Care Planning at the End-of-Life: Potential Use of the interRAI Palliative Care Assessment Instrument Clinical Assessment Protocols (interRAI PC CAPs) to Identify the Needs of Persons Receiving Palliative Home Care Services in Ontario, Canada

by

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Author's Declaration

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. I understand that my thesis may be made electronically available to the public.

Abstract

Relief from pain and distressing symptoms associated with a life limiting illness is an issue relevant to all Canadians. Provision of high quality care for persons nearing the end of life may improve the health and quality of life of the person and affects the health and well-being of members of their informal support network including family, friends, and caregivers. Palliative care, a person-centered approach to care for persons faced with a life limiting illness and their informal support network, focuses on the 'total person' or 'whole self' addressing the multifaceted complex needs of each person on an individualized basis. Palliative care is recognized by the World Health Organization (WHO) to be "achieved through prevention and relief of suffering by means of early identification, comprehensive assessment, and treatment of pain and physical, psychosocial, or spiritual problems" (World Health Organization [WHO], 2010). The palliative care philosophy prioritizes self-determination of the person and supports their engagement in the care planning and decision making process across the illness trajectory.

Approximately one fifth of persons who die annually experience unrelieved suffering (Doyle & Woodruff, 2013). Persons nearing the end-of-life face can face a wide range of challenges that may include: uncontrollable pain and physical symptoms, unresolved and emotionally distressing psycho-social issues, and fear of one's own mortality and of an unknown future. Nearly two thirds of Canadians who die each year may benefit from palliative care (Canadian Hospice Palliative Care Association [CHPCA], 2010), however only approximately one in eight of those persons are able to access palliative care services (Carstairs & Beaudoin, 2000).

Comprehensive clinical assessment supports clinicians to make evidence-informed decisions and promotes a person-centered approach to care planning. The interRAI Palliative Care assessment instrument (interRAI PC) is a comprehensive standardized assessment instrument, designed for use by facility and community based palliative care services, with applications that include care planning, outcome measurement, quality monitoring, and resource allocation (Hirdes et al., 1999; Steel, et al., 2003;

Gray, et al., 2009; Hirdes et al., 2008). Using pilot data gathered from the interRAI PC, this thesis examines the potential use of interRAI PC assessment data, and in particular how evidence from the interRAI PC Clinical Assessment Protocols (CAPs) has the potential to inform individualized care plan development for persons with a life limiting illness.

This thesis begins with a scoping literature search that describes palliative care in a Canadian context and explores care planning with the interRAI PC. This is followed by three research based chapters (Chapters 6, 7, and 8) that include analysis based on pilot data gathered between 2006 and 2011 using the interRAI PC assessment instrument. Community dwelling persons with a life limiting illness receiving palliative home care services in six geographic locations across Ontario, Canada, were included in these analyses. Persons with a life limiting illness residing in institutional or hospice facilities, or in jurisdictions outside of Ontario, were excluded. Analyses were performed using SAS Version 9.2 with an alpha level of $p< 0.05$ for all statistical tests unless otherwise stated. The University of Waterloo's Office of Research Ethics granted ethics clearance for this research (ORE# 19424) November 29th, 2013.

The first research chapter (Chapter 6) describes how clinicians may use the interRAI PC Clinical Assessment Protocols (CAPs) to inform care planning. It includes an overview of the suite of eight CAPs and provides a background description of the CAP development process. Discussion addresses the unique distributional characteristics of each CAP and describes a hierarchical triggering structure.

Following, chapter six which provides an overview of the interRAI PC CAPs from a broad perspective; chapter seven (the second research chapter) takes a more in-depth focus investigating the Dyspnea CAP. Dyspnea was selected as the symptom of focus because it is the one of the most commonly triggered CAPs affecting nearly half of the sample palliative home care population used in this thesis and is reported to be one of the most distressing symptoms affecting both the person faced with a life limiting illness and their informal caregivers (Ng &von Gunten, 1998; Potter, Hami, Bryan, & Quigley, 2003; Dellon et al., 2010; Kroenke, Johns, Theobald, Wu, & Tu 2013). Chapter seven examines the Dyspnea CAP and describes the prevalence of dyspnea. This chapter demonstrates the relationship between dyspnea and prognosis as well as other clinical factors. Moreover, how the presence of dyspnea changes over time is examined and person-level characteristics, some of which are potentially amenable to change, that affect the risk for dyspnea over time are identified. In addition, risk and protective factors for persons who over time developed new dyspnea symptoms and for those who recovered from dyspnea are examined.

Recognizing that a hallmark of the palliative care philosophy is its aim to provide the highest quality of care and support for both the person nearing the end of life and members of their care network including their informal caregivers, the third research chapter (Chapter 8) examines distress experienced by both the caregiver and the care recipient as a unit of care. As quality palliative care may increase satisfaction with care, improve global quality of life for client and their caregiver, reduce physical symptoms like dyspnea, decrease signs of depression or anxiety, and improve access to health care resources (Kane, Bernstein, Wales, Leibowitz, & Kaplan, 1984; Melin-Johansson, Axelsson, Gaston-Johansson, & Danielson, 2010) the association between the presence of dyspnea and distress experienced by members of the caregiver-client unit of care is examined to illustrate how dyspnea relates to distress, a major problem affecting over half of the caregiver-client units of care.

Together, findings from this thesis show that if one or more interRAI PC CAPs are triggered then the clinician should take notice. Data from the interRAI PC and more specifically from the interRAI PC CAPs examined in this thesis provide evidence on their potential to inform greater understanding of the complex needs of palliative home care clients. Better understanding of the interRAI PC CAPs and identification of patterns in CAP triggering structure suggest symptoms where clinicians may focus increased attention. To address the accumulative complex needs of persons who are faced with a life-limiting illness and the needs of their caregivers, resource allocation focused on evidence gathered from a comprehensive standardized assessment instrument should be prioritized.

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Dedication

To my husband, Samuel— I thank you for your support every step of this long journey.

and

To my three amazing children Alexandria, Violet, and Henry— May I have instilled in you all, my passion for life-long learning and an understanding of the importance and great value of education.

“How people die remains in the memories of those who live on”

-Dame Cicely Saunders

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1. Introduction and Overview

From the local to regional, national, and global levels, the value of palliative care to address the needs of persons faced with a life limiting illness and to improve health and well-being is gaining increased attention. Provision of the highest quality care for persons nearing the end of life is as an important public health priority (Emanuel, Fairclough, Wolfe, & Emanuel, 2004; World Health Organization [WHO], 2004). It is commonly accepted that provision of palliative care services improves both the quality of living and dying for persons faced with a life limiting illness and for their family, friends, and caregivers (the persons faced with a life limiting illness' informal support network). Palliative care is a person-centered approach recognized by the World Health Organization (WHO) to be "achieved through prevention and relief of suffering by means of early identification, comprehensive assessment, and treatment of pain and physical, psychosocial, or spiritual problems" (World Health Organization [WHO], 2010). Palliative care prioritizes self-determination for persons faced with a life limiting illness not only in control over their own life, but also to function as an active informed participant in their treatment and care planning process. Palliative care focuses on the 'total person' or 'whole self'. While pain and symptom management for the person faced with a life limiting illness is a well-known focus, quality palliative care simultaneously recognizes the need to support families and caregivers. Palliative care services have been found to lead to improved survival, (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007) and increased satisfaction with care for both the persons faced with a life limiting illness and for their informal support network (Kane, Bernstein, Wales, Leibowitz, & Kaplan, 1984; Brumley et al., 2007). With appropriate timing of referral, quality palliative care may lead to a reduction of unnecessary health care resource utilization (Tulskyc & Steinhauserc, 2007; Kamal, Currow, Ritchie, Bull, & Abernethy, 2012).

The International Association for Hospice and Palliative Care (IAHPC) notes that of the more than 52 million people who die in the world each year about one fifth are likely to die with unrelieved suffering

(Doyle & Woodruff, 2013). The IAHPC emphasizes that in all regions of the world "people are living and dying in unrelieved pain, with uncontrolled physical symptoms, with unresolved psychosocial and spiritual problems, and in fear and loneliness" (Doyle & Woodruff, 2013). The WHO has prioritized raising global awareness of the value of palliative care in the relief of pain and suffering among persons faced with a life limiting illness, regardless of geographic location (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). It is estimated that of the more than 252,000 persons who die in Canada each year (Statistics Canada, 2011), nearly two thirds may benefit from palliative care (Canadian Hospice Palliative Care Association [CHPCA], 2010). However, in Canada, it has been found that less than 15% of persons with a need for palliative care are able to access services (Carstairs & Beaudoin, 2000).

The first palliative care programs in Canada were developed in Montreal, Quebec and Winnipeg, Manitoba during the mid-1970s in response to the unmet needs of dying persons. During these early beginnings, palliative care across Canada was primarily a grass roots movement, reliant on charitable or local funding and lacked a clear united direction. More recently, with the leadership of the Canadian Hospice Palliative Care Association (CHPCA), palliative care in Canada has evolved into an increasingly united movement with a growing shared voice, which advocates for access to palliative care for all persons faced with a life limiting illness (CHPCA, 2005). Palliative care continues to be limited by a lack of clear national funding policy strategy and remains an uninsured service under the Canada Health Act (CHA). A 2005 Senate Commission noted that despite advances in the palliative care movement since 1995, progress had been slow. A 2010 Senate of Canada report highlighted the current Canadian reality of unequal access to palliative care services, inconsistencies in type and quality of service provision across the country, and that the majority of persons faced with a life limiting illness are unable to access high quality palliative care services to meets their needs as they progress towards the end of life (Carstairs, 2010).

With support from informal care networks in combination with community based palliative services, dying at home is becoming increasingly accessible to more persons with a life limiting illness. Grant, Elk, Ferrell, Morrison, and von Gunten, (2009) reported on the challenges for persons at end of life to achieve their preferred place of death. Disparities in preferences at the end of life and actual outcomes were evident as Grant et al. found that although the vast majority of persons expressed the wish for a home death more than half died in hospital and a quarter died in a nursing home (2009). Palliative care services, allocated to meet person-specific need at the appropriate time in the preferred setting, are critical to support persons faced with a life limiting illness who prefer a home death. Yet, it is also important to recognize that not all persons faced with a life limiting illness prefer a home death. Yamasaki et al., (2008) found that only half of study participants wished for a home death, and this preference differed significantly by gender. Community based palliative home care has been found to have a positive impact on quality of life and reduce health care expenditures for persons faced with a life limiting illness and their informal support network (Pereira & Bruera, 2001). Palliative home care programs have also been shown to improve quality of life, reduce physical symptoms, reduce psychological distress, and improve accessibility to formal care providers (Melin-Johansson, Axelsson, Gaston-Johansson, & Danielson, 2010).

Palliative care promotes person-specific care where resources and supports are tailored to meet need on a case-by-case basis. Comprehensive clinical assessment is a key tool that clinicians must use to provide an evidence-informed, person-centered approach to care planning. The interRAI Palliative Care assessment instrument (interRAI PC) is a comprehensive assessment instrument designed for use by facility and community based palliative care services, including those that specifically target persons with a life limiting illness. The applications of the interRAI PC and related interRAI instruments include care planning, outcome measurement, quality monitoring, and resource allocation (Hirdes et al., 1999; Steel, et al., 2003; Gray, et al., 2009; Hirdes et al., 2008). Using pilot data gathered from the interRAI PC, this thesis examines how data from the interRAI PC has the potential use to inform individualized care plan development for persons faced with a life limiting illness. This thesis begins with a scoping literature search to describe palliative care in a Canadian context. The nature of services and target populations for palliative care are defined and its key components outlined. Dyspnea, a major challenge in symptom management that commonly affects persons with a life limiting illness is explored with greater depth. An overview of care planning with attention to care planning in palliative care is provided in chapter three, followed by introduction to the interRAI suite of assessment instruments in chapter four. A discussion of how clinicians may use the interRAI PC Clinical Assessment Protocols (CAPs) to inform care planning follows. The strengths and limitations of the interRAI PC are compared and contrasted to three other prominent palliative care assessment instruments described in section 4.4; the Palliative Performance Scale (PPS), the Edmonton Symptom Assessment System (ESAS), and the Liverpool Care Pathway (LCP). The study rationale described shows gaps in current knowledge from a Canadian context and introduces the data source and measures to be used in the three research chapters (Chapters 6, 7, and 8). The three research chapters, each formatted as articles for publication, focus on the potential use of the interRAI PC CAPs beginning with a broad overview of the eight interRAI PC CAPs. This is followed by a more in-depth investigation into the Dyspnea CAP and finally a focus on the relationship between the Dyspnea CAP and distress experienced within the caregiver-care recipient unit of care.

1.1 Literature Review Strategy

The literature search was performed between September 2012 and March 2013 using the SCOPUS, PubMed, CINAHL, and Google Scholar databases. Various combinations of the following MeSH keywords were used: “Palliative care”, “Terminal care”, “Hospice” “Clinical Protocol”, “Patient Care Planning”, “Community Health Planning”, Patient Care Management”, “Nursing Assessment”, “Health Care”, “Risk Adjustment”, “Standard of Care”, “Symptom Assessment”, “Geriatric Assessment’, “Nursing Assessment”, “Quality Assurance, Health Care”, “Best Practice Guideline” and “Gold

Standard". Other search words and combinations used included: "End of Life", "interRAI", and "Clinical Assessment Protocol". Articles published in non-English languages were excluded as were articles published prior to 1995. Articles that focused on children and youth, under the age of 18, were excluded. Publication year limitation criteria were removed if an article was identified as being important.

For selected papers forward checking of articles citing the paper and backward checking of articles cited was performed using functions in SCOPUS. As key authors were identified, their names were searched in Google Scholar and SCOPUS databases to ascertain any related articles. This process continued until saturation was reached and no new articles were identified. Federal publication databases were searched to identify senate and policy documents vital to the development of palliative care services in Canada.

For inclusion, studies must have met the following criteria: 1) focus primarily on palliative care for persons faced with a life limiting illness, 2) examine palliative care clinical assessment protocols, care planning, practice guidelines, OR palliative care symptoms and treatments, 3) apply predominately to the Canadian context, and 4) be applicable for persons over the age of 18.

2. Background

Palliative care recognizes that self-determination and the rights of the person with a life limiting illness and when appropriate, the needs of their informal support network, are the foundation to identify need, choose individualized goals of care, and direct treatment. IAHPC identifies that the goals of palliative care are:

- To provide relief from pain and other physical symptoms;
- To provide psychosocial and spiritual care;
- To support and help the support network during the persons illness trajectory and through the bereavement process; and
- To maximize the quality of life of the person with a life limiting illness and their support network. (Doyle & Woodruff, 2013)

Palliative care prioritizes the importance of quality of life (QOL) and personal choice, recognizing that desire for a cure and the preference to receive aggressive or life-prolonging treatments are not incompatible with palliative care's priority for pain and symptom management and for peace and dignity through all stages of the illness trajectory (National Consensus Project [NCP], 2013). To address the complex needs on a case-by-case basis, palliative care should be provided by multidisciplinary teams whom are equipped with all necessary tools to the address the context of the person faced with a life limiting illness. Effective palliative care depends on leadership, collaboration, coordination, and communication (NCP, 2013). In some cases, palliative teams may be led by a physician with a strong medical focus aimed at relief of distressing physical symptoms such as pain or dyspnea, but others may be led by a social worker focused on examining the financial and psycho-social issues faced by the person with a life limiting illness and members of the informal support network. In the United States, social workers are integral members to the multidisciplinary palliative care teams, and are required to be available by Medicare regulations (Gwyther et al., 2005). For most teams, a diverse range of health and community care providers and supports will be required ranging from physicians, medical specialists, and nurses to social workers, spiritual care workers, and volunteers. The multidisciplinary team approach to palliative care aims to respond to the ‘whole person’ needs, preferences, values, and beliefs in a manner that is collaborative, personalized and culturally appropriate (NCP, 2013).

