recognizing the abilities of caregivers. This may reduce the likelihood of caregiver burden and help patients reach their goals of care.

A number of recommendations can be made to CCACs. First, existing regulations determining service maximums must be reviewed. Although service maximums can be waived when appropriate, such as during the final days of life of a patient, some circumstances demand higher rates of formal care earlier during the care period. CCACs need to mobilize assistance for informal caregivers in an effort to prevent caregiver distress and minimize physical decline. An assessment of caregivers' needs must be determined using a standardized approach, thus facilitating the early detection of caregiver burden. Bridging the connection between community support and hospice care may be beneficial to both patients and caregivers in reducing the barriers to home death.

GLOSSARY OF TERMS

interRAI[5]
is a non-profit organization of over 20 researchers that are committed to improving health care. Their goal is to promote evidence-based clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of persons served across a variety of health and social services settings.

Case Manager
Is someone who works at the CCAC. It is the person who determines the patient's eligibility for services.
CCAC
Community Care Access Centre – is an organization that determines eligibility for services and arranges delivery of home care services to patients in Ontario.

Informal Support
Can be a family member or friend that helps the patient with assistance. This can include any unpaid caregiver.

interRAI Palliative Care Instrument[6]
The interRAI Palliative Care (interRAI PC) is a comprehensive, standardized instrument for evaluating the needs, strengths, and preferences of those in palliative care or hospice settings. The inter*RAI* PC has been designed to be compatible with other internationally-used inter*RAI* instruments for long-term care facilities, home care, community mental health, in-patient mental health, acute care, and post-acute care. The compatibility of assessment elements improves the continuity of care through a seamless health assessment system across multiple settings, and promotes a person-centred approach to care.

Objective Burden
Is the tangible effects that caregiving has on the caregiver. It includes infringement on work, privacy, recreation, and vacation.

Outcome Measure
Is an algorithm that measures changes in status, these measures are comparable to the "gold standards" used in the industry.

Subjective Demand Burden
Is the degree to which the caregiver perceives the role of caregiving as demanding
Subjective Stress Burden

Subjective Stress Burden
Is the stress associating with caregiving.

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[5] Taken from the interRAI.org website
[6] The following description was taken from the User's Guide for the inter*RAI* Palliative Care (inter*RAI* PC)

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APPENDIX

A) CAREGIVER SURVEY

B) PILOT STUDY MATERIAL

C) INFORMATION LETTER AND CONSENT FORM – CCAC

D) INFORMATION LETTER AND CONSENT FORM – CLIENT INFORMATION

E) INFORMATION LETTER AND CONSENT FORM – CAREGIVER INFORMATION

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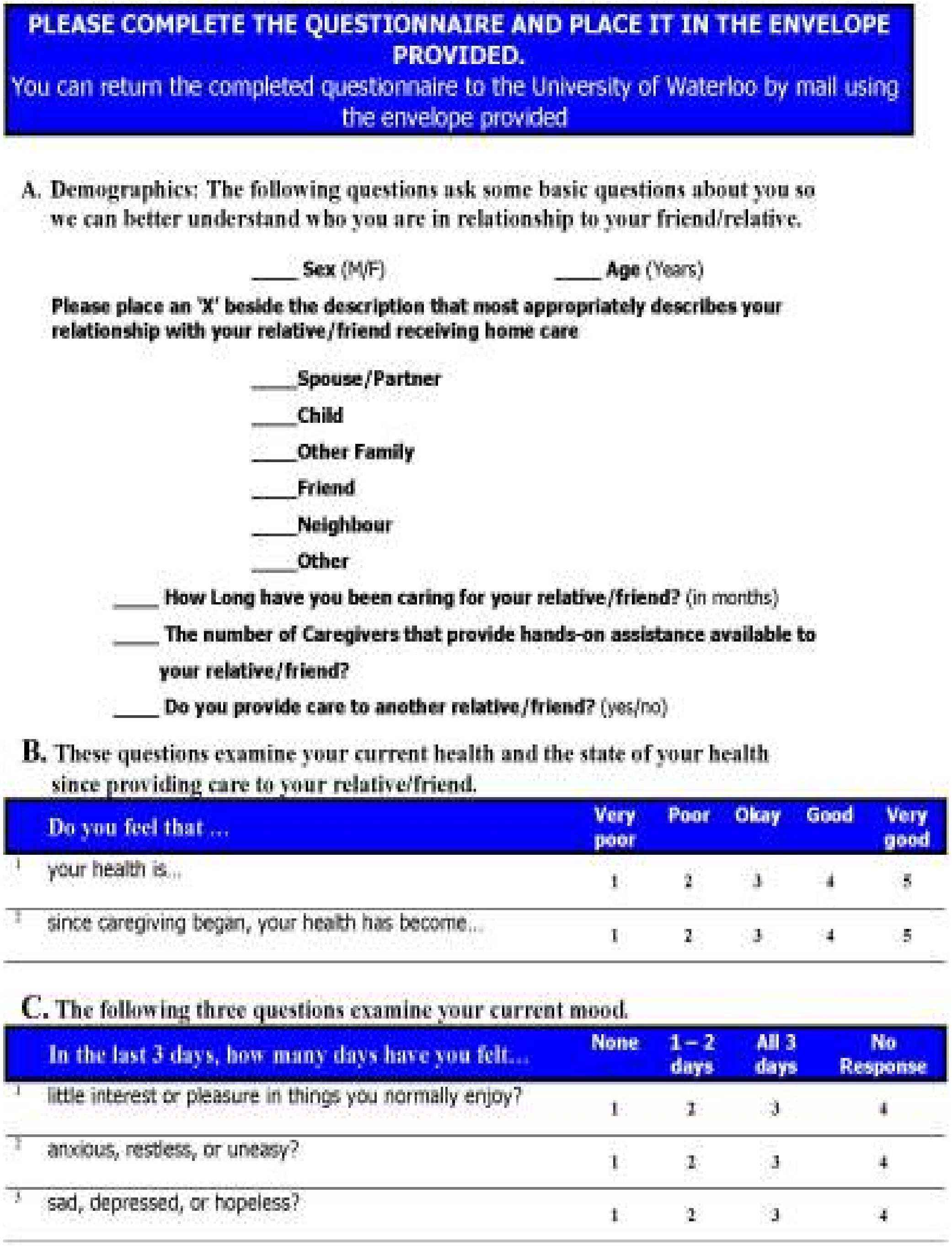
APPENDIX A – CAREGIVER SURVEY