2.1 Defining Palliative Care

The origin of the term palliative care is rooted in the word ‘palliate’, derived from the Latin word palliatius, which means to ‘cloak or cover’ (McCusker et al., 2013). This creates a comforting image of surrounding the person with a cozy blanket, wrapping them in support to decrease pain and distressing symptoms (NCP, 2013). Numerous terms and definitions of care of persons with a life limiting illness exist including palliative care, hospice care, hospice palliative care, supportive care, end-of-life care, supportive end-of-life care, and terminal care. The meanings of each term may vary by time, context, language, and location of application. Yet, although they are individually defined, these terms are often used interchangeably. For the purpose of this thesis, palliative care will be defined as a philosophy of care that stresses alleviation of suffering and aims “to improve the quality of living and of dying” (Government of British Columbia, 2006; CHPCA, 2013). Palliative care seeks to improve QOL through “the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2010). In addition, palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death and to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families including bereavement counseling if indicated;
- Will enhance QOL and may also positively influence the course of the illness; and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (WHO, 2010)

The focus of palliative care is multidisciplinary providing a wide range of care services addressing the practical, physical, psychological, social, spiritual, and holistic needs of each person (Doyle & Woodruff, 2013). Palliative care aims to alleviate current symptoms and distress, prevent subsequent issues before they develop, and help the person find meaning, purpose, and growth over the course of the illness trajectory (CHPCA, 2005). Palliative care may be the total focus of care or it may be provided as a secondary focus in conjunction with disease modifying curative treatments.

CHPCA recognizes seven core values of palliative care:

1. The intrinsic value of each person as autonomous and unique;
2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization;
3. The need to address suffering, expectations, needs, hopes, and fears of both the person with a life limiting illness and their support network;
4. Care is only provided when the patient and/or family is prepared to accept it;
5. Care is guided by QOL as defined by the person with a life limiting illness
6. The therapeutic relationship be based on dignity and integrity; and
7. A unified response to suffering strengthens communities (CHPCA, 2005).

In its definition of palliative care, the WHO recognizes palliative care may enhance the QOL of the person and “positively influence the course of illness” (2010). It is important that potential disparity between the subjective perspective of the person with a life limiting illness and the objective view of those surrounding the person (including both formal care providers and the person’s informal support network) may exist (Randall, Downie, & Downie, 1999 pp. 250; Kaasa and Loge, 2003). Recognition of the person’s subjective assessment of QOL and support that promotes its attainment through self-determination is a foundation principle of the palliative care philosophy.

The perceived change in life trajectory after diagnosis with a life limiting illness can be perceived as a serious threat to the viability of the person’s hopes, dreams and aspirations for the future. When a person is faced with a life limiting illness, it may be the first time that the person challenged to address in realist terms the fact that that they will die. This change may affect the person’s self-perception of health and QOL, as well as challenge their perceived role in society and relationships with others. These challenges may be negative (examples: financial insecurity and decreased or lost productivity (Covinsky et al., 1994; Albert, Williams, Legowski, & Remis, 1998)) or may be more positive in the form of opportunities for personal growth, motivation to resolve unfinished business or reconcile past relationships, promote recognition of inner resilience, and drive a desire to resolve conflicts and attain inner peace (CHPCA, 2013b). Palliative care encourages enhancing self-empowerment through personal choice. Palliative care support may assist the person to adjust their expectations for change in their life trajectory and assist them to prioritize issues and need on an individualized basis. Palliative care recognizes the importance of self-determination and choice as the driving force in identification of need and in development of a plan for care.

2.1.1 Defining Dying

For the purpose of this thesis, the term dying will refer to active dying in the final days or hours during the terminal phase. When a person is actively dying, the goals of care and methods in which they are addressed should adapt to the volatile and unpredictable changes in distressing symptoms during the terminal phase (Heidrich, 2007). Physicians, trained within a medical model that promotes the importance to ‘cure patients’ and provide ‘aggressive and life-saving’ treatments whenever possible, may feel conflicted and hesitant to label a person as ‘actively dying’ if any hope for improvement remains (McCusker et al., 2009). This reluctance to refer to palliative care by physicians due to the perception by the physician that they have ‘failed’ creates a barrier for persons to be referred to or to receive care from palliative care services.

It is well established that dying persons are at increased risk to experience distressing symptoms. Multiple complex symptoms require a plan of action, subject to continuous adjustment, to address treatment challenges and promote QOL as persons near the end of life (Fürst, & Doyle, 2004; Heidrich, 2007). Common signs and symptoms, as detailed by Heidrich (2007) and the NCP (2013), that indicate the person with a life limiting illness may be in the dying stage include: delirium, increased periods of sleep, lethargy, or fatigue, decreased food and liquid consumption, abnormal breathing patterns or dyspnea, inability to heal or recover from wounds or infections, increased swelling, or severe agitation with hallucinations or changes in personality (Heidrich, 2007; NCP, 2013).

2.1.2 Challenges to Defining Palliative Care

Misunderstanding of the meaning of palliative care, the depth of its benefits, and breath of its applicability creates substantial barriers to access palliative care. Historically, in Canada, it has been the case that palliative care has been access predominantly by persons with cancer in the final stages of life. In a 2003 report by the Ontario Association of Community Care Access Centers (OACCAC), it was noted that 80 to 85% of patients who accessed palliative care teams had a diagnosis of cancer (Ontario Association of Community Care Access Centers [OACCAC], 2003 in Dudgeon et al., 2007). Incorrect beliefs that palliative care is only useful for persons who are actively dying, for persons who no longer respond to curative treatment, or whose death is imminent, can also result in limited access to or effectiveness of palliative care services. In the final stages of the end-of-life, dying may be complex requiring increased levels of specialized palliative care. However, the scope of palliative care is not limited to the later stages of the illness trajectory. Palliative care is often misunderstood as solely beneficial for persons with a cancer diagnosis, resulting in its under-utilization by persons with non-cancer diagnoses.

Recognizing that the term palliative care may be a barrier, global efforts to clarify the definition, scope, and utility of palliative care are underway. The WHO (2010) has focused on mass global education campaigns and publications to broaden understanding of the ideology of palliative care. In Canada, CHPCA emphasizes the broad applicability of palliative care to all persons with a life limiting illness (CHPCA, 2013a). As a result, the term palliative care has been receiving wider recognition as more than simply pain relief in the final days and hours of life when hope for a cure is lost. Palliative care is applicable to any person with a life limiting illness during any stage of the illness. Therefore, use of the phrase ‘life limiting illness’ as used in this thesis rather than ‘terminal disease’ widens the scope and applicability to a more diverse range of persons. This broad definition of palliative care enables clinicians to apply palliative care principles in multiple settings, earlier in the illness trajectory and tailor care planning to address needs of persons with a life limiting illness on a case-by-case level.

Palliative care applies to persons who are dying as described above and persons who are predicted to be nearing the end of their life, but also to persons faced with the possibility or reality of life limiting illness from the time of evaluation or diagnosis, early in the disease trajectory. Palliative care may benefit persons with a life limiting illness not traditionally perceived as a ‘terminal illness’ but instead have an illness or condition that results in reduced life expectancy such as multiple sclerosis, cerebral palsy, or muscular dystrophy. Persons with progressive neurological conditions are a specific subpopulation with complex health needs that may benefit from palliative care not typically recognized as being within the scope of palliative care (Kristjanson, Aoun, & Oldham, 2006). As there is no known cure for the majority of progressive neurological conditions, treatments that address the effects of the condition (e.g., pain, symptom management, support) fit well within a palliative care philosophy. From the onset of symptoms through potentially lengthy periods of diagnosis to an ongoing response to deterioration across the disease trajectory, persons with a progressive neurological condition and members of their informal support network may benefit from education and support from a palliative care provider. The definition of palliative care clearly states that it is appropriate for persons with a life limiting illness, such as persons with progressive neurological conditions, who may benefit from and should have access to palliative care at any time during the illness trajectory.

When a person is diagnosed with a life limiting illness, it not only affects the person faced with a life limiting illness but also the lives of his/her informal support network including family, friends, caregivers, or co-workers (CHPCA, 2005). CHPCA estimates that death affects the health, wellbeing, and QOL of over 1.25 million Canadians each year, an average of five persons per death (2010). Effective palliative care depends on a strong informal support network to respond to the needs of persons with a life limiting illness. Palliative care also recognizes the impact caregiving and bereavement has on members of the informal support network. Palliative care includes access to caregiver-focused resources in addition to collaboration with and support from health professionals. Palliative care may assist members of the informal support network across the illness trajectory and during bereavement.

2.2 Palliative Care in Canada

Dame Cicely Saunders, founder of St. Christopher's Hospice in the United Kingdom, the world's first hospice center, conceived the modern idea of the hospice movement in the mid-1960s (Saunders, 1996). During the 1970s the first Canadian palliative care programs were initiated at two teaching hospitals in Montreal and in Winnipeg. Dr. Balfour Mount, a physician influenced by his relationship with Dr. Saunders, opened the Royal Victoria Palliative Care Unit in Montreal, Quebec. Dr. Mount coined the term 'palliative care' as it is now used in the contemporary context in Canada (Seely, Scott, and Mount, 1997). In 1991, the Canadian Palliative Care Association, presently known as the Canadian Hospice Palliative Care Association (CHPCA), a national organization dedicated to palliative care was established (CHPCA, 2013). Since then, issues regarding health care for the persons with a life limiting illness have attracted increasing attention from the general public, researchers, clinicians, and policy makers across Canada.

In recognition of lack of a formal policy on palliative care and in response to national attention from the Rodriguez Supreme Court Challenge (Government of Canada, 1993), the Special Senate Committee on Euthanasia and Assisted Suicide was struck. In 1995, the Senate Committee released the pivotal report: "On Life and Death: Final Report" in which they noted the right to euthanasia or assisted suicide could not be adequately addressed without first examining access to palliative care in Canada. This report gained national attention highlighting the disarray in co-ordination and lack of understanding of palliative care among health care professionals. More importantly, this report raised awareness that Canadians were dying with unrelieved pain and suffering (Special Senate Committee on Euthanasia and Assisted Suicide, 1995). In 2000, the Senate Commission released a follow-up report "Quality End-Of-Life Care: The Right of Every Canadian," which found minimal progress had been made and brought attention to the unmet needs of informal caregivers, the need for improved access to home care and medications, and the importance to increase education and research capacity (Senate Commission, 2005; Health Canada, 2005). Palliative care programs remained unevenly distributed, with limited capacity, across Canada (Carstairs & Beaudoin, 2000). Publicity from the Kirby and Romanow reports fueled a national campaign advocating for increased access to palliative care for persons with life limiting illnesses and emphasizing the important role for palliative home care services to assist persons to remain in the community and to die at home (Kirby & LeBreton, 2002; Romanow, 2002; Williams et al., 2010). In 2005, the Senate Commission's report "Still Not There. Quality End-Of-Life Care: A Progress Report" recognized significant advancements in policy since 2000 with development of the Canadian Strategy on Palliative and End-of-Life Care. However, it noted continued disparities in accessibility and emphasized that without federal leadership, the 'patchwork' of available palliative care services would continue (Senate Commission, 2005).

2.2.1 Accessing Palliative Care Services

Currently, palliative care is offered in almost every sector of the Canadian health care system, from acute care and complex continuing care hospitals, to long-term care facilities (LTC) and community based home care (Dudgeon et al., 2007). On a provincial level, the Ontario Association of Community Care Access Centers (OACCAC) (2003) recognized palliative care lacked "coordination, integration, and consistency" which resulted in great difficulty for persons with a life limiting illness and their informal support network to navigate palliative care services. Although palliative care is recognized by both health care professionals and the Canadian public as a valuable compassionate support for persons faced with a life limiting illness, without political advocacy and pressure, provincial and federal support, and health care policy reform, palliative care is projected to remain on the periphery of the Canadian health care system (Health Canada, 2007; Williams et al., 2010). Canada does not yet have legislation to mandate provision of palliative care for dying persons under the CHA. Because the current focus of the Canadian health care system is on ‘cure’ in the medical sense rather than ‘care’ as promoted in palliative care the provinces and territories are not required by law, under the CHA, to provide care oriented services like palliative care.

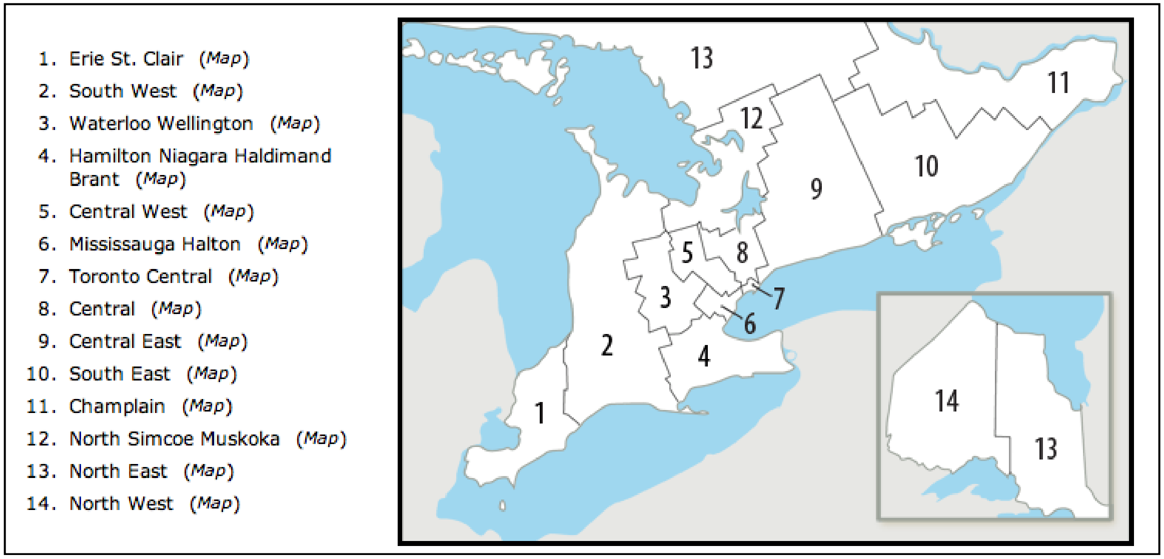
2.2.2 Ontario’s Health Care Structure

As the three research chapters (Chapters 6, 7, and 8) of this thesis utilize data gathered from the province of Ontario, it is important to understand the background context of Ontario’s health care structure. In Ontario, the first points of access to community based care are the fourteen Community Care Access Centers (CCAC’s) located in various regions across the province (Figure 2.1.). The goal of each CCAC is to coordinate specialized supports for persons under its jurisdiction and to connect those requiring care with available services and resources in the person’s home or within the respected community. Each CCAC has been tasked with the following responsibilities:

- Assess and determine eligibility for professional health services, homemaking, and personal support services to be provided in community, client’s homes, or schools;
- Assess and determine eligibility for the professional health and personal support services for children attending school or being home schooled;
- Develop service plans;
- Inform and refer members of the community to available services;
- Through a procurement process, purchase home care services from providers;
- Manage admissions to long-term care facilities;
- Co-ordinate delivery of CCAC provided home care services. (CCAC Client Services Policy Manual, 2007. Chapter 1, pp. 15)

In Ontario, palliative care consultation services and palliative care education are recognized as 2 of the 15 key community support services provided to persons by the CCAC in the geographic region in which they reside.

Figure 2.1. Map of Community Care Access Center (CCAC) Districts, Ontario, Canada.