PLEASE COMPLETE THE QUESTIONNAIRE AND PLACE IT IN THE ENVELOPE PROVIDED.

You can return the completed questionnaire to the University of Waterloo by mail using the envelope provided

A. Demographics: The following questions ask some basic questions about you so we can better understand who you are in relationship to your friend/relative.

____ **Sex** (M/F)

____ **Age** (Years)

Please place an 'X' beside the description that most appropriately describes your relationship with your relative/friend receiving home care

____**Spouse/Partner**
____**Child**
____**Other Family**
____**Friend**
____**Neighbour**
____**Other**

____ **How Long have you been caring for your relative/friend?** (in months)

____ **The number of Caregivers that provide hands-on assistance available to your relative/friend?**

____ **Do you provide care to another relative/friend?** (yes/no)

B. These questions examine your current health and the state of your health since providing care to your relative/friend.

	Do you feel that ...	Very poor	Poor	Okay	Good	Very good
1	your health is...	1	2	3	4	5
2	since caregiving began, your health has become...	1	2	3	4	5

C. The following three questions examine your current mood.

	In the last 3 days, how many days have you felt...	None	1 – 2 days	All 3 days	No Response
1	little interest or pleasure in things you normally enjoy?	1	2	3	4
2	anxious, restless, or uneasy?	1	2	3	4
3	sad, depressed, or hopeless?	1	2	3	4

D. **Since you began caregiving, how has assisting or having contact with your relative/friend affected the following aspects of your life?**

	Do you have…	A Lot Less	A Little Less	The Same	A Little More	A Lot More
1	time to yourself?	1	2	3	4	5
2	stress in your relationship with your relative/friend?	1	2	3	4	5
3	personal privacy?	1	2	3	4	5
4	attempts by your relative to manipulate you?	1	2	3	4	5
5	time to spend in recreational activities?	1	2	3	4	5
6	unreasonable requests made of you by your relative/friend?	1	2	3	4	5
7	tension in your life?	1	2	3	4	5
8	vacation activities and trips?	1	2	3	4	5
9	nervousness and depression concerning your relationship with your relative/friend?	1	2	3	4	5
10	feelings that you are being taken advantage of by your relative/friend?	1	2	3	4	5
11	time to do your own work and daily chores?	1	2	3	4	5
12	demands made by your relative/friend that are over and above what s/he needs?	1	2	3	4	5
13	anxiety about things?	1	2	3	4	5
14	time for friends and other relatives?	1	2	3	4	5

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E. The purpose of the following questions is to examine your feelings as they relate to your relative/friend.

	Do you Feel…	Never	Rarely	Sometimes	Quiet Frequently	Nearly Always
1	that because of the time you spend with your relative/friend that you don't have enough time for yourself?	1	2	3	4	5
2	stressed between caring for your relative/friend and trying to meet other responsibilities (work/family)?	1	2	3	4	5
3	angry when you are around your relative/friend?	1	2	3	4	5
4	that your relative/friend currently affects your relationship with family members or friends in a negative way?	1	2	3	4	5
5	strained when you are around your relative/friend?	1	2	3	4	5
6	that your health has suffered because of your involvement with your relative/friend?	1	2	3	4	5
7	that you don't have as much privacy as you would like because of your relative/friend?	1	2	3	4	5
8	that your social life has suffered because you are caring for your relative/friend?	1	2	3	4	5
9	that you have lost control of your life since your relative/friend's illness?	1	2	3	4	5
10	uncertain about what to do about your relative/friend?	1	2	3	4	5
11	you should be doing more for your relative/friend?	1	2	3	4	5
12	you could do a better job in caring for your relative/friend?	1	2	3	4	5

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F. **The following 5 questions examine your overall satisfaction with life. They include five statements that you may agree or disagree with. Using the 1 - 7 scale below indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.**

Do you feel that…	**Strongly Disagree**	**Disagree**	**Slightly Disagree**	**Neither Agree Nor Disagree**	**Slightly Agree**	**Agree**	**Strongly Agree**
in most ways my life is close to my ideal	1	2	3	4	5	6	7
the conditions of my life are excellent	1	2	3	4	5	6	7
I am satisfied with my life	1	2	3	4	5	6	7
so far I have gotten the important things I want in life	1	2	3	4	5	6	7
if I could live my life over, I would change almost nothing	1	2	3	4	5	6	7

Date Completed (**MM/DD/YYYY**)

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE
YOUR CONTRIBUTION IS GREATLY APPRECIATED!

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APPENDIX B – PILOT STUDY MATERIAL

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SCRIPT INTRODUCING THE PILOT STUDY TO THE PILOT STUDY PARTICIPANTS

- Thanking you for coming today.
- This study is being conducted as part of my doctoral degree.
- I am working under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo.

What is the pilot test about?