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The Ministry of Health funds the CCAC's through Local Health Integration networks. Eligibility for services including nursing, personal support, and palliative care, are determined by CCAC policy and rely on both clinical judgment and established criteria. Established criteria, outlined in the Community Care Access Centre's Client Services Policy Manual (2007) include but are not limited to: Being eligible for the Ontario Health Insurance Plan (OHIP) (having residency in Ontario), having a recognized need for at least one professional service (e.g. nursing, physiotherapy, or occupational therapy), and the ability to receive care in a setting which ensures the safety, space, and privacy of both the care provider and care recipient. Community based services may be temporary/periodic or ongoing/long-term (CCAC Client Services Policy Manual, 2007, Chapter 1, pp. 3). Among all specified professional health services, maximum service provision is specified, only for nursing services, under the Long-term Care Act regulation number 386/99 (CCAC Client Services Policy Manual, 2007). These regulations allow special exceptions for persons who are palliative with complex or intensive needs to access additional personal support of homemaking services above suggested maximum service provisions based on special circumstances. Although not a focus of the current thesis, CCACs may coordinate funding support for residential hospices within their associated jurisdictions.

An important clarification in eligibility criteria for CCAC support is that "the person can only access the services that are available within the person's CCAC catchment area (e.g., in some cases, not all services may be available within the area)" (CCAC Client Services Policy Manual, Chapter 3, pp. 2). This may result in geographic variation not only in service availability, funding, and allocation, but also in client referrals. Although there may be a recognized need for a program, a client may not be referred because there is no program to refer the client too. Provincial eligibility criteria for CCACs in Ontario state that availability of services may affect client referrals for services. This is important when addressing palliative care needs and examining what population is assessed for services throughout the province of Ontario. As palliative care is an uninsured service under the Canada Health Act, variation in program and resource availability is common. Provision of palliative care services are based on annual budgetary decisions at the regional level. As an optional or add-on service, it is important to recognize some CCACs may be unable in times of fiscal constraint to fund and support specialized palliative care programs.

When a person is referred to a CCAC for service, a case manager assesses the person's needs, evaluates their service/resource eligibility, develops a plan of care in conjunction with the person's identified goals of care, and arranges for and coordinates service/resource delivery. The case manager is a point of information for the person and their informal support network to discuss availability of service options to meet desired and perceived need both at the current time of assessment and in the person's anticipated future. When appropriate, the case manager may also recommend and facilitate admission to a LTC or residential hospice facility. Since spring 2012, when a person is referred to a CCAC and recognized as potentially benefitting from palliative home care services, the case manager will assess the needs of the person using the interRAI Palliative Care Assessment instrument (interRAI PC) (OACCAC, 2012). Information gathered during the interRAI PC assessment is then used to inform creation of a care plan and conduct goal setting with the client.

It is important to note that while it is not the focus of this thesis, volunteer based and fee-for-service private companies offer a variety of palliative care focused services in Ontario, Canada. Persons who wish to purchase extra services from a private company such as additional homemaking services through a home care company, or who seek care from a private free-standing non-government funded hospice are able to do so throughout the province of Ontario. The ability for persons to seek these added services depends foremost on the financial capacity of the person, the availability of the services to meet their required needs, and the ability to find the resources to meet their perceived needs. For the purpose of this thesis, any reference to community based palliative home care services will be limited to those funded by the LHINs and allocated through the CCACs in Ontario, Canada.

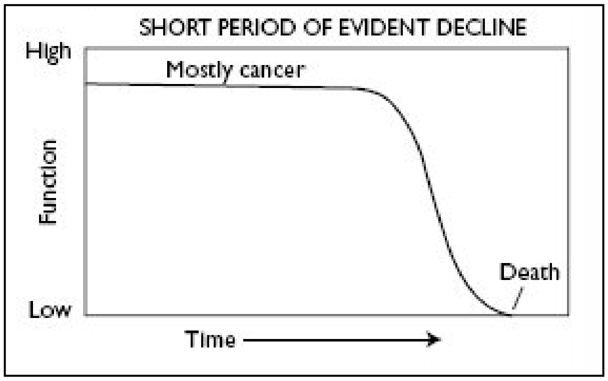
2.3 Trajectories of Death

Critical to discussions of palliative care are issues related to disease diagnosis and more specifically, as is discussed later in this thesis, in terms of persons with a cancer versus non-cancer diagnosis. Therefore, section 2.3 examines differing ways persons die and provides descriptions of characteristic patterns of clinical and functional decline associated with major illness or disease as persons near the end of life (Lorenz et al., 2008). Four distinct trajectories of death: cancer; organ system failure; frailty and dementia; and sudden or unknown death, are useful to understand the roles of disease and difficulties of prognosis at end of life. Persons with cancer are most often high functioning until late in the disease trajectory while persons with frailty and dementia may continue to function with low levels of functional abilities and experience a slow progressive prolonged decline. Persons with organ systems failure tend of experience a gradual decline interrupted over time by illness exacerbations. Trajectory of death analysis in 2001-2002 in Alberta found that terminal illness (primarily cancer) accounted for 29% of deaths, organ system failure accounted for 26.9% of deaths, frailty and dementia accounted for 26.7% of deaths, sudden deaths accounted for 6.3% of deaths, and the cause of death could not be determined in the remaining 13.8% of cases (Fassbender, Fainsinger, Carson, & Finegan, 2009). Since sudden or unknown deaths are not believed to require palliative care prior to death they are not discussed further. To elucidate patterns the majority of persons who are assumed to be able to benefit from palliative care may follow towards death, focus will be placed on the three chronic illness trajectories of death: cancer, organ system failure, and frailty and dementia.

2.3.1 Cancer Trajectory

The cancer trajectory, as shown in Figure 2.2, is characterized by a variable period after diagnosis where the person with a cancer maintains comfort and function. From the time of diagnosis through early and mid-stages of the illness trajectory, persons with cancer may experience a continued period of high functional status where most symptoms are managed (NCP, 2013). As the illness progresses, there is a tipping point where the person's health status begins to progressively decline and symptoms may become uncontrolled or overwhelming. From this point, the health of the person with a cancer may deteriorate rapidly as he/she approaches death (Lynn & Adamson, 2003). After reaching the tipping point, persons characteristically follow a pattern of decline which clinicians are often able to predict. Therefore clinicians may be able to with reasonable reliability predict a prognosis in the few months preceding death (Shugarman, Lorenz, & Lynn, 2005).

Figure 2.2. Cancer Illness Trajectory of Death.



Source: Lynn, J. & Adamson, D.M. (2003) Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. Washington: Rand Health, pp. 11.
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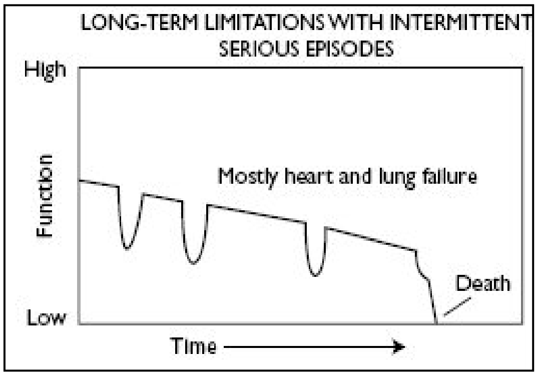
Research used to inform current palliative care practice focuses almost exclusively on the needs of persons with a cancer diagnosis (McClement, 2006). “At the moment, there is only one model for palliative care in Canada: The cancer model” (S. Baxter, personal communication, March 1, 2010). Because benefits of palliative care for persons with a cancer diagnosis and their informal support network during the rapid decline phase preceding death are well recognized, palliative care has been best shown to benefit persons with cancer during the final months before death (Shugarman, Lorenz, & Lynn, 2005; Lorenz, Shugarman, & Lynn, 2006). Less than 30% of total deaths in Canada each year are related to cancer (Public Health Agency of Canada, 2007; Public Health Agency of Canada, 2013). Yet people with cancer account for more than 90% of those receiving palliative care (Canadian Heart Health Strategy and Action Plan, 2009). This reflects provincial comparisons where persons with cancer receive 80-85% of palliative care services in Ontario yet account for only one third of persons who die (Seow, King, & Vaitonis, 2008), and international comparisons where persons with a cancer diagnosis receive up to 90% of palliative care services in the UK (Eve, Smith, & Tebbit, 1997), in the United States (Hogan, Lunney, Gabel & Lynn, 2001) and in Australia (Australia P.C., 1998).

Strict reliance on disease-specific eligibility guidelines (in particular the common entry criteria of a prognosis of less than three or six months to live) often result in the systematic exclusion for access to palliative care among persons dying from non-cancer diagnoses (Zerzan, Stearns, & Hanson, 2000). Gaudette et al. (2002) found that while all palliative programs accepted persons with a cancer diagnosis, not all accepted persons with other life limiting illnesses. Palliative care policies in Canada commonly target those persons with a life limiting illness whom clinicians expect are likely to die within a six month time period (Fassbender, Fainsinger, Carson, & Finegan, 2009). Potential cost savings through reduction of unnecessary treatments drives this rationale that accessibility to palliative care be based on an average six-month decline in functional status frequently experienced among persons with advanced stage terminal cancer (Teno, Weitzen, Fennel, & Mor, 2001; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003).

2.3.2 Organ Systems Failure Trajectory

The organ systems failure trajectory shown in Figure 2.3. is characterized by a saw tooth pattern, where periods of general stability are interrupted by sharp downward inflections reflecting exacerbations and acute illnesses. Persons diagnosed with congestive heart failure, chronic obstructive pulmonary disease, or renal failure, are examples of chronic diseases that commonly follow the organ systems failure trajectory towards death. During an exacerbation, medical interventions may improve the person's health status however after recovery the person usually does not typically return to the level of their pre-episode level of function. Therefore, the trajectory exhibits an overall slow downward slope.

Figure 2.3. Organ Systems Failure Trajectory of Death.



Source: Lynn, J. & Adamson, D.M. (2003) Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. Washington: Rand Health, pp. 11.
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Chronic diseases, such as diseases of the circulatory system and respiratory systems, excluding cancer, account for nearly half of all deaths annually in Canada (Statistics Canada, 2005). Although recognized as potentially benefitting from palliative care, persons with life limiting chronic illnesses often do not receive palliative care (Love & Sawatzky, 2007). Criteria for palliative care referral, such as a six-month prognosis, systematically exclude persons with non-cancer diagnoses creating a major barrier to service access and utilization. The inability to accurately prognosticate the end stage of chronic (non-cancer) diseases currently results in the denial of access to palliative programs for many persons with a life limiting illness and their informal support networks. This often includes inaccessibility to palliative care hospital based care, institutional and community hospice programs, as well as many provincial palliative home care programs..

Chronic disease prognostication can be extremely difficult. Ongoing medical care is often successful to prevent or reduce severity of exacerbations and to extend survival (McAlister, Stewart, Ferrua, & McMurray, 2004) however, death may occur suddenly from an unexpected complication or exacerbation (Lorenz, Shugarman, & Lynn, 2006). Many persons with chronic diseases such as COPD or heart failure often have a prognosis of two to six months, even in their last week of life (Ostchega, Harris, Hirsch, Parsons & Kingstong, 2000; Schron et al., 2002; Shugarman, Lorenz, & Lynn, 2005). Clinical prediction prognostic criteria for seriously ill patients with advanced chronic illnesses have been found to be ineffective and have poor discrimination (Fox et al., 1999; Coventry, Grande, Richards, & Todd, 2005). In contrast to the rapid linear decline experienced by many persons with a cancer diagnosis, those diagnosed with cardiovascular disease or heart failure may experience an erratic course of disease decline with periods of relative stability interrupted by episodes of acute decompensation (Goodlin, 2005; McClung, 2007). Due to prognostic uncertainty, health care providers may focus solely on life prolonging or lifesaving treatments and fail to recognize the progressive life-limiting nature of the disease. This in turn results in failure to recognize the benefits of or need for palliative care (Love & Sawatzky, 2007).

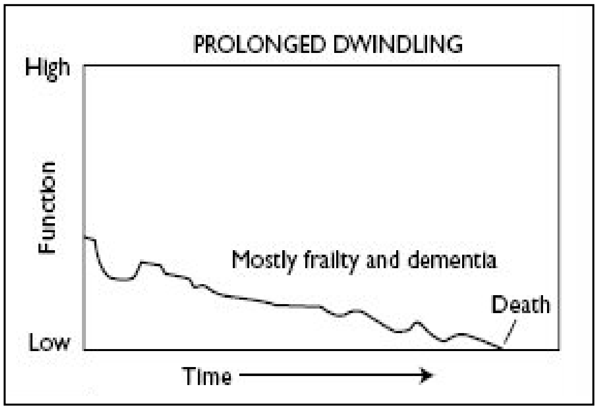
Palliative care for persons with organ system failure is often perceived as conflicting with the goals of chronic disease management (Gott et al., 2009). The Canadian Action Heart Health Strategy and Action Group recognized that cardiovascular care emphasized acute intervention and end of life care planning guidelines for cardiac care were lacking (2009). In a medical setting which prioritizes “optimizing medical management, prolonging life, and reducing or eliminating classical cardiac symptoms”, clinicians may feel uncomfortable discussing palliative care and end of life planning (Howlett et al. 2010, page 137). Some clinicians may perceive referral to palliative care services as a personal failure to ‘cure’ the patient. This represents a fundamental misperception of palliative care as being in conflict with the goals of chronic disease management. Instead, clinicians should recognize palliative care as being symbiotic with the chronic disease model, able to work alongside curative or life prolonging treatments to improve the health and QOL of the person with a life limiting illness.

2.3.3 Dementia and Frailty Trajectory

Persons who do not fit within the cancer or organ system failure trajectories may die from dementia or generalized frailty (Lynn & Adamson, 2003). People with dementia or frailty experience a slow and progressive decline (shown in Figure 2.4.). Over many years prolonged dwindling is characterized by multimorbidity and progressive physical and cognitive impairment. Eventually persons with dementia or frailty become unable to care for themselves and will require extensive personal care for an extended period of time imposing significant demands on both formal care services and their informal support network (Shugarman, Lorenz, & Lynn, 2005). Estimates of median length of survival from time of diagnosis to death range from seven to eight years (Sachs, Shega, & Cox-Hayley, 2004). Cary et al. (2007) found one-year mortality for frail persons to be 13% and three-year mortality 35%. Persons with dementia or frailty are at increased risk to die with uncontrolled pain and suffering (Teno, 2001). Although it is documented that persons with dementia or frailty (Singer, Martin & Kelner, 1999), and formal and informal caregivers, often prefer palliative care (Hughes, Robinson, & Volicer, 2005) they are often not referred to palliative care services, fail to receive optimal pain and symptom management and are likely to receive unnecessary life prolonging treatment such as artificial hydration or feeding tubes at the end of life (Sachs, Shega, & Cox-Hayley, 2004).

Persons with dementia or frailty may not be perceived as suffering from a life-limiting condition and therefore are not referred to palliative care services. Often persons with dementia or frailty are recognized to die from other diagnoses such as pneumonia or heart failure. If a diagnosis of dementia or characteristics of frailty are recognized as a cause of death, they are more likely to be perceived as a secondary predisposing or contributing factors rather than the primary cause of death (Sachs, Shega, & Cox-Hayley, 2004). Similar to challenges in prognostication mentioned previously for persons on the organ systems failure trajectory, differentiation of a terminal event from an exacerbation for persons with dementia or frailty is challenging.

Figure 2.4. Dementia and Frailty Trajectory of Death.



Source: Lynn, J. & Adamson, D.M. (2003) Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. Washington: Rand Health, pp. 11.
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In addition, due to the highly unstable nature of both dementia and frailty, persons with dementia or frailty may require periods of palliative pain and symptom management during an acute exacerbation from which their health condition may improve. Their health condition may then stabilize to a point where they cease to require palliative pain and symptom management. As will be shown in the Trajectory Model of Care (Figure 2.6.), the need for palliative care is projected to increase over time and that benefits from aggressive or curative treatments will decrease. The system for palliative care services is not structured to address the needs of persons with frailty and dementia who may benefit from periodic palliative care in which services start and stop as required. For example, palliative care may be beneficial to address uncontrollable pain during an exacerbation but then no longer required or reduced during periods of relative stability when the pain is controlled. In this case, the “revolving door” complicates the design, coordination, and delivery of palliative care (Tilly & Fok, 2008).

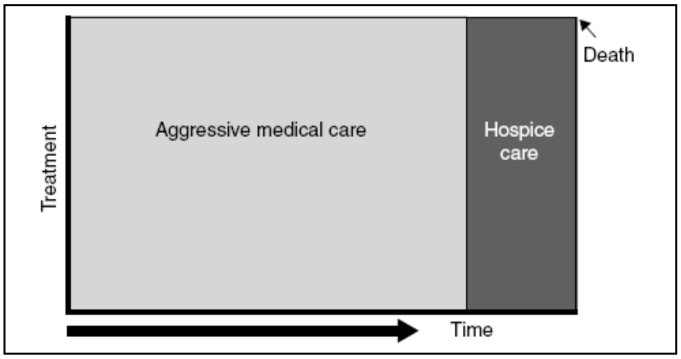
2.3.4 Alternative Trajectory

It must be noted that the four trajectories (cancer, organ system failure, dementia/frailty, and sudden death) are theoretical guides and there are always exceptions. With advancements in cancer treatments, some types of cancer have become a chronic illness following other illness trajectories making them increasingly challenging to prognosticate. Some cancers, such as prostate cancer, may result in long-term disability rather than a short-term decline and follow the organ system trajectory. Conditions including strokes may follow the cancer trajectory with a short period of quick decline while diseases such as HIV/AIDS may fit multiple trajectories depending on the phase or co-morbidities experienced. Persons with a progressive neurological condition may also fit both the organ systems failure trajectory and the dementia and frailty trajectory. And finally, any person may fall victim to a sudden death or unexpected trauma.

2.4 Models of Palliative Care

The IAHPC advocates that there is no “right or wrong” or one size fits all model of palliative care (Doyle & Woodruff, 2013). In Canada, there are three prevailing models of care: the Transition Model of Care (Figure 2.5.) and the Trajectory Model of Care (Figure 2.6.) as postulated by Lynn and Adamson (2003), which describe the dying process, and the CHPCA Square of Care (SoC) (2005; Figure 2.7.), used to organize and direct the steps in the process of providing palliative care.

Figure 2.5. Transition Model of Care.



Source: Lynn, J. & Adamson, D.M. (2003) Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. Washington: Rand Health, pp. 10.
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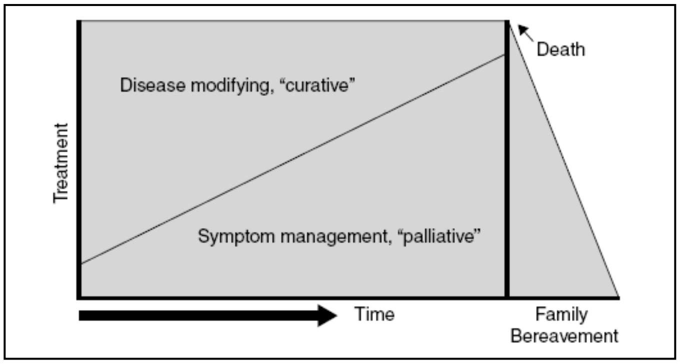
In the Transition Model of Care (Figure 2.5.) there is a specific point in the disease trajectory when the care needs of the person change from a curative or aggressive medical treatment focus, to hospice care focus where the person is recognized as 'terminally ill' with limited expectations for survival. Curative treatment is stopped, a comfort plan initiated until the point of death, which marks the end of care. Eligibility requirements for programs fitting in the Transition Model of Care may include:

- Request comfort and symptom management and refuse any curative or aggressive treatment;
- Have clearly stated advance directives including a do not resuscitate order (DNR) refusing any extraordinary measures
- Person has a specified limited prognosis (e.g. less than 3 months)

These criteria conflict with the definition of palliative care and limit access for a large number of persons with a life limiting illness. They reinforce misperceptions that palliative care is appropriate only when all other options have failed, is beneficial only for persons at the end of life or who are actively dying, and is not to be provided at the same time as curative or aggressive treatment.

In contrast, the Trajectory Model of Care (Figure 2.6.) recognizes that over the course of an illness, persons may simultaneously require varying amounts of disease modifying curative treatment and palliative symptom management and incorporates a period of palliative care for family bereavement after death. The diagonal line indicates that as the person progresses towards death they will require increased levels of palliative care and symptom management and decreasing amounts of curative and active care. The Trajectory Model of Care does not require a limited prognosis like the Transition Model of Care and instead, expands to include persons with a life limiting illness and their informal support network.

Figure 2.6. Trajectory Model of Care.



Source: Lynn, J. & Adamson, D.M. (2003) Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. Washington: Rand Health, pp. 10.
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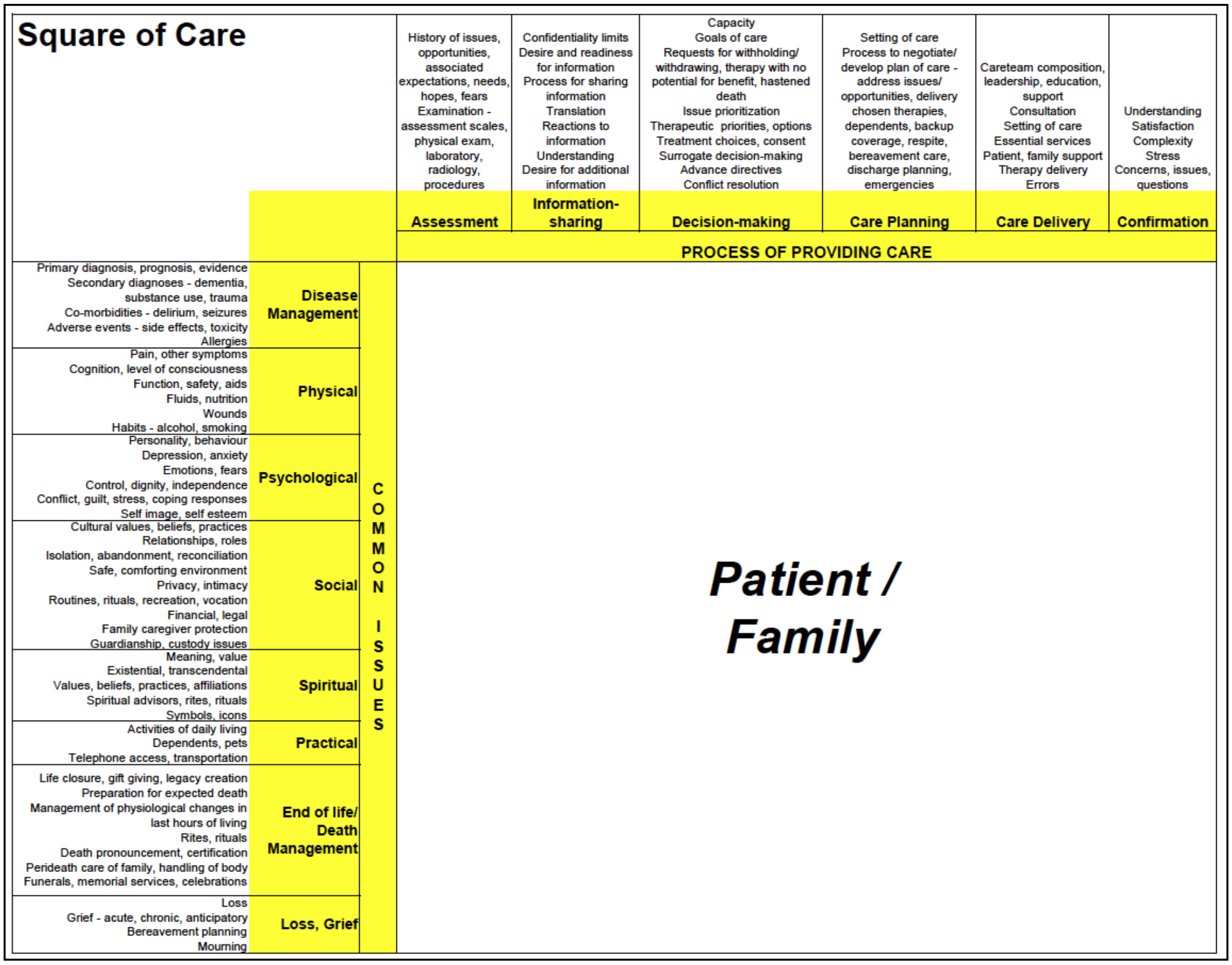
The 'Square of Care' (SoC) utilizes a bottom up approach based on recognition of cultural and ethnic diversity to marry the strengths of the Transition Model of Care and the Trajectory Model of Care (Figure 2.7.) (CHPCA, 2005). The SoC provides a foundation to address the individuality of person-specific need for palliative care in relation to the availability of services. It is based on two interacting dimensions. The SoC takes a holistic approach emphasizing consideration of multiple aspects of patient need and disease management, all highly relevant concerns to be addressed by clinicians during the care planning process (Shahidi, Bernier, & Cohen, 2009). Care provision is organized from assessment and decision making through care planning and delivery to address common issues including disease management, physical, psychological, social, spiritual, practical, end of life/death management, and loss/grief domains. Ferris et al., (2002) note the value of standardized needs assessment to gather evidence to inform care planning, identify need, and set the goals of care with the person faced with a life limiting illness and when appropriate also with their informal support network.

Figure 2.7. CHPCA Square of Care.



Square of Care

Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation
History of issues, opportunities, associated expectations, needs, hopes, fears Examination - assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity Goals of care Requests for withholding/ withdrawing, therapy with no potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/ develop plan of care - address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions

PROCESS OF PROVIDING CARE

Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	Disease Management	COMMON ISSUES
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	Physical	
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	Psychological	
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	Social	
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	Spiritual	
Activities of daily living Dependents, pets Telephone access, transportation	Practical	
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Perideath care of family, handling of body Funerals, memorial services, celebrations	End of life/ Death Management	
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	Loss, Grief	

Patient / Family

Source: Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., … West, P. (2004). In: A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, Ottawa, Canada, pp. 112.

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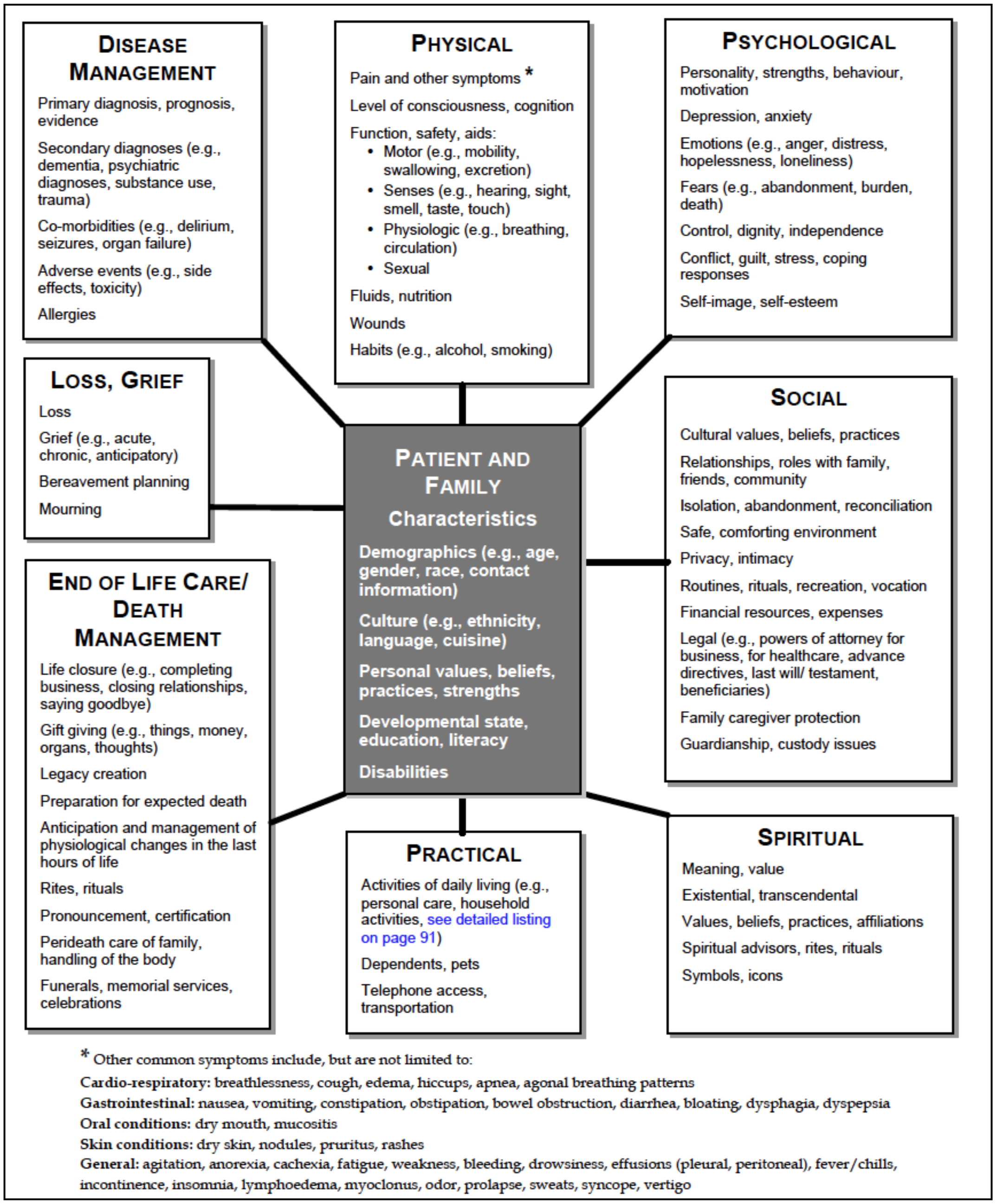
As persons with a life limiting illness progress across the illness trajectory it is important they be able to access the appropriate level of care to match their needs in the right place at the right time (O'Brien, 2003). Early phases may be characterized by allocation of both curative treatments and palliative care in the form of focused pain and symptom management or psychological counseling to reduce anxiety as promoted in the Trajectory Model of Care. As the illness progresses, the need for palliative care usually changes and tends to increase while availability of cure oriented intervention options often decrease. Over time, the person with a life limiting illness may reach a point where they no longer benefit from or desire curative or aggressive treatments and wish to set comfort oriented symptom management goals of care as advocated in the Transition Model of Care. In contrast, the SoC advocates use of a person-driven approach where the self-defined needs of the person drive resource allocation within the context of available resources at any time across the illness trajectory. Only the SoC prioritizes persons with a life limiting illness access the level of care matched to their individualized needs at the right time irrespective of prognosis or preference for cure oriented treatment.

2.5 Overview of Symptoms Common among Persons Receiving Palliative Care

Resources focused on directing and informing symptom management for persons with a life limiting illness are diverse. CHPCA recognizes eight key domains of issues associated with illness and bereavement, outlined in Figure 2.8. (CHPCA, 2005), which illustrate the wide range of symptoms experienced by persons with a life limiting illness. The examples listed in each the domain do not represent an exhaustive list. The symptom experience of persons with a life limiting illness as they near the end of life may differ by context (diagnosis, prognosis, and care setting); symptoms may intensify, subside, or disappear over time while new symptoms may appear, (Heidrich, 2007).

Figure 2.8. CHPCA Domains of Palliative Care.