- The reason why I asked you to be here today is to pilot test of the information letter and caregiver survey to ensure that materials used in the main study are clear, easy to read and understand.

What will I be asked to do?

- If you choose to participate, you will be asked to review the study materials. The materials include two Information Letters, one for the home care client and one for the primary caregiver, and a caregiver survey about the experiences of the caregiver.
- I will also ask you a few questions about the study materials.
- Afterwards I will ask you to participate in a discussion about your reactions to the letters and survey.
- The study materials may not apply to you, however, you will be asked to read the letters and complete the survey from the perspective of a person who is caring for someone, such as a spouse, receiving home care.
- The questions are quite specific and some are very personal. For example, they ask whether you feel uncertain about what to do about your relative, whether you have enough time for yourself, whether you have tension in your life, and about your perception of your own health.
- The entire process should last between 1 to 2 hours.
- If you decide to proceed, please complete the attached consent forms (2 forms).
- The first consent form is for your own personal records, the second is for my records.

Can I change my mind about participating in this study?

- Participation in this project is voluntary. You can choose not to answer questions, and if you wish, you can withdraw from participation at any time.

Will information be kept confidential and who will see my responses?

- All information will be kept confidential.
- Any information that you may be privy to during the discussion should be kept confidential.
- The data collected through this study will be kept for a period of 7 years in a locked, secure location at the University of Waterloo. Data will be incinerated after 7 years.

- The only persons who will see your responses are the researchers. Your names will be withheld from all published sources – verbal or written .

Who can I contact if I have questions or concerns?

- If you have any questions after participating in this study, or would like additional information, please feel free to contact me or Professor Trevor Smith, our contact information is listed on your copy of the consent form.
- I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo.
- Please contact Dr. Susan Sykes in the Office of Research Ethics should you have any comments or concerns resulting from your participation in this study. Her contact information is listed in the Information Letter.

Executive Summary

- Whether or not you choose to participate in the project, I invite you to review the executive summary upon completion of this research project.
- You can contact me to obtain a copy of the Executive Summary.
- It is expected that the project will be completed by spring of 2008.
- I remind you that the final decision about participation is yours.

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University of Waterloo

Department of Health Studies and Gerontology

Faculty of Applied Health Sciences

University of Waterloo
200 University Avenue West
Waterloo, Ontario, Canada
N2L 3G1

519-885-1211 or 519-888-4567
Fax 519-746-2510

March 29, 2007

I would like to begin by first thanking you for your consideration in participating in the pilot test. This study is being conducted as part of Peter Brink's doctoral degree under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo.

What is the pilot study about?

The pilot test is intended to examine the study materials that will be used by a community care access centre (CCAC). The study materials include two Information Letters and one Caregiver Survey. This is an important part of my study, it hopes to ensure that materials used in the main study are clear, easy to read and understand.

The overall objective of the project is to look at how the experiences of family members or friends relate to the experiences of home care clients.

What will I be asked to do?

If you choose to participate, your involvement includes reviewing two Information Letters, completing a survey concerning the caregiver's experiences, and participating in a discussion that focuses on your opinions about and reactions to the letters and survey. If you decide to proceed, please complete the attached consent forms (2 forms). The first consent form is for your own personal records, the second is for the researchers.

Completion of the survey is expected to take about 10 to 20 minutes of your time. Please understand that the research materials may not apply to you, however, you will be asked to read the letters and complete the survey from the perspective of a person who is caring for someone, such as a spouse, receiving home care from the CCAC. Therefore, the questions may be hypothetical at this point, they are quite specific and some are very personal. For example, they ask whether you feel uncertain about what to do about your relative, whether you have enough time for yourself, whether you have tension in your life, and about your perception of your own health. After reviewing the study materials, you will be asked to participate in a 30-40 minute discussion of the letters and survey that will include 5 other people participants.

Can I change my mind about participating in this study?

Participation in this project is voluntary. You can choose not to answer questions, and if you wish, you can withdraw from participation at any time.

Will information be kept confidential and who will see my responses?

All information you provide will be considered confidential. Please be advised that any information that you may be privy to during the discussion should also be kept confidential. The only persons who will see your responses are the researchers. The data collected through this study will be kept for a period of 7 years in a locked, secure location at the University of Waterloo. It will be confidentially shredded after 7 years.

Who can I contact if I have questions or concerns?

If you have any questions about participating in this study, or would like additional information, please feel free to contact me or Professor Trevor Smith at 519-888-4567 ext. 35879.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. Please contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567 Ext. 36005 should you have any comments or concerns resulting from your participation in this study.

Will the results of the study be available to me?

Whether or not you choose to participate in the project, I invite you to review the Executive Summary upon completion of this research project. You can contact me (Peter Brink) to obtain a copy of the Executive Summary, it is expected that the project will be completed by early spring of 2008.

Thank you in advance for your interest in this project.
Sincerely,

Peter Brink
Health Studies & Gerontology
University of Waterloo

Contact Information:

Dr. Trevor Smith
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CONSENT OF PARTICIPANT – Pilot Study

I have read the information presented in the information letter about this study being conducted by Peter Brink under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study at any time.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that I may contact the Director, Dr. Susan Sykes at the Office of Research Ethics at 519-888-4567 ext. 36005 if I have any comments or concerns resulting from my participation in this study.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Print Name ____

Signature of Participant ______________________________

Date ____

Witnessed ____

If you have any questions or comments regarding the study
Please feel free to get in touch with my supervisor using the contact information below.

Contact Information:

Dr. Trevor Smith
Health Studies & Gerontology
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200 University Ave West,
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With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Print Name ____

Signature of Participant ______________________________

Date ____

Witnessed ____

If you have any questions or comments regarding the study
Please feel free to get in touch with my supervisor using the contact information below.

Contact Information:

Dr. Trevor Smith
Health Studies & Gerontology
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APPENDIX C – INFORMATION: CCAC

University of
Waterloo

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Faculty of Applied Health Sciences

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Waterloo, Ontario, Canada
N2L 3G1

519-888-4567
Fax 519-746-2510

May 25, 2007

This study, The Impact of Formal and Informal Care and Caregiver Burden on Place of Death in Palliative Home Care, is being conducted to fulfill the thesis requirement of Peter Brink's doctoral degree. This study is being supervised by Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo. Contact information for the researchers listed is provided below.

INTRODUCTION:

I would like to begin by first thanking you for your consideration in participating in this research project. This project intends to identify the needs of palliative care clients and their caregivers and to help community care access centres (CCAC) to meet those needs. This research project aims to determine how to help terminally ill home care clients achieve their preferred place of death by helping family and friends to care for their dying family member/friend. The results of this study may lead to recommendations to reduce levels of burden.

The Hamilton Niagara Haldimand Brant (HNHB) CCAC was selected to participate in this research project because of its continuing use of the interRAI - Palliative Care (interRAI PC) instrument, making it an ideal location for this research project. However, we do understand that you and your staff are extremely busy. As such, we will try to minimize the impact of conducting the study on the everyday activities of case managers. This is possible because: a) the interRAI PC is currently used by you, b) much of the health care information that will be requested from you is already collected as part of normal practice, and c) case managers who will be involved have already been trained to assess clients using the interRAI PC.

Upon completion, this study will provide the HNHB CCAC with an Executive Summary detailing the results of the study. The anticipated completion date is December 2007. The Executive Summary is expected to be available to you by early spring of 2008.

OBJECTIVES:

The aim of the proposed research is four fold. First, it will confirm the caregiver burden items in the interRAI Palliative care with that of the Caregiver Burden Scale. The second substudy will examine the determinants of caregiver burden. The third substudy will examine the determinants of place of death and congruency between preferred vs. actual place-of-death. The final substudy will examine the role of caregiver burden as a mediator between preferred vs. actual place-of-death.

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METHODS:

The proposed research is a prospective cross sectional study. It will employ scales measuring caregiver burden (Montgomery Caregiver Burden Scale and the Zarit Burden Scale), the interRAI Palliative Care instrument, CMIS data, and Discharge abstracts.

Primary data will be collected directly from the primary caregiver. This substudy (substudy I) is expected to take 3 months. In addition to normal practice, the case manager will be asked to recruit the primary caregiver of terminally ill home care clients when they enter the home to evaluate the home care client. Primary caregivers will be asked to complete the caregiver survey. The caregiver survey includes the Montgomery Caregiver Burden Scale and the Zarit Burden Scale. Caregiver who agree to participate will be asked to return the caregiver survey by mail.

Secondary data (substudies II, III, IV) will include interRAI PC assessments, CMIS data, and Discharge abstracts from all home care clients receiving in-home palliation from the HNHB CCAC over one years time (August 2006 to August 2007).

THE inter*RAI* PALLIATIVE CARE?

The inter*RAI* PC is an evolving, client-focused assessment instrument for patients/clients receiving palliative/end-of-life care in either the community (home care) or institutional (hospital, complex continuing care, long-term care, and hospice palliative care) setting (http://www.interrai.org/section/view/?fnode=18).

WHAT IS THE CAREGIVER BURDEN SURVEY?

The Caregiver Burden Scale is a multidimensional scale that was initially developed by Montgomery (1985) as a scale to assess objective and subjective caregiver burden. It was later modified to improve parsimony (6 questions were dropped). It now measures three domains of burden: objective burden, subjective stress burden, and subjective demand burden. The Zarit Burden Scale is the gold standard for measuring caregiver burden. The version of the Zarit Burden Scale that will be used is the shortened version (from 21 items to 14 items).

DATA COLLECTION/PROCESSING:

interRAI Palliative Care

The HNHB CCAC will be asked to assess new clients entering service (palliative care) or existing clients as per their current practice. For each client, the initial (Time 1) assessments will be completed within the first 7 days of admission/entry into the palliative care program. Subsequent assessments will only be completed if the client is still receiving home care at 45 days, 6 months, and 1 year. Additional assessments will be required in the event of a significant change in condition. These conditions represent your current practices at the HNHB CCAC.

Consent

No clients will be approached about the study if the primary caregiver is not present. The CCAC case manager will complete the assessment of the client as per usual practice. Upon completion of the assessment, the client will be approached about this study by using the script provided. The client will be informed that participation is voluntary and non-participation will not influence the services received. The client will be furnished with the Information Letter and be given adequate time to come to a decision about participation. Clients who agree to participate will sign two consent forms, one for his/her own records and one for the researchers. If the client agrees to participate, the CCAC case manager will approach the client's primary caregiver.

The primary caregiver will be approached about the study with the script provided. The CCAC case manager will ensure that the primary caregiver understands that participation is voluntary and non-participation will not influence the services the client receives. The primary caregiver will be furnished with the Information Letter and be given adequate time to come to a decision about participation. Any primary caregiver who agrees to participate will sign two consent letters, one for his/her own records and one for the researchers.

The CCAC case manager will collect any signed consent forms (client & primary caregiver) and forward them to the researchers at the University of Waterloo.

Caregiver Survey
The CCAC will be asked to identify the client's primary caregiver and present the caregiver (*when present*) with a package containing a) an invitation to participate in the project, b) a consent form, c) a caregiver survey, and d) a postage paid, return envelope. Caregivers who participate will be asked to return completed forms by mail directly to the University of Waterloo.