* Other common symptoms include, but are not limited to:
Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns
Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia
Oral conditions: dry mouth, mucositis
Skin conditions: dry skin, nodules, pruritus, rashes
General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Source: Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., … West, P. (2004). In: A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, Ottawa, Canada, pp. 15.
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A founding principle of palliative care is ‘pain and symptom management’. Among persons requiring palliative care, pain is often the most frequently reported symptom (Doyle & Woodruff, 2013). Pain and symptom management must address multiple complex issues as recognized and prioritized by the person with a life limiting illness on a case-by-case basis. Common to textbook or print publications on palliative care which address symptom management is a primary emphasis detailing in-depth pain management followed by follow-up sections highlighting a plethora of other symptoms. In the Palliative Care Manual 2nd Edition released by the IAHPC (Doyle & Woodruff, 2013), pain and its management are the clear focus. Pain is the first symptom addressed and is discussed in its own chapter accounting for approximately one third of the manual (45/150 pages). In contrast, the chapter on symptom control that emphasizes multiple respiratory (breathlessness, cough, terminal respiratory congestion), gastrointestinal (nausea and vomiting, bowel obstruction, constipation), and constitutional (anorexia, weight loss, weakness and fatigue, neurological—confusion/delirium/ terminal restlessness) symptoms key for clinicians to address are all contained and described in less than one quarter of the manual (35/150 pages) (Doyle &Woodruff, 2013). The IAHPC manual also contains a separate section on guidelines of care for psychosocial issues including psychological distress, depression, anxiety, and spiritual/existential distress (Doyle &Woodruff, 2013), which accounts for only 15 pages. In contrast, the Oxford Handbook of Palliative Care (Fürst & Doyle, 2004) first describe the management of pain followed by a long list of individual symptoms including cachexia, anorexia, fatigue, sweating, fever, and the symptoms grouped into respiratory, gastrointestinal, genitourinary, and skin conditions. Fürst and Doyle (2004) include sections specific to head and neck cancers, endocrine and metabolic complications in advanced cancer, neurologic problems in advanced cancer, and sleep disorders. They provide specific reference to disease specific issues such as AIDS in adults, renal failure, or palliative care in non-malignant respiratory disease. These examples highlight an imbalance in the amount of information and emphasis placed on pain in comparison to other physical and psychological issues and symptoms experienced by persons nearing the end of life in the context of palliative care.

In their study measuring the prevalence and patterns of symptoms among 400 persons receiving palliative care, Potter, Hami, Bryan and Quigley, (2003) found that the five most prevalent symptoms were pain, anorexia, constipation, weakness, and dyspnea. Ng and von Gunten (1998) found the most common symptoms among 100 patients admitted to an acute hospice palliative care unit to be: pain, constipation, nausea, vomiting, anorexia, confusion, dyspnea, weakness, insomnia, and depression. In a study of somatic symptoms among cancer patients with pain and/or depression, Kroenke, Johns, Theobald, Wu, & Tu, (2013) found high prevalence of symptoms at baseline where 15 of the 22 symptoms they were investigating were present among more than 50% of their respondents. The most prevalent of the 22 symptoms included: fatigue, sleep problems, pain, memory problems, dry mouth, shortness of breath, gastrointestinal problems, and numbness. Kroenke et al. (2013) also noted that differences in prevalence of symptoms differed when compared to other studies by Esther Kim, Dodd, Aouizerat, Jahan, & Miaskowski, (2009) and Teuuissen et al. (2007) yet all three studies reported fatigue as the most common symptom. In order of highest prevalence, fatigue was followed by pain, lack of appetite, dry mouth, constipation, insomnia, and shortness of breath in Teuuissen et al. (2007) and followed by dry mouth, insomnia, pain, drowsiness, lack of appetite, dyspepsia, numbness, and shortness of breath in the study by Esther Kim, Dodd, Aouizerat, Jahan, & Miaskowski, (2009).

With the diversity of symptoms experienced at end of life and each symptom's unique relationship to both disease diagnosis and illness trajectory, a person specific plan of care addressing the symptoms perceived as most distressing by the person is warranted. If one or more issues perceived as central to the experience of the person with a life limiting illness are not addressed, they can snowball and result in increased symptom complexity, distress and more severe complications (CHPCA, 2005). Failure to address distressing symptoms can be a barrier to goal attainment and to the ability of the person with a life limiting illness to adapt their perceptions of healthiness and find meaning or value. Moreover, unaddressed and uncontrolled symptoms are highly disturbing for members of the person's informal support network and can be a source of increased stress and anxiety.

2.5.1 Dyspnea

Dyspnea, also referred to as shortness of breath or breathlessness, is one of the most frequently reported and highly distressing symptoms affecting persons nearing end of life (Ng and von Gunten, 1998; Potter, Hami, Bryan and Quigley, 2003; Kroenke, Johns, Theobald, Wu, & Tu, 2013). The American Thoracic Society (1999) defines dyspnea as:

> a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity, is derived from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioral responses.

Dyspnea may be "acute or chronic, progressive, recurrent, paroxysmal, or episodic" (Wilkins, Dexter, & Heuer, 2009, page 41) depending on the frequency, symptom features, and experiences of the person. Subtypes of dyspnea include orthopnea, platypnea, and trepopnea. Dyspnea may be referred to as orthopnea if the shortness of breath occurs solely when the person is in a reclining position or is lying down (Wilkins, Dexter, & Heuer, 2009). To obtain relief from orthopnea, the person may use pillows to elevate their upper body. Clinicians commonly refer to orthopnea as 'two- or three- pillow orthopnea' depending on how many pillows are used by the person to obtain symptom relief (Wilkins, Dexter, & Heuer, 2009). Orthopnea commonly occurs among persons with congestive heart failure (Wilkins, Stoller, & Scanlan, 2003). If dyspnea is present solely in the upright position, dyspnea may be referred to as platypnea. Platypnea, the opposite of orthopnea, is often relieved when the person changes to a recumbent position (Wilkins, Dexter, & Heuer, 2009). Platypnea is an uncommon symptom and may be hereditary or occur in relation to chronic liver disease (hepatopulmonary syndrome) (Wilkins, Stoller, & Scanlan, 2003). Trepopnea is when dyspnea occurs when the person is lying in one lateral position but not the other; meaning the dyspnea may occur when the person is lying down on either their left or right side, but not both (Wilkins, Dexter, & Heuer, 2009). Wilkins, Dexter, and Heuer (2009) note that trepopnea is most commonly associated with chest disorders that affect only one side of the body and provide examples where this may occur including unilateral lung disease, unilateral pleural effusion, and unilateral airway obstruction.

The subjective nature of dyspnea means that it is experienced both physically (body) and cognitively (mind) (Booth, Moosavi, & Higginson, 2008). Dyspnea directly affects functional ability and mobility. It can also cause anxiety and fear increasing the risk of social isolation (Bredin, et al., 1999; Parshall et al., 2012). It can be physically and psychologically distressing for the person and for members of their informal support network. Despite its high prevalence and severity of distress, attention to dyspnea in the literature is lacking (Dudgeon & Rosenthal, 1996; Currow, Smith, Davidson, Newton, Agar, & Abernethy, 2010). Dyspnea may be described in different ways including: ‘tightness in their chest’, ‘feelings of suffocation’, ‘air hunger’, increased difficulty to breath’, or ‘increased effort to breath’ (Wilkins, Dexter, & Heuer, 2009). Accordingly, dyspnea has been selected as the symptom of focus of this thesis to not only illustrate potential benefits of care planning using data gathered from a comprehensive assessment instrument (interRAI PC) but also in order to expand current understanding and awareness of this highly distressing symptom among persons with a life limiting illness and members of their informal support network.

2.5.1.1 Prevalence

Dyspnea is a complex and multifaceted symptom. It may be challenging to address, as the level of severity shows no clear relation to pulmonary functioning or disease status (Booth, Moosavi, & Higginson, 2008). With no clearly accepted ideal measurement scale for dyspnea (Dorman, Byrne, & Edwards, 2007) and no universally recognized evaluation criteria (Bruera, Sweeney, & Ripamonti, 2002), estimated prevalence rates for dyspnea vary greatly from 3 to 25% in the general population (Michelson

& Hollrah, 1999) to 16 to 80% among persons with a life limiting illness (Ng & von Gunten 1998; Watson, Lucas, Hoy, & Wells, 2009). Prevalence rates vary by both disease diagnosis and point in illness trajectory (expected time toward death). It is one of the most common symptoms experienced by up to 95% of persons with COPD, up to 70% of persons with advanced cancer and over 85% of persons with cardiac failure and motor neuron disease (Oliver, 2005; Solano, Gomez, & Higgenson, 2006). In their review of published studies, Solano, Gomez, & Higgenson (2006) noted prevalence of dyspnea ranges from 54 to 85% for persons with AIDS, 69-82% for persons with heart disease, and 11 to 62% for persons with renal disease.

Edmonds, Karlsen, Khan, & Addington-Hall (2001) found that in the final year of life, 94% of persons with chronic lung disease (CLD) experienced dyspnea compared to 78% of persons with lung cancer. Moreover, they note the prevalence of dyspnea was 91% for persons with CLD and 69% for those with lung cancer in the final week of life (Edmonds, Karlsen, Khan, & Addington-Hall, 2001). The prevalence of dyspnea also ranged within disease diagnosis. In an international multi-site study of persons with cancer receiving palliative treatment, Vainio and Auvinen, (1996) reported the overall prevalence of dyspnea (19%) ranged greatly by cancer diagnosis from only 6% for persons with head and neck cancer to 46% of persons with lung cancer. In the last six weeks of life it is estimated that 70% of persons receiving palliative care experienced dyspnea and this increases to 90% during the active dying phase (Tarzian, 2000).

Development of and experiences with dyspnea vary greatly by disease trajectory. Persons following a chronic disease trajectory (e.g. persons with COPD) may not experience dyspnea early in the illness trajectory even though there is substantial impairment to their respiratory system. The person may be more likely to develop dyspnea gradually and increase in severity as the person progresses across the illness trajectory towards death. It is usually not until the advanced stages of the disease when persons with COPD are likely to develop severe dyspnea (Booth, Moosavi, & Higginson, 2008). Booth et al.

(2008) notes how this gradual progression experienced by persons with COPD is contrasted by the experience of persons with cancer who more often experience episodic dyspnea characterized by rapid progression and increasing severity in the final weeks and days prior to death. Moreover, the duration that persons with COPD may experience dyspnea for is often longer compared to persons with cancer (Edmonds, 2001).

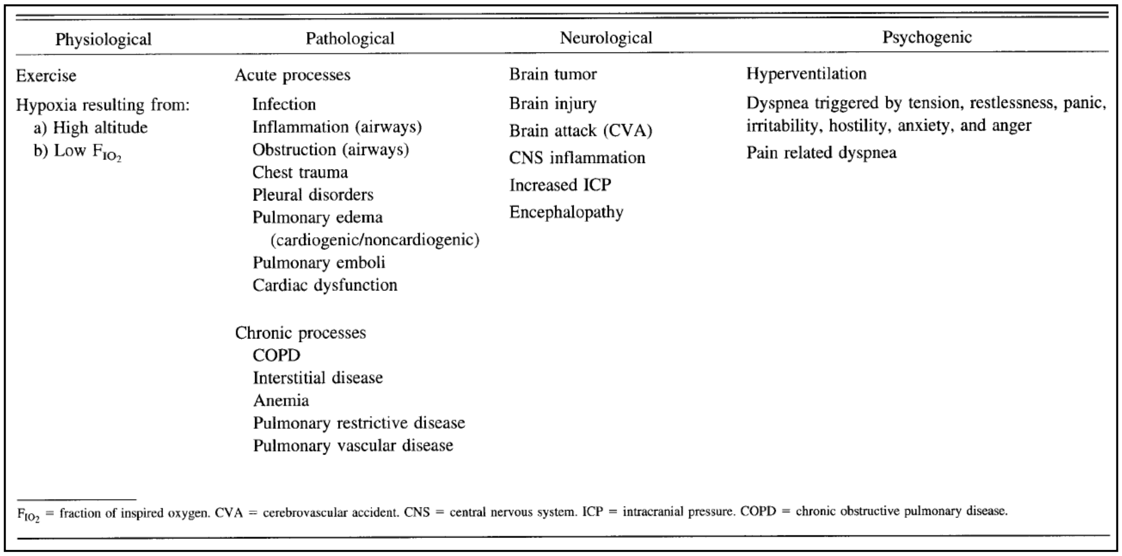
2.5.1.2 Pathophysiology

The pathophysiology of dyspnea is multifactorial and not fully understood yet in the scientific and medical world. As the cause may involve single or multiple organ systems, it is important to first isolate which organ system is involved (example: respiratory, cardiovascular, neither system, or both systems) and then conduct follow-up diagnostic testing as needed.

Thomas and von Gunten (2002) aim to simplify understanding of the complexity of the pathophysiology of dyspnea organized through three important components: Work of Breathing; Chemical; and Neuromechanical Dissociation. Work of breathing refers to greater effort needed to breathe when there is increased resistance (e.g. COPD) or when there is muscle deconditioning or weakness (e.g. ALS). Thomas and von Gunten (2002) note that the most important factor is this "increased respiratory work". Chemical refers to hypoxaemia ("subnormal oxygenation of arterial blood"; Dirckx, 2005) and hypercapnia ("abnormally increased arterial carbon dioxide tension"; Dirckx, 2005). In contrast to general perceptions, hypercapnia is believed to be more important for persons with dyspnea than hypoxaemia (Thomas & von Gunten, 2002). Moreover, Thomas notes that the majority of persons with cancer do not exhibit dyspnea related to hypoxaemia. Neuromechanical dissociation refers to discordance between the brain's perception of required respiratory function and the sensory feedback it receives regarding the actual existing respiratory function. This discordance may lead to dyspnea (O'Donnell & Webb, 1993). Accordingly, clinicians may understand dyspnea in relation to these three factors of pathophysiology viewed as independent factors or clinicians may conceptualize dyspnea as an inter-related interaction between more than one of these factors.

Sorenson (2000) categorized dyspnea into four different groups: Physiologic, pathologic, neurologic, or psychogenic. These categories assist to organize understanding of the diverse range of potential causes (Figure 2.9.). Wilkins, Dexter, and Heuer (2009) provide an expanded list including the following clinical types of dyspnea: Physiologic, pulmonary (restrictive and obstructive), cardiac, circulatory, chemical, central, and psychogeneic. They note that each clinical type of dyspnea is associated with a specific list of conditions or features depicted by different signs and symptoms (Wilkins, Dexter, & Heuer, 2009, pp.36).

Figure 2.9. General Classifications of Dyspnea.



Physiological	Pathological	Neurological	Psychogenic
Exercise Hypoxia resulting from: a) High altitude b) Low F_{IO_2}	Acute processes Infection Inflammation (airways) Obstruction (airways) Chest trauma Pleural disorders Pulmonary edema (cardiogenic/noncardiogenic) Pulmonary emboli Cardiac dysfunction Chronic processes COPD Interstitial disease Anemia Pulmonary restrictive disease Pulmonary vascular disease	Brain tumor Brain injury Brain attack (CVA) CNS inflammation Increased ICP Encephalopathy	Hyperventilation Dyspnea triggered by tension, restlessness, panic, irritability, hostility, anxiety, and anger Pain related dyspnea

F_{IO_2} = fraction of inspired oxygen. CVA = cerebrovascular accident. CNS = central nervous system. ICP = intracranial pressure. COPD = chronic obstructive pulmonary disease.