Place & Date of Death
The CCAC will be asked to provide each client's date and place (home vs. institution) of death. If applicable, the participating CCAC is also asked to provide the date the client is transferred to hospice or re-admitted to home care. Inclusion criteria for this study will be any adult (18 years or older) client receiving palliative home care by the CCAC.

CMIS Data
Finally, the CCAC will be asked to provide information on the type and level of formal care provided to their palliative home care clients.

POTENTIAL HARM:
There are no known harms associated with participating in this research project. However, there is the potential that one or more unknown harms may exist.

POTENTIAL BENEFITS:
There are no known associated benefits to participating in this research project. To our knowledge, the HNHB CCAC will not benefit directly from participation in this research.

CONFIDENTIALITY:
Confidentiality will be respected. Information that discloses you or your client's identity will be withheld from any published material (verbal or written). Information sent to the University of Waterloo will be de-identified upon arrival. All Information on health will be stored in a

secure, locked location at the University of Waterloo for 7 years, when it will be confidentially shredded. Electronic data will be held on a secure server indefinitely.

DATA FLOW:

Secondary Data. CCAC case managers will continue to collect interRAI PC data, discharge information, and CMIS data from new and existing clients in the HNHB CCAC's care during regular assessment intervals outlined by the participating CCAC (Time 1 assessment Battery = inter*RAI* PC) . For example, CCAC case managers collect inter*RAI* PC data within 7 days of entry, 45 days post-entry, 6 months, and one year after entry into the palliative care program (as part of normal practice by the CCAC). Dates and place of death, along with CMIS data will be maintained as per normal CCAC practice.

Primary Data. CCAC case managers will identify and distribute to primary caregivers the caregiver burden packages containing the caregiver survey, consent forms, information letter, and return envelope. Client/caregiver dyads will not be approached if the primary caregiver is not present or if the primary caregiver is not 18 years of age or older or does not speak English. The CCAC case manager will distribute the Information Letters and collect the signed consent forms destined for the researchers. The CCAC case manager will forward the signed consent forms to the researchers.

For tracking purposes, a unique identifier will be assigned to each caregiver package. This same unique identifier will also be affixed to the interRAI PC by the researchers. Therefore, in addition to the caregiver package, the interRAI PC will also be provided by the researchers for the duration of substudy I (3-months). The case manger will ask participating caregivers to return the caregiver burden inventory package by means of a postage paid, return envelope.

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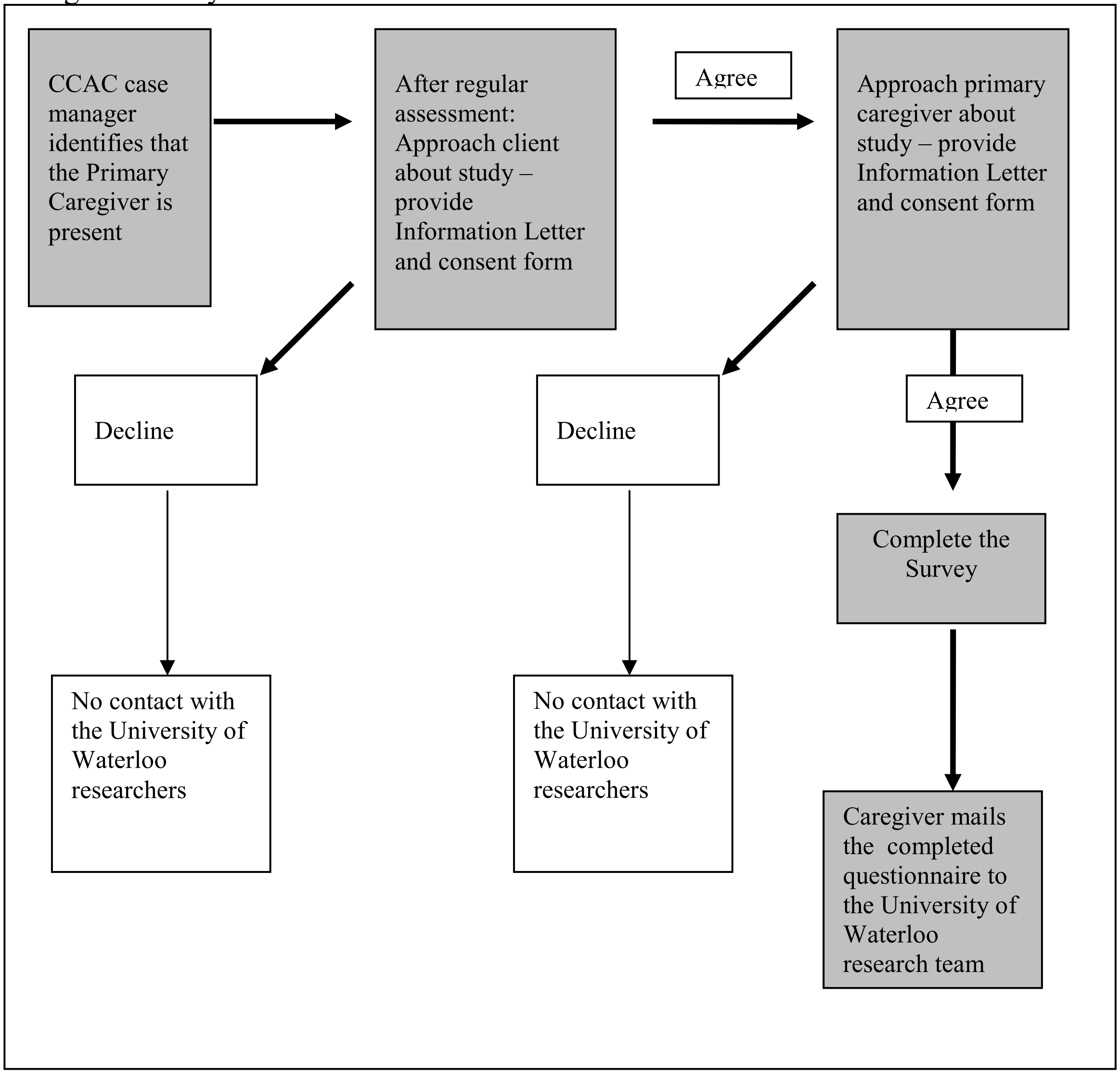
Caregiver Survey data flow chart.



NOTE:

1) For tracking purposes, it is important that the case manager affix the appropriate tracking number to the Caregiver Survey when the caregiver agrees to participate.

2) The CCAC case manager is only to approach the client about the project if the client agrees, the caregiver is English speaking, and the caregiver is 18 years of age or older.

Address for sending data → *ideas* for Health – Palliative Care - Caregiver Project
c/o Dr. Trevor Smith
Health Studies & Gerontology
University of Waterloo
200 University Ave West.
Waterloo, Ontario, Canada, N2L 3G1

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If you have any questions or comments
Please feel free to get in touch with us using the contact information below.

Investigators address →
Peter Brink
Health Studies and Gerontology
Ideas for Health – Palliative Care
University of Waterloo
200 University Ave West.
Waterloo, ON, N2L 3G1
Ph: 807-623-7026
E-mail: pbrink@ahsmail.uwaterloo.ca

Dr. Trevor Smith
Health Studies and Gerontology
Ideas for Health – Palliative Care
University of Waterloo
200 University Ave West.
Waterloo, ON, N2L 3G1
Ph: 519-888.4567 ext. 35879
E-mail: tfsmith@healthy.uwaterloo.ca

If you would like more information concerning this research project to help with your decision about participating, please feel free to contact me at the University by leaving a message with Professor Trevor Smith at 519-888-4567, Ext. 35879. Please indicate a convenient time for me to return your call.

I would like to assure the HNHB CCAC that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes, director of the Office of Research Ethics, at 519-888-4567, Ext. 36005.

Thank you, in advance, for your consideration of this request. We hope this study will further strengthen the ability of people to help one another. Please indicate on the attached page whether the HNHB CCAC intends to participate and how we can get in touch with you. Thank you.

Yours sincerely,
Peter Brink

THANK YOU FOR YOUR VALUABLE ASSISTANCE AND SUPPORT WITH THIS PROJECT

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CONSENT FORM

On behalf of the HNHB CCAC, I agree to participate in a study being conducted by Peter Brink of the Department of Health Studies and Gerontology under the supervision of Professor Dr. Trevor Smith and Dr. John Hirdes. I have made this decision based on the information I have read in the Information letter. All information which I provide will be held in confidence and I will not be identified in any way in the final report.

I also understand that this project has been reviewed by and has received ethics clearance through the Office of Research Ethics at the University of Waterloo and that I may contact Dr. Susan Sykes at 519-888-4567 ext. 36005 at this office if I have any concerns or comments resulting my involvement in this study.

I agree to participate in this study

YES NO (Please circle your choice)

Participant's Name (*for CCAC*): ______________________________(Please print)

Participant's Signature (*for CCAC*): ____

Witness' Signature: ____

Date: ______________________

If you have any questions or comments regarding the study
Please feel free to get in touch with my supervisor using the contact information below.
Investigators address → Dr. Trevor Smith
Health Studies and Gerontology
Ideas for Health – Palliative Care
University of Waterloo
200 University Ave West
Waterloo, ON, N2L 3G1
Ph: 519-888.4567 ext. 35879
E-mail: tfsmith@healthy.uwaterloo.ca

Dr. John Hirdes
Health Studies and Gerontology
Ideas for Health – Palliative Care
University of Waterloo
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E-mail: hirdes@healthy.uwaterloo.ca

Peter Brink
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Ideas for Health – Palliative Care
University of Waterloo
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Waterloo, ON, N2L 3G1
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E-mail: pbrink@ahsmail.uwaterloo.ca

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APPENDIX D – CCAC CLIENT INFORMATION

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Hamilton Niagara Haldimand Brant Community Care Access Centre

Script for Case Manager Concerning the Client

Instructions to the client upon completion of the assessment process.
* Please do not approach the client about the project if the CCAC client is unable to make the decision to participate.
* Please do not approach the client if:

1) the caregiver is not present,
2) the caregiver does not speak English
3) the caregiver is not 18 years of age or older.

CCAC case manager:
At this point I would like to introduce you to a study being conducted by Peter Brink, under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo. Would you have a few minutes for me to tell you about the study?

If the answer is 'yes' then proceed.

Peter is conducting a study to look at how information about the client relates to information obtained from the caregiver. The client's information is obtained through the assessment conducted by the CCAC case manager visiting your home. The caregiver's information is obtained through a survey that the caregiver will be asked to complete. The survey asks questions describing the experiences of caring for a home care client.

The main reason for this project is to look at how the experiences of relatives or friends might relate to the well-being of home care clients.

The researchers would like you to examine the Information Letter and allow me to approach your primary caregiver about participating in this study. If you decide to let me talk to your caregiver, your caregiver will be asked to complete a survey.

The information letter has the names and contact information for the researchers and for the Office of Research Ethics at the University of Waterloo. Any information collected will of course be confidential.

Please be assured that the care and services that you receive from your local CCAC will not be affected if you decide not to let me talk to your caregiver about this study. Participation in this study is strictly for research purposes and will not impact your care.