Source: Sorenson, H. M. (2000). Dyspnea assessment. Respiratory care, 45(11), 1331. Copyright Permission received Sept. 5th, 2013 from Ray Masferrer, Managing Editor of Respiratory Care

In general the most common causes for dyspnea include asthma, pneumonia, myocardial ischemia, and deconditioning (Porter & Kaplan, 2012). However, for persons with COPD or cardiac disorders the most common cause of dyspnea is disease exacerbation (Porter & Kaplan, 2012). Other factors associated with increased prevalence of dyspnea include: advanced age, low socio-economic status, history of smoking, morbid obesity, and gender (female) (Michelson & Hollrah, 1999). The wide range of possible causes for dyspnea is known to vary based on the acuity of the onset of the symptoms. The Merck Manual for Health Care Professionals (Porter & Kaplan, 2012) lists some causes and risk factors for development of dyspnea broken down by the type of dyspnea: acute (occurs almost immediately following the event), sub-acute (occurs within a few hours or days following the event), and chronic (occurs within a few hours or up to years following the event). Causes of acute dyspnea may include but are not limited to:

- Pulmonary causes:
  - Pneumothorax;
  - Pulmonary embolism;
  - Asthma, bronchospasm, or reactive airway disease;
  - Foreign body inhalation;
  - Toxin-induced airway damage.
- Cardiac causes:
  - Acute myocardial ischemia or infarction;
  - Papillary muscle dysfunction or rupture;
  - Heart failure.
- Other causes:
  - Diaphragmatic paralysis;
  - Anxiety disorder causing hyperventilation (Porter & Kaplan, 2012).

Causes of sub-acute dyspnea may include but are not limited to:

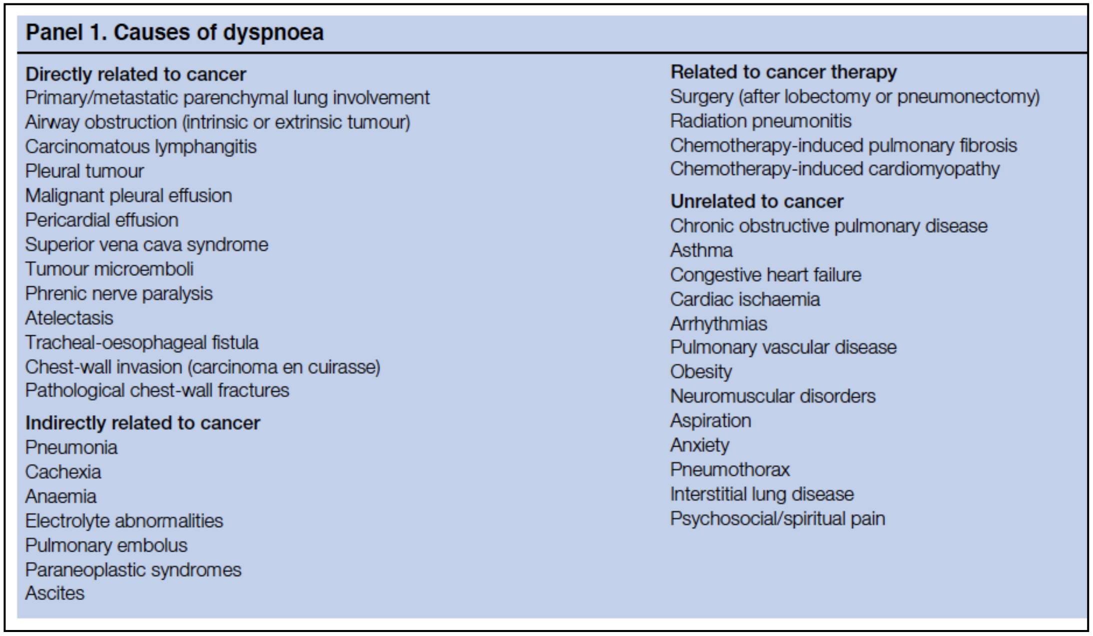
- Pulmonary causes:
  - Pneumonia;
  - COPD exacerbation.
- Cardiac causes:
  - Angina;
  - Coronary artery disease;
  - Pericardial effusion or tamponade (Porter & Kaplan, 2012).

Causes of chronic dyspnea may include but are not limited to:

- Pulmonary causes:
    - Obstructive lung disease;
    - Restrictive lung disease;
    - Interstitial lung disease;
    - Pleural effusion.
- Cardiac causes:
    - Heart failure;
    - Stable angina;
    - Coronary artery disease;
- Other causes:
    - Anemia;
    - Physical deconditioning (Porter & Kaplan, 2012).

When addressing dyspnea experienced by persons with a life limiting illness, it is critical that the cause be identified where possible. In addition to the causes for acute, sub-acute, and chronic dyspnea as listed above potential causes of dyspnea specific for persons at end of life may include: obstructing tumors, pulmonary embolism, pleural effusions, infections, anemia, arrhythmia, bronchospasm, pneumothorax, cardiac failure, abdominal ascites, and superior vena cava syndrome (Kristjanson 2006; McCusker et al., 2009). In Figure 2.10., Thomas (2003) lists various causes of dyspnea in categories emphasizing the heterogeneity of causes of dyspnea in relation to cancer vs. non cancer diagnoses as well as direct vs. indirect causes related to cancer. In addition it also provides a sub-list of causes of dyspnea known to be associated with cancer therapy in contrast to the diagnosis of cancer itself (Thomas, 2003). Wilkins, Dexter, and Heuer (2009) note that common causes of dyspnea range by the associated body system(s). For example, they note that common causes of dyspnea for the neurologic system may include: brain tumor, increased intracranial pressure, hypertensive encephalopathy, and some cardiovascular accidents; while common causes for the metabolic and endocrine system may include: toxins, uremia, hepatic coma, thyrotoxicosis, and myxedema (Wilkins, Dexter, & Heuer, 2009).

Figure 2.10. Causes of Dyspnea.



Panel 1. Causes of dyspnoea

Directly related to cancer
- Primary/metastatic parenchymal lung involvement
- Airway obstruction (intrinsic or extrinsic tumour)
- Carcinomatous lymphangitis
- Pleural tumour
- Malignant pleural effusion
- Pericardial effusion
- Superior vena cava syndrome
- Tumour microemboli
- Phrenic nerve paralysis
- Atelectasis
- Tracheal-oesophageal fistula
- Chest-wall invasion (carcinoma en cuirasse)
- Pathological chest-wall fractures

Indirectly related to cancer
- Pneumonia
- Cachexia
- Anaemia
- Electrolyte abnormalities
- Pulmonary embolus
- Paraneoplastic syndromes
- Ascites

Related to cancer therapy
- Surgery (after lobectomy or pneumonectomy)
- Radiation pneumonitis
- Chemotherapy-induced pulmonary fibrosis
- Chemotherapy-induced cardiomyopathy

Unrelated to cancer
- Chronic obstructive pulmonary disease
- Asthma
- Congestive heart failure
- Cardiac ischaemia
- Arrhythmias
- Pulmonary vascular disease
- Obesity
- Neuromuscular disorders
- Aspiration
- Anxiety
- Pneumothorax
- Interstitial lung disease
- Psychosocial/spiritual pain

Source: Thomas, L. A. (2003). Clinical management of stressors perceived by patients on mechanical ventilation. AACN Advanced Critical Care, 14(1), page 225.

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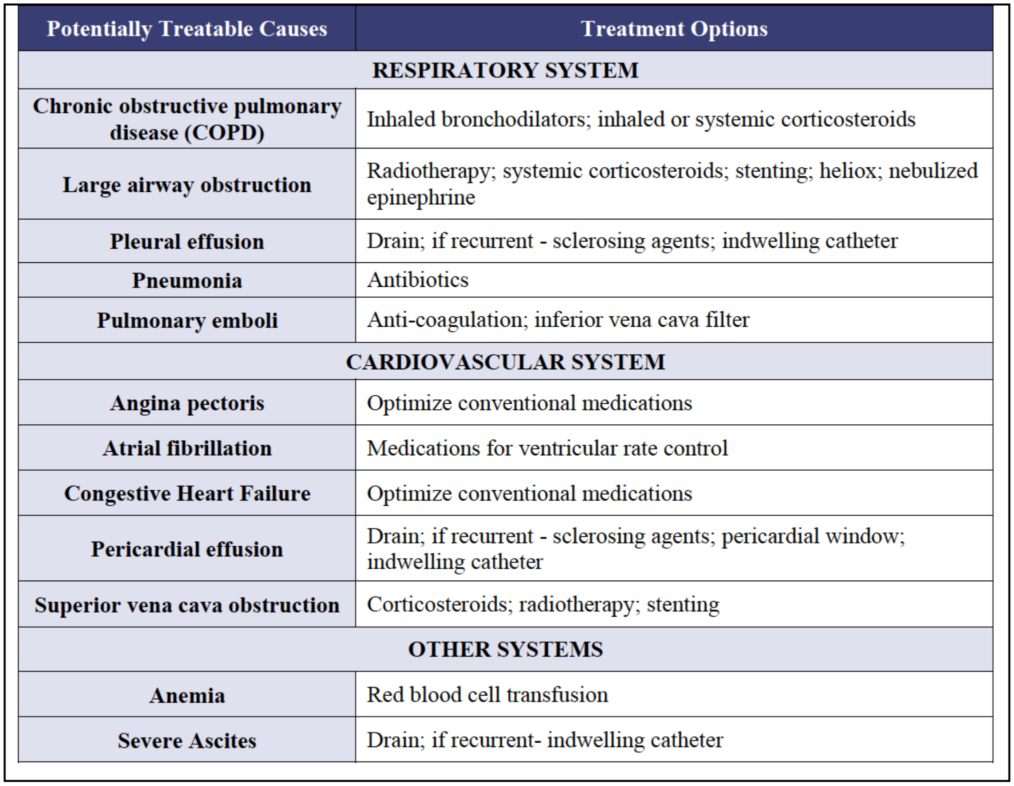
Dyspnea may not always be directly attributed to somatic disease and may instead be exacerbated by factors such as fear or anxiety. Dyspnea may trigger a cycle of distress where the symptoms of dyspnea cause anxiety, which then elevates the symptoms of dyspnea thereby increasing further the psychological distress experienced by the person with a life limiting illness (Kristjanson, 2006). Common psychological causes of dyspnea include severe anxiety and hyperventilation syndrome (Wilkins, Dexter, & Heuer, 2009).

Table 2.1. illustrates a number of potentially treatable causes of dyspnea for persons with a life limiting illness matched to examples of treatment options (Cancer Care Ontario [CCO], 2010). Care planning should investigate person specific causes for dyspnea and tailor pharmacological and non-pharmacological treatments where possible and desirable in accordance with established goals of care, co-morbidities, and life expectancy of the person with a life limiting illness (McCusker et al., 2009; NHS

Lothian, 2009; CCO, 2010). It is important for clinicians to recognize which causes may respond to treatment and which may not. In the case where the cause may not respond to treatment then the goals of care should focus on reducing the symptom severity of dyspnea and educating the person on the progression of the symptom as the illness progresses.

Table 2.1. Potentially Treatable Underlying Causes of Dyspnea.



Potentially Treatable Causes	Treatment Options
RESPIRATORY SYSTEM	
Chronic obstructive pulmonary disease (COPD)	Inhaled bronchodilators; inhaled or systemic corticosteroids
Large airway obstruction	Radiotherapy; systemic corticosteroids; stenting; heliox; nebulized epinephrine
Pleural effusion	Drain; if recurrent - sclerosing agents; indwelling catheter
Pneumonia	Antibiotics
Pulmonary emboli	Anti-coagulation; inferior vena cava filter
CARDIOVASCULAR SYSTEM	
Angina pectoris	Optimize conventional medications
Atrial fibrillation	Medications for ventricular rate control
Congestive Heart Failure	Optimize conventional medications
Pericardial effusion	Drain; if recurrent - sclerosing agents; pericardial window; indwelling catheter
Superior vena cava obstruction	Corticosteroids; radiotherapy; stenting
OTHER SYSTEMS	
Anemia	Red blood cell transfusion
Severe Ascites	Drain; if recurrent- indwelling catheter

Source: Cancer Care Ontario. (2010). Cancer Care Ontario's Symptom Management Guide-to-Practice: Dyspnea. Retrieved from: https://www.cancercare.on.ca/toolbox/symptools/

Permission received from Cancer Care Ontario, Communications division, Sept. 4th, 2013. "Table and information borrowed with permission from Cancer Care Ontario's Symptom Management Guide-to-Practice: Dyspnea".

2.5.1.3 Treatment Options

As the diagnosis of dyspnea is based on the subjective perceptions of the person, acknowledgement and acceptance of their self-report experience should be the foundation for any plan of care (CCO, 2010). Attention during assessment, care planning, and treatment phase should focus on minimizing physical and psychological distress to address the persons self-perceived QOL. Treatment should first be based on a comprehensive assessment to clarify precipitating and alleviating factors on the individual or person level. In the respiratory community, clinicians recognize that the vast majority (over 75%) of information required about dyspnea can be ascertained through a comprehensive clinical assessment (Sorenson, 2000). During the initial assessment clinicians should discuss with the person their perceptions of dyspnea and then elucidate any abnormal experiences the person may have with their breathing. This may assist the clinician to identify if dyspnea is present and inform further investigation into the source of the symptoms of dyspnea. A detailed comprehensive patient history may also assist to identify any precipitating factors. If a source of the dyspnea is identified, potential underlying conditions or reversible causes should be examined. Table 2.2. lists of causes of dyspnea for persons with cancer and provides examples of specific management techniques to match the cause (Booth, Moosavi, & Higginson, 2008). They illustrate the wide range of causes and strategies for client care of dyspnea. The effects of current treatments should be determined and any associated symptoms affecting dyspnea addressed. The clinician should also investigate whether the person is experiencing fear and anxiety associated with the dyspnea and to determine the effects on the person’s QOL and activities of daily living (ADLs).

Table 2.2. Causes of Dyspnea in Advanced Cancer.

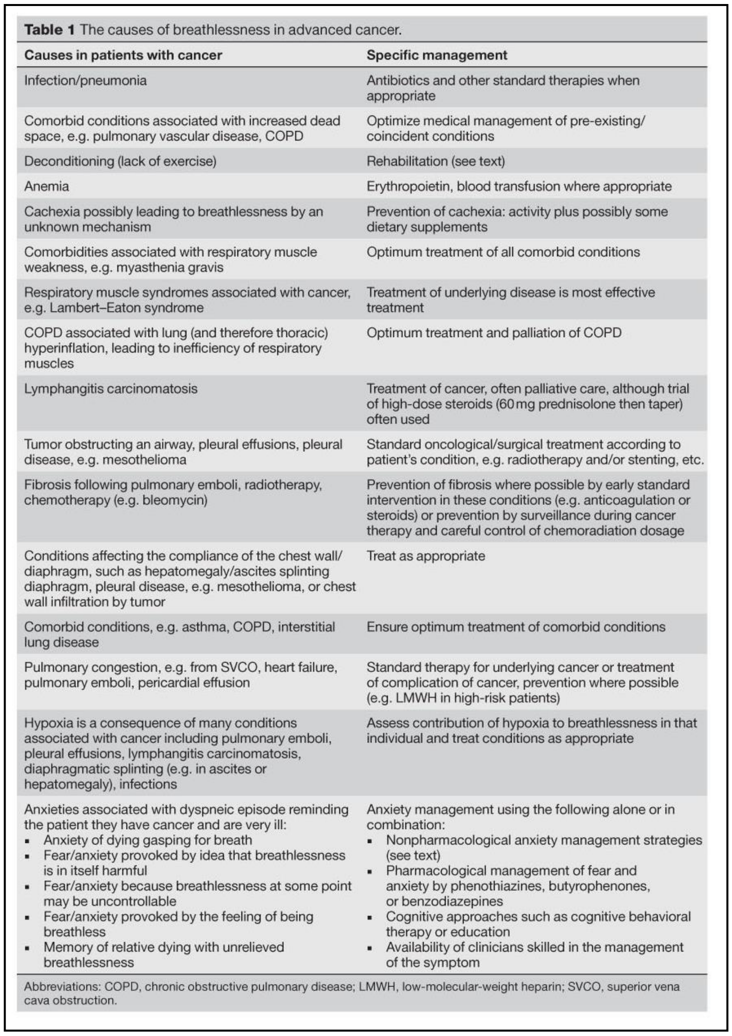


Table 1 The causes of breathlessness in advanced cancer.