If you would like to participate in this study by letting me talk to your caregiver, please sign the two consent forms. The first consent form is for your records and the second is to be given back to the CCAC case manager who will forward it to the researchers.

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University of Waterloo

Department of Health Studies and Gerontology
Faculty of Applied Health Sciences

University of Waterloo
200 University Avenue West
Waterloo, Ontario, Canada
N2L 3G1

519-888-4567
Fax 519-746-2510

Dear CCAC Client:
I am a doctoral student in the Department of Health Studies and Gerontology at the University of Waterloo conducting research under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo.

What is this study about?
This study intends to look at how information about the client relates to information obtained from the caregiver. Client information is obtained through the assessment conducted by the Hamilton Niagara Haldimand Brant Community Care Access Centre (HNHB CCAC). The caregiver information is obtained through a survey that the caregiver completes about his/her experiences caring for the client.

The overall purpose of the project is to look at how the experiences of family members or friends relate to the experiences of home care clients.

What will I be asked to do?
As a participant in this study, you will be asked to identify your primary caregiver and allow us to ask him or her to participate in a survey.

The survey is expected to take your caregiver between 10 to 20 minutes to complete. Participation by you and your caregiver is strictly voluntary. Please be assured that the services you receive from the HNHB CCAC will not be affected if you decide not to allow us (the researchers) to survey your caregiver. In addition, you and your caregiver’s participation in this study is strictly for research purposes and not for the provision of care.

If you decide to allow us survey to your primary caregiver, please sign the attached consent forms (2 forms). The first consent form is for your own personal records. The second consent form is to be given to the HNHB CCAC case manager. The case manager will forward the researchers’ copy of the consent form to the researchers at the University of Waterloo.

The information on the survey will be linked to your assessment at the HNHB CCAC. The HNHB CCAC will be providing the researchers with assessments from all home care clients but without any personal identifying information. The researchers will link this information to the survey completed by your caregiver using a unique number code. The survey will not include any personal identifying information.

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Will information be kept confidential and who will see my responses?
Participation in this project is voluntary. Furthermore, all information you and your caregiver provide will be kept confidential. The only persons who will see your responses are the researchers. All identifying information like the HNHB CCAC client or caregiver’s name will be removed from all research materials before storage. Any information collected through this study will be kept for a period of 7 years in a locked, secure location in the LHI-N Building, ideas for Health floor, University of Waterloo. All information will be confidentially shredded after 7 years.

Who can I contact if I have questions or concerns?
I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. If you have any questions about this study or would like additional information to assist you in reaching a decision about participation, please feel free to contact Professor Trevor Smith at 519-888-4567 ext. 35879 or Dr. Susan Sykes in the Office of Research Ethics at the University of Waterloo at 519-888-4567 Ext. 36005.

Will the results of the study be available to me?
Whether or not you chose to contribute to the project, I invite you to review the Executive Summary provided to your local CCAC upon completion of this research project. You can contact your CCAC case manager to obtain a copy of the Executive Summary. The project is expected to be completed by December 2007. The Executive Summary is expected to be available to you from your local CCAC by early spring of 2008.

Thank you for your interest in this project.
Sincerely,

Peter Brink

Health Studies and Gerontology
University of Waterloo
200 University Ave West
Waterloo, ON, N2L 3G1
Ph: 807-623-7026
E-mail: pbrink@ahsmail.uwaterloo.ca

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CONSENT OF PARTICIPANT - Client

I have read the information presented in the information letter about a study being conducted by Peter Brink under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study at any time.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study that I may contact the Director, Dr. Susan Sykes, in the Office of Research Ethics at the University of Waterloo at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Print Name ____

Signature of Participant ______________________________

Date ____

Witnessed ____

If you have any questions or comments regarding the study
Please feel free to get in touch with my supervisor using the contact information below.
Investigators address → Dr. Trevor Smith
Health Studies and Gerontology
University of Waterloo
200 University Ave West, Waterloo, ON, N2L 3G1
Ph: 519-888.4567 ext. 35879
E-mail: tfsmith@healthy.uwaterloo.ca

Dr. John Hirdes
Health Studies and Gerontology
University of Waterloo
200 University Ave West, Waterloo, ON, N2L 3G1
Ph: 519-888.4567 ext. 32007
E-mail: hirdes@healthy.uwaterloo.ca

Peter Brink
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University of Waterloo
200 University Ave West, Waterloo, ON, N2L 3G1
Ph: 807-623-7026
E-mail: pbrink@ahsmail.uwaterloo.ca

\

CONSENT OF PARTICIPANT - Client

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This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study that I may contact the Director, Dr. Susan Sykes, in the Office of Research Ethics at the University of Waterloo at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Print Name ____

Signature of Participant ______________________________

Date ____

Witnessed ____

If you have any questions or comments regarding the study
Please feel free to get in touch with my supervisor using the contact information below.
Investigators address → Dr. Trevor Smith
Health Studies and Gerontology
University of Waterloo
200 University Ave West, Waterloo, ON, N2L 3G1
Ph: 519-888.4567 ext. 35879
E-mail: tfsmith@healthy.uwaterloo.ca

Dr. John Hirdes
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Peter Brink
Health Studies and Gerontology
University of Waterloo
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Ph: 807-623-7026
E-mail: pbrink@ahsmail.uwaterloo.ca

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APPENDIX E – CCAC CAREGIVER INFORMATION

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Script for Case Manager Concerning the Caregiver
(Upon consent of the client)

CCAC Case Manager:
I would like to introduce you to a study being conducted by Peter Brink, under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo. Peter is conducting a study to look at how information about the client relates to information obtained from the caregiver. Client information is obtained through the assessment conducted by the CCAC. The caregiver information is obtained through a survey that the caregiver completes about his or her experiences caring for the client.

The reason for this project is to look at how the experiences of family members or friends relate to the experiences of home care clients.

As a participant in this study, you will be asked to complete a survey examining your experiences as a caregiver. Participation is voluntary and you can change you mind about participating at any point.

The survey will take about 10 to 20 minutes. You can choose not to respond to any questions that you wish and you can also have a family member or friend assist with completing the survey.

Please feel free to contact me if you have any questions about the survey. Because the questions are very specific and personal, I can also help you or refer you to agencies that can provide help to you if the questions raise any concerns or create distress for you.

The information letter has the names and contact information for the researchers and for the Office of Research Ethics at the University of Waterloo. The researchers invite you to examine the information letter to decide whether you would like to be involved in this study.

Please be assured that the services that you receive and your family member receives from the your local CCAC will not be influenced if you decide not to participate. Participation in this study is strictly for research purposes and not for the provision of care.

If you would like to participate in this study, please sign the two consent forms. The first consent form is for your records and the second is to be given back to me so I can forward it to the researchers for their records.

University of Waterloo

Department of Health Studies and Gerontology

Faculty of Applied Health Sciences

University of Waterloo
200 University Avenue West
Waterloo, Ontario, Canada
N2L 3G1

519-888-4567
Fax 519-746-2510

Dear Caregiver:
I am a doctoral student in the Department of Health Studies and Gerontology at the University of Waterloo conducting research under the supervision of Professors Trevor Smith and John Hirdes.

What is this study about?
This study intends to look at how information about the client relates to information obtained from the caregiver. Client information is obtained through the assessment conducted by the Hamilton Niagara Haldimand Brant West Community Care Access Centre (HNHB CCAC). The caregiver information is obtained through a survey that the caregiver completes about his/her experiences caring for the client.

The overall purpose of the project is to look at how the experiences of family members or friends relate to the experiences of home care clients.

There is no doubt that caregivers provide a great deal of support in home care. As such, it is important that their needs be addressed. Your opinions are important to this study because you provide care to someone receiving home support.

What will I be asked to do?
As a participant in this study, you will be asked to complete a survey examining your experiences as a caregiver. If you decide to proceed, please complete the attached consent forms (2 forms) and survey. Completion of the survey is expected to take about 10 to 20 minutes of your time. The questions are quite specific and some are very personal. For example, they ask whether you feel uncertain about what to do about your relative/friend, whether you have enough time for yourself, whether you have tension in your life, and about your perception of your own health. You can contact your CCAC case manager if the survey raises any concerns or creates any distress for you. They are able and willing to help you through any problems or concerns you may have.

Please be assured that the services you and your family member/friend receive from the HNHB CCAC will not be affected if you decide not to complete the questionnaire or begin the questionnaire but do not complete it. Your participation is strictly for research purposes and not for the provision of care.

Can I change my mind about participating in this study?
Participation in this project is voluntary. You can opt not to complete the questionnaire or, if you decide to proceed, omit any question you prefer not to answer.

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Will information be kept confidential and who will see my responses?
The information on the questionnaire will be linked to your family/friend's assessment at the HNHB CCAC. The HNHB CCAC will be providing the researchers with electronic data concerning the person for whom you, the caregiver, are providing care but without any personal identifying information (e.g., name, address, Social Insurance Number). The researchers will link the information from the survey with data concerning the client provided by the HNHB CCAC using a unique number code. The survey does not include any personal identifying information. Any identifying information will be removed from the research materials before storage. Also note that all information will be kept confidential. The data collected through this study will be kept for a period of 7 years in a locked, secure location in the LHI-N Building, ideas for Health floor, University of Waterloo. All information will be confidentially shredded after a period of 7 years.

Who can I contact if I have questions or concerns?
If you are interested in participating in this study, please return the completed questionnaire in the envelope provided by mail directly to the University of Waterloo. If after receiving this letter, you have any questions about this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact Professor Trevor Smith at 519-888-4567 ext. 35879.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567 Ext. 36005.

Will the results of the study be available to me?
Whether or not you chose to contribute to the project, I invite you to review the Executive Summary provided to your local CCAC upon completion of this research project. You can contact your CCAC case manager to obtain a copy of the Executive Summary. The project is expected to be completed by December 2007. The Executive Summary is expected to be available to you from your local CCAC by early spring of 2008.

Thank you in advance for your interest in this project.
Sincerely,

Peter Brink
Health Studies and Gerontology
University of Waterloo
200 University Ave West
Waterloo, ON, N2L 3G1
Ph: 807-623-7026
E-mail: pbrink@ahsmail.uwaterloo.ca

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CONSENT OF PARTICIPANT - Caregiver

I have read the information presented in the information letter about a study being conducted by Peter Brink under the supervision of Professors Trevor Smith and John Hirdes of the Department of Health Studies and Gerontology at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty at any time.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study that I may contact the Director, Dr. Susan Sykes, in the Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Print Name ____

Signature of Participant _________________________________

Date ____

Witnessed ____

If you have any questions or comments regarding the study
Please feel free to get in touch with my supervisor using the contact information below.
Investigators address → Dr. Trevor Smith
Health Studies and Gerontology
University of Waterloo
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CONSENT OF PARTICIPANT - Caregiver

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With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

Print Name ____

Signature of Participant ______________________________

Date ____

Witnessed ____

If you have any questions or comments regarding the study

Please feel free to get in touch with my supervisor using the contact information below.

Investigators address → Dr. Trevor Smith
Health Studies and Gerontology
University of Waterloo
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Dr. John Hirdes
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E-mail: pbrink@ahsmail.uwaterloo.ca