Causes in patients with cancer	Specific management
Infection/pneumonia	Antibiotics and other standard therapies when appropriate
Comorbid conditions associated with increased dead space, e.g. pulmonary vascular disease, COPD	Optimize medical management of pre-existing/ coincident conditions
Deconditioning (lack of exercise)	Rehabilitation (see text)
Anemia	Erythropoietin, blood transfusion where appropriate
Cachexia possibly leading to breathlessness by an unknown mechanism	Prevention of cachexia: activity plus possibly some dietary supplements
Comorbidities associated with respiratory muscle weakness, e.g. myasthenia gravis	Optimum treatment of all comorbid conditions
Respiratory muscle syndromes associated with cancer, e.g. Lambert–Eaton syndrome	Treatment of underlying disease is most effective treatment
COPD associated with lung (and therefore thoracic) hyperinflation, leading to inefficiency of respiratory muscles	Optimum treatment and palliation of COPD
Lymphangitis carcinomatosis	Treatment of cancer, often palliative care, although trial of high-dose steroids (60 mg prednisolone then taper) often used
Tumor obstructing an airway, pleural effusions, pleural disease, e.g. mesothelioma	Standard oncological/surgical treatment according to patient's condition, e.g. radiotherapy and/or stenting, etc.
Fibrosis following pulmonary emboli, radiotherapy, chemotherapy (e.g. bleomycin)	Prevention of fibrosis where possible by early standard intervention in these conditions (e.g. anticoagulation or steroids) or prevention by surveillance during cancer therapy and careful control of chemoradiation dosage
Conditions affecting the compliance of the chest wall/ diaphragm, such as hepatomegaly/ascites splinting diaphragm, pleural disease, e.g. mesothelioma, or chest wall infiltration by tumor	Treat as appropriate
Comorbid conditions, e.g. asthma, COPD, interstitial lung disease	Ensure optimum treatment of comorbid conditions
Pulmonary congestion, e.g. from SVCO, heart failure, pulmonary emboli, pericardial effusion	Standard therapy for underlying cancer or treatment of complication of cancer, prevention where possible (e.g. LMWH in high-risk patients)
Hypoxia is a consequence of many conditions associated with cancer including pulmonary emboli, pleural effusions, lymphangitis carcinomatosis, diaphragmatic splinting (e.g. in ascites or hepatomegaly), infections	Assess contribution of hypoxia to breathlessness in that individual and treat conditions as appropriate
Anxieties associated with dyspneic episode reminding the patient they have cancer and are very ill: ▪ Anxiety of dying gasping for breath ▪ Fear/anxiety provoked by idea that breathlessness is in itself harmful ▪ Fear/anxiety because breathlessness at some point may be uncontrollable ▪ Fear/anxiety provoked by the feeling of being breathless ▪ Memory of relative dying with unrelieved breathlessness	Anxiety management using the following alone or in combination: ▪ Nonpharmacological anxiety management strategies (see text) ▪ Pharmacological management of fear and anxiety by phenothiazines, butyrophenones, or benzodiazepines ▪ Cognitive approaches such as cognitive behavioral therapy or education ▪ Availability of clinicians skilled in the management of the symptom

Abbreviations: COPD, chronic obstructive pulmonary disease; LMWH, low-molecular-weight heparin; SVCO, superior vena cava obstruction.

Source: Reprinted by permission from Macmillan Publishers Ltd: Nature Clinical Practice Oncology, Booth, S., Moosavi, S. H., & Higginson, I. J. (2008). The etiology and management of intractable breathlessness in patients with advanced cancer: a systematic review of pharmacological therapy. Nature Clinical Practice Oncology, 5(2), 90-100.

Management and treatment of dyspnea should be tailored to meet the needs identified by the person. A wide array of pharmacological and non-pharmacological interventions is available as will be discussed below; however, any potential benefits of the chosen approach must be weighed against potential burdens.

Available options may or may not be appropriate depending on symptom severity, estimated prognosis, and the identified goals of care of the person. Effective treatment and management of dyspnea is difficult. It is not always possible to relieve or alleviate the symptoms of dyspnea especially in the final weeks, days, and moments of life

2.5.1.3.1 Non-Pharmacological Treatments

Non-pharmacological interventions include counseling, breathing retraining, relaxation techniques, psychosocial support and coping and adaptation strategies (Bredin, et al., 1999; Corner, Plant, A'hern, & Bailey, 1996; Parshall et al., 2012). Counseling should involve listening to the person describe their experiences surrounding dyspnea and also be directed to addressing the experiences of members of the person's informal support network. Any fears experienced by the person should be discussed and a care plan to address current symptoms and future episodes of dyspnea crafted. Education should target both the current symptom experience associated with the dyspnea and also inform the person and their informal support network of situations and experiences which may occur over the future course of the illness. Referral for follow-up to a physiotherapist, respiratory therapist, or social worker may be useful to support understanding of dyspnea and the plan of care. Other strategies may include: keeping the room well-ventilated such as opening a window or having a cool fan, physiotherapy, positioning, acupuncture, acupressure, reducing the need for physical exertion, and education (Kristjanson, 2006; Booth, Moosavi, & Higginson, 2008). Cognitive behavioral therapy interventions have been shown beneficial when provided for one to two month duration (CCO, 2010). Relief from dyspnea may also be found in noninvasive positive pressure ventilation (NIPPV, also referred to as BiPAP). NIPPV may assist in reducing the amount of effort required to breathe reducing the person's reliance on opioids and thereby enabling the person to remain more wakeful and comfortable (Pinna, 2012).

2.5.1.3.2 Pharmacological Treatments

The majority of persons with dyspnea at the end of life will require pharmacological treatment to address their symptoms (Jennings, 2002). Pharmacological treatments used to manage dyspnea may include oxygen, sedatives, bronchodilators, steroids, opioids, and benzodiazepines (Kristjanson, 2006; NHS Lothian, 2009). Morphine may be effective to reduce symptoms of dyspnea among persons with advanced cancer and advanced lung disease (Mazzocato, Buclin, & Rapin, 1999; Qaseem et al., 2008). Low doses of sustained release oral morphine have been found useful in relieving dyspnea (Abernethy et al., 2003). Inhaled corticosteroids benefit patients who have lung cancer or who have dyspnea associated with an inflammatory component (for example: among persons with asthma or COPD) (McCusker et al., 2009). As the person's illness progresses, need for medication may increase and the preferred method for medication may change from an oral to a subcutaneous route. Oral and parenteral opioids are beneficial to treat dyspnea (Jennings, Davies, Higgins, Gibbs, & Broadley, 2002) however nebulized opioids, and phenothiazines are not recommended (CCO, 2010). Benzodiazepines are not recommended to manage dyspnea but are often used to treat the anxiety associated with dyspnea (DiSalvo, Joyce, Tyson, Culkin, & Mackay, 2008).

2.5.1.3.3 Special Considerations for Dyspnea Related to Palliative Care

As dyspnea is a subjective experience, the gold standard for diagnosis should remain the person's self-report. Treatments should be designed to meet person-specific needs on a case-by-case basis. For persons who are in the final stages of the disease trajectory or who have entered the actively dying phase, the priorities for treatment, care, and options for dyspnea may change substantially from the care plan crafted when expected prognosis was longer. Booth, Moosavi, & Higginson (2008), emphasize that while both the prevalence and severity of dyspnea increase as a person nears death, evidence is lacking regarding the effectiveness of interventions to improve dyspnea. The burden-benefit of dyspnea treatment should always be addressed especially when the person has entered the active dying phase. Although not discussed above, palliative sedation is an option for persons experiencing severe dyspnea and psychological distress in the final days and hours of life. Much controversy surrounds the use of palliative sedation but that is not a focus of this thesis.

Another key consideration when addressing potential treatment options is to recognize the challenges surrounding research and product testing. Development and testing of pharmaceuticals can be difficult from both practical and ethical perspectives. An interesting challenge for researchers and pharmacologists is the inability to conduct in vitro drug testing due to the lack of an animal model for breathlessness (Booth, Moosavi, & Higginson, 2008). Development of Randomized Controlled Trials (RCTs) to test and develop pharmacological treatment may be ethically challenging among a complex population at the end of life. With reduced functional abilities and anxiety, persons experiencing severe dyspnea may lack the physical capacity to perform clinical tests such as exercise or pulmonary function testing, or to remain still for an MRI (Booth, Moosavi, & Higginson, 2008). Ethical concerns raised when conducting RCTs involving participants nearing the end of life include: vulnerability of a medically fragile or clinically complex participant population requiring palliative care, treatment allocation and use of placebos, and issues surrounding informed consent (Addington-Hall, Bruera, Higginson, & Payne, 2009).

3. Care Planning

A care plan is “a carefully prepared outline of care showing both identified needs and the means to address them” (Farflex, 2012). It is an integral component of the care assessment, allocation, and management process and is key to ensuring care is directed to meet person-specific need. A care plan should be initiated upon program admission and reviewed and adjusted regularly to respond to change in clinical status affecting progress toward the desired or predicted outcomes of care (Dirckx, 2005). Care planning most often addresses a subset of defined problems on a person-by-person basis that require immediate medical nursing care interventions without which the problem may worsen (Carpenito-Moyet, 2007). The care planning process involves selection of the problem of focus, prioritization of the goals of care, identification of indicators to be addressed and selection of appropriate interventions (Caprentio-Moyat, 2007).

Key components of the care planning process are prioritization, delegation, and critical thinking (Haugen & Galura, 2010). Prioritization involves the identification of needs that necessitate a priority response in contrast to long-term issues that may be less urgent. The care plan to be developed should incorporate best practice guidelines that may include treatment with pharmacological, non-pharmacological, complimentary or supportive care and prevention strategies, to avoid the onset of distressing symptoms and unwanted side effects. The assessor then should delegate to whom and in what context the needs should be addressed. Critical thinking is key to triangulate knowledge gathered from multiple sources and to ensure the plan of care will effectively address the identified needs of the person.

It is important that the care plan is an accurate representation of the persons preferred goals of care. CHPCA (2005) note comprehensive assessment of need and allocation of palliative care provision as required during the care process should be guided by nine important principles:

1- Patient/family focused;
2- High quality;
3- Safe and effective;
4- Accessible to all patients in a timely manner regardless of location of care;
5- Adequate resourced to enable service or organization to function effectively;
6- Collaborative;
7- Knowledge-based and evidence informed recognizing importance of education;
8- Advocacy-based; and
9- Research focused on development, dissemination, and integration of knowledge.

A care plan, as is suggested by Carpenito-Moyet (2007), may be organized by first defining the problem, outlining related factors such as pathophysiology, treatment-related issues and situational (personal, environmental). Following, the care plan outlines key concepts including related factors and person specific considerations (e.g. Geriatric or end-of-life characteristics) and focuses the assessment criteria that incorporate both objective and subjective perspectives. Subsequently, the goals should be clearly defined with a set of indicators and general interventions identified which are based upon an included rationale for each suggested intervention. Clinicians may use pre-made care plans (e.g. Nursing Care Plans by Gulanick & Myers, 2011) as a framework and adjust them according to the person-specific needs of the client and their informal support network.

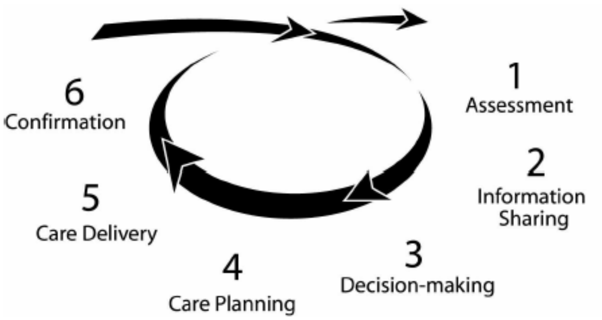
3.1 Care Planning in Palliative Care

Dr. Saunders, founder of the hospice care movement, emphasized that “the goal of the palliative care planning process, based on a careful assessment of symptoms from the person with a life limiting illness’ perspective, [is] not to make a diagnosis and treat solely pain, but to treat pain in addition to all the other issues that add up to a general state of misery” (Saunders, 1996). This founding principle of addressing the needs of the ‘whole person’ remains a critical focus for palliative care (Cohen, 2009) and important component for care planning. When care planning for persons with a life limiting illness, clinicians combine their clinical judgment with a comprehensive assessment to ensure all major issues affecting the person with a life limiting illness and their informal support network are identified (Morrison & Meier, 2004). White, McMullan, & Doyle (2009) reported among persons receiving palliative care, the number of symptoms detected using systematic assessment was ten times higher than those volunteered during the patient assessment. Moreover, they found that nearly two thirds of all symptoms experienced at the end of life not self-reported (White, McMullan, & Doyle, 2009). In the absence of detailed assessment, important symptoms that affect quality of life at the end of life may remain undetected (Homsi, et al., 2006; White, McMullan, & Doyle, 2009). Heyland et al., (2010) note the potential for improved end of life care in a Canadian context through prioritization of better care planning and stronger communication between the person with a life limiting illness and their health care team. Comprehensive clinical assessment should inform the care planning process to ensure that all symptoms experienced are discussed, support a person-driven goal setting and decision-making process, and improve communication between the person with a life limiting illness, their informal support network, and the care team.

Care planning typically follows three phases: intake, ongoing care, and closure (discharge) (CHPCA, 2005). Unique to care planning for persons with palliative care is the closure or discharge phase, which not only focuses upon death of the person but also should include the bereavement period for members of their informal support network. Although it is possible for persons with a life limiting illness to improve and no longer require care, the vast majority will receive services, which increase in response to increased health complexity and symptom burden as the person progresses towards death. The major focus of care planning for persons with a life limiting illness becomes pain and symptom management and maximizing QOL as they near end of life.

Persons with a life limiting illness seek guidance from the health care system to: develop a plan of care which upholds self-determination in treatment options; inform risks and benefits of treatment options; direct access to services; and recognize the effectiveness or futility of the plan of care (CHPCA, 2005). Palliative care provides this guidance through a therapeutic client driven relationship between the person with a life limiting illness, their informal support network, and the health care team. In Figure 3.1. the CHPCA illustrates six basic steps in a therapeutic encounter: 1-Assessment, 2-Information sharing, 3-Decision-making, 4-Care planning, 5-Care delivery, and 6-Confirmation. The therapeutic relationship prioritizes: communication of treatment and care options; discussion of associated risks and benefits; and empowerment of the person with a life limiting illness to make informed choices and decisions at all stages during the therapeutic relationship (CHPCA, 2005).

Figure 3.1. Steps During a Therapeutic Encounter.



1. Assessment
- History of active and potential issues, opportunities for growth, associated expectations, needs, hopes, fears
- Examine with assessment scales, physical examination, laboratory, radiology, procedures

2. Information sharing
- Confidentiality limits
- Desire and readiness for information
- Process for sharing information
- Translation
- Reactions to information
- Understanding
- Desire for additional information

3. Decision-making
- Capacity
- Goals for care
- Issue prioritization
- Therapeutic options with potential for benefit, risk, burden
- Treatment choices, consent
- Requests for:
  - withholding, withdrawing therapy
  - therapy with no potential for benefit
  - hastened death
- Surrogate decision-making
- Advance directives
- Conflict resolution

4. Care Planning
- Setting of care
- Process to negotiate and develop plan of care that:
  - Addresses issues and opportunities, delivers chosen therapies
  - Includes plan for:
    - Dependents
    - Backup coverage
    - Respite care
    - Emergencies
    - Discharge planning
    - Bereavement care

5. Care Delivery
- Careteam
  - Composition
  - Leadership, coordination, facilitation
  - Education, training
  - Support
- Consultation
- Setting of care
- Essential services
- Patient, family, extended network support
- Therapy delivery
  - Process
  - Storage, handling, disposal
  - Infection control
- Errors

6. Confirmation
- Understanding
- Satisfaction
- Complexity
- Stress
- Concerns, other issues, questions
- Ability to participate in the plan of care

Source: Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A., & West, P. (2002). In: A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, Ottawa, Canada, pp. 26.

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Stage 4 of the therapeutic process in Figure 3.1. is the care planning stage. Clinicians use the information they have gathered during the assessment through shared communication with, by, and about the person with a life limiting illness, and apply their own clinical judgment to inform decision making and care planning. The clinician then formulates a client specific goal oriented care plan tailored to meet the identified and prioritized needs of the person and their informal support network. Often this done by nurses or trained case managers. Nursing care plans typically begin with a defined diagnosis and identify how that diagnosis relates to other key issues (Haugen & Galura, 2010). This initial step is also referred to as recognizing diagnostic clusters (Carpenito-Moyet, 2009). Following, the clinician integrates both subjective and objective characteristics to identify risk factors for further decline or complication on a case-by-case basis. In consultation with the client, desired outcomes should be matched with available interventions and a clear rationale provided to educate the person and their informal support network. Together with the person and their informal support network, a plan of care should be crafted based on the identified goals of care of the person and the recognized needs requiring care or intervention.

The therapeutic relationship depends on an ongoing process of effective communication throughout three main phases of care (CHPCA, 2005). Care planning during the intake phase establishes the initial approach identifying the person's strengths, preferences and needs based on a collaborative dialogue between the clinical team, the person with a life limiting illness and their informal support network. The ongoing care phase promotes continuous revision of the care plan examining progress toward the person's goals of care and any changes in clinical status. Follow-up assessments track person-specific changes and may be used to evaluate outcomes including the effectiveness of interventions or treatments. For example, if the person with a life limiting illness exhibited a pressure ulcer at initial assessment, the clinician may refer the person to a wound care program. With consistent assessments, the clinician can monitor the person's skin integrity and pressure ulcer status to determine whether adjustments are required to the approach to care. Baseline and follow-up assessments allow the clinician to evaluate whether change has occurred and provide evidence to inform an ongoing, collaborative approach to care planning in partnership with the person with a life limiting illness and their informal support network. Care planning in the final phase focuses on transitions to ensure continuity of care and optimal symptom management for the person as they reach end of life and, for members of the informal support network, during the bereavement phase.

Care planning for persons with a life limiting illness can be complex and involve issues where added sensitivity, patience, and understanding are needed. While the priority for general care planning is usually outcomes based focusing on cure or rehabilitation of function to a previous level, care planning for persons receiving palliative care prioritizes maintenance or improvements in QOL through pain and symptom management. Notwithstanding, clinicians must be careful to recognize that opportunities may arise for cure of some symptoms, especially when the expected prognosis is longer, and tailor the care plan accordingly. Yet, even in the final moments of life, persons may still respond to treatment. For example, dyspnea is one of the most distressing symptoms for persons with a life limiting illness and their caregivers (Ng and von Gunten, 1998; Potter, Hami, Bryan and Quigley, 2003; Kroenke, Johns, Theobald, Wu, & Tu, 2013). It is highly prevalent and known to increase in severity as the person nears death (Booth, Moosavi, & Higginson, 2008). Yet dyspnea should not be accepted as a normal part or expected part of the dying process. Kuebler, Andry, and Davis (2007) note that in almost all cases, dyspnea will respond to intervention or treatment. Therefore, while cure is not possible, symptom alleviation may remain an important and realistic goal of care for persons and treatment/management strategies aimed at reducing symptoms like dyspnea should be considered within the context of the burden/benefit ratio as well as the persons expected prognosis.

Care planning for persons with a life limiting illness must address the treatment burden/benefit balance from the perspective and best interests of the person with a life limiting illness. Clinicians must communicate available treatment and management options available throughout the care planning process and empower the person with the knowledge needed to determine whether treatments offered will cause added burden or distress. In palliative care, it can be a challenging feat to balance the potential for treatment efficacy with futility in the context of expected prognosis. Moreover, the burden that undergoing a treatment may cause such as physical exertion, pain, or time must also be factored in. Specific to care planning at end of life is the need to balance quality versus quantity of life. The care plan must address this quandary to ensure that the goals of the desired treatment are positioned within a realistic understanding. It is important that decisions be made within the person's individual cultural, religious, and spiritual context. For example, persons from a Western culture may focus on prioritizing treatment addressing relief of pain and suffering while a person from a non-Western culture, who perceives the journey of pain and suffering before death as a test of faith, may not (Wold, 2008). Communication is key to unlock understanding between the clinician and the person and their informal support network during the care planning process to ensure that it is the goals of care of the person, which are being addressed, and not the goals recognized from within the socio-cultural perspective of the clinician.

Another key consideration during the care planning process for persons with a life limiting illness is the role of the persons informal support network. In community based palliative care, the responsibility for the majority of care often falls on the shoulders of the informal support network (Taube, 2005). Without adequate support, the magnitude and intensity of care provision necessitated to keep the person at home in the community as they progress along the illness trajectory may quickly overwhelm the person with a life limiting illness and his/her informal support network. Therefore, the care plan must include educational interventions to support and inform not only the person with a life limiting illness but also their informal support network with respect to current and projected expectations of need, level of care to be required, and availability of formal support services (Taube, 2005). For example, the care needs for a person recently diagnosed with early stage dementia differ greatly from projected care needs in the later stages of the disease. Awareness of future needs and illness progression, may empower the person with a life limiting illness to prepare and communicate preferred goals of care while they remain capable.

4. Introduction to the interRAI Suite of Assessment Instruments

interRAI, an international not-for-profit research consortium of clinicians, researchers, health administrators, and health/social service professionals from over 35 countries in five continents, promotes "person-specific care" rather than "site specific care" (www.interrai.org) (Steel et al., 1999; Carpenter, Bernabei, Hirdes, Mor, & Steel, 2000; Bernabei et al., 2009). The aim of interRAI is to enhance the health and well-being of vulnerable populations such as persons with a mental illness, frail older adults, or persons with disabilities, who require health care services in a variety of settings across the health care continuum. The goal of interRAI "is to promote evidence-informed clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of persons served across the continuum of care" (interRAI Canada, 2013). Each instrument offers multiple applications, including: CAPs for care planning to elucidate client needs; Outcome measures (scales such as the Activities of Daily Living Hierarchy or the Cognitive Performance Scale) to examine how the client is doing both at that moment and over time; and Quality indicators to assess quality of care and to benchmark how organizations may compare to others (e.g. across facilities, organizations, geographic regions). The interRAI suite of assessment instruments forms "an integrated system of health information linking person-specific data across the care continuum" (e.g. from home care and long-term care to acute and mental health services) (Hirdes et al., 1999; Hirdes et al., 2008; Gray et al., 2009).

In Canada, the interRAI suite of assessment instruments are used in multiple care settings including: home care, assisted living, complex continuing care (CCC), LTC, acute care, inpatient and community mental health, and post-acute rehabilitation (Hirdes, 2006; Hirdes, Mitchell, Maxwell, & White, 2011). Clinicians may use full comprehensive assessments such as the RAI-HC for use in the home care setting or the MDS 2.0 for use in CCC and LTC, or may use shorter screening tools such as the interRAI Contact Assessment (Hirdes et al., 2010). Different instruments have been adopted or mandated in various jurisdictions across Canada (Table 4.1.).

Table 4.1. Implementation and Testing of interRAI Instruments by Canadian Provinces, 2012.

	British Columbia	Alberta	Saskat-chewan	Manitoba	Ontario	Quebec	Newfound-land	New Brunswick	Nova Scotia	Prince Edward Island	Yukon	Northwest Territories	Nunavut
RAI 2.0	**X**	**X**	**X**	**X**	**X**		**X**	**X**	**X**		**X**		
RAI-Home Care Assessment Instrument	**X**	**X**	**X**	**X**	**X**		**X**		**X**		**X**		
RAI-Mental Health Assessment Instrument				*	**X**	*	*						
interRAI Community Mental Health					*	*	*						
interRAI Emergency Screener for Psychiatry					*								
interRAI Palliative Care Assessment Instrument		*	*		**X**				**X**		**X**		
interRAI Intellectual Disability Instrument					*								
interRAI Acute Care/Emergency Department Screener	*			*	*				*				
interRAI Contact Assessment				*	**X**								
interRAI Community Health Assessment					**X**								
interRAI Assisted Living Assessment Instrument		*											
interRAI Long-term Care Facility Instrument				**X**	*								
interRAI Subjective Quality of Life Assessment Instrument	*		*	*	*				*				

* denotes research/evaluation is underway

X denotes instrument is mandated or recommended by the provincial government

Adapted from:

Hirdes, J.P. (2006). Addressing the health needs of frail elderly people: Ontario's experience with an integrated health information system. Age and Ageing, 35, 329–331.

Hirdes, J. P., Mitchell, L., Maxwell, C. J., & White, N. (2011). Beyond the 'iron lungs of gerontology': using evidence to shape the future of nursing homes in Canada. Canadian Journal on Aging, 30(3), 371.

While the focus of all interRAI instruments remains person specific care at an individual level, there are multiple benefits for organizations, researchers, health authorities, and policy makers to leverage these data to inform policy and organizational change at a systems level (Landi et al., 2000; Jones, Perlman, Hirdes, & Scott, 2010). In addition to care planning, other uses of the interRAI suite of assessment instruments include:

- Development of a resource use case mix system;
- Targeting and evaluation of intermediate care;
- Modeling of intermediate care service requirements;
- Development of performance indicators for hospital service utilization; and
- Benchmarking quality of care across care settings. (Carpenter, 2006)

4.1 interRAI Palliative Care Assessment Instrument (interRAI PC)

The interRAI PC is a standardized assessment instrument developed to provide a comprehensive assessment of the strengths, preferences, and needs of all adults receiving palliative care (Steel et al., 2003). Two versions of the instrument, the full interRAI PC assessment (interRAI PC) and the shorter interRAI hospice form (interRAI PC-H), are designed to be used across the continuum of palliative care from community to residential or facility-based settings. The full interRAI PC assessment includes more than 280 items covering 75 key areas which are grouped into 17 domains that include: identification and intake information, disease diagnosis, health conditions, oral status, nutritional status, skin condition, cognition, communication, treatments and procedures, mood, psychosocial wellbeing, functional status, continence, medications, responsibility and directives, social supports, and discharge information (Smith et al., 2010). In contrast, the interRAI-PC-H is a shorter assessment designed for persons with a very limited prognosis (making it relevant to the final stage of care planning) and includes a subset of less than 180 items from the full interRAI PC.

The interRAI PC is not a questionnaire but rather a “standardized minimum assessment tool” (Smith et al., 2009) that uses all sources of information including interviews of the person and caregivers, chart reviews, and interaction with other clinical team members. The assessments are to be completed by trained assessors and use a three-day observation period for most domains. The breadth of items collected inform a comprehensive evidence base, which when combined with clinical judgment, are useful to inform the development and implementation of care plans tailored to address the unique needs of persons with a life limiting illness. Items contained in the interRAI PC have shown excellent inter-rater and test-retest reliability (Steel et al., 2003; Hirdes et al., 2008).

In Canada, piloting of the interRAI PC and the process to develop the interRAI PC CAPs began in the winter/spring of 2004 (Smith, 2009). Partly funded by the Ontario Ministry of Health and Long-term Care, data were initially collected from five Community Care Access Center's (CCACs) in Ontario (Smith, 2009). A sixth CCAC joined the pilot in the later years of the pilot. An on-going feedback system was created between the interRAI Instrument and System Development (ISD) committee and case managers, clinicians, and decision makers involved in the pilot. Focus groups were held with all pilot sites to gather feedback and face validity of the assessment form (Smith, 2009). An assessor feedback form was used to inform which items to add, drop, or modify in order to meet the country specific needs of the Canadian population (Smith, 2009). The interRAI PC was piloted, using different software supports, in numerous sites and care settings across Canada. Research grade software developed included a fillable pdf form for use in a paper-based format, a web-based assessment form, and an excel-form version (Smith, 2009). Data were collected from: home care regions in Ontario, Manitoba, Saskatchewan, Alberta, British Columbia, and the Yukon; Complex Continuing Care facilities and hospitals in Ontario, Manitoba, and Alberta; and in Specialized Palliative Care hospice programs in Alberta, and Ontario. International pilot sites for the instrument included the Czech Republic, Sweden, USA, Netherlands, Iceland, Germany, and Japan. Interest has recently been expressed in New Zealand and South Korea.

4.2 interRAI Clinical Assessment Protocols (CAPs)

Clinical Assessment Protocols (CAPs) empower clinicians with knowledge to inform development of a person-specific, tailored plan of care. While the interRAI instruments enable care providers to address key factors such as aspects of function, health, and social support; the CAPS assist care providers investigate in greater depth areas where specific intervention may be warranted. They enable clinicians to organize their clinical observations in a systematic manner to identify factors that influence clinical and other outcomes (Gray et al., 2009).

Each CAP contains four core components: Issue Statement, Goals of Care, Triggers, and Best Practice Guidelines. The issue statement provides a clear rationale for why the specific CAP domain should be considered an important part of the palliative care services approach and how it impacts on the person with a life limiting illness' life. While the goals of care may vary by CAP, each focuses on resolving the problem, reducing risk of further decline, maximizing potential for improvement, or maintaining function to the best extent possible. CAP triggers use clinical decision support algorithms (available on the interRAI website www.interRAI.org) to link information gathered from the assessment to the specific problem referenced by the CAP. Because CAPs identify problems or issues that may not have been previously identified by the clinician, they have been found to assist in the prevention of further decline, reduction of unnecessary hospital or emergency room visits, and can assist to delay or prevent admission to LTC (Carpenter, 2006).

Assessment specific CAP manuals are available to accompany various instruments including the RAI-HC, the MDS. 2.0, RAI-MH and the interRAI-CMH. The CAP manuals are a resource guide directing clinical interpretation and understanding of the CAPs. Each CAP manual details background information to the problem of focus and providing guidance on the goals of treatment to be considered during the care planning process (Carpenter, 2006). Within each CAP description, best practice guidelines are summarized to assist clinicians to reflect on potential underlying issues to be considered during the care planning process.

Previous versions of the interRAI suite of instruments included assessment specific care planning protocols such as the Resident Assessment Protocols (RAPs) (Fries, Morris, Bernabei, Finne-Soveri, & Hirdes, 2007) to be used when care planning in LTC, and the Mental Health Assessment Protocols (MHAPs) (Martin et al., 2009) used when care planning for persons receiving community or in-patient mental health services. Recently, RAPs and MHAPs have been revised into newly labeled CAPs to reflect interRAI's emphasis on communication and compatibility of the suite of assessment instruments across care settings. Over forty CAPs have been developed ranging from clinically oriented problems such as dyspnea and fatigue to psychosocial issues including depression and self-harm. The interRAI PC CAPs are unique as they address issues framed within an end-of-life context, allowing for greater attention to symptoms that may or may not be appropriate to treat depending on estimated prognosis.

4.3 interRAI Palliative Care Clinical Assessment Protocols (interRAI PC CAPs)

The first generation of the interRAI PC CAPS (Steel et al., 2013e) use algorithms based on the items and scales in the interRAI PC assessment and they provide specific guidelines on eight CAP issues most relevant to persons with a life limiting illness with special consideration to the importance of estimated prognosis. Three types of CAPs: Performance (Fatigue and Sleep Disturbance CAPs); Clinical Complexity (Nutrition, Pressure Ulcers, Pain, and Dyspnea CAPs); and Cognition and Mental Health (Mood Disturbance and Delirium CAPs); each address how the clinical issue may affect the person. An overview of the trigger levels for each CAP shown will be discussed in greater depth in the following sections.

The interRAI PC CAPs development process was a three phase multiyear initiative involving an international committee representing nine countries. The CAP development process was comprised of several tasks:

- A review of relevant scientific literature;
- Analysis of existing interRAI data holdings to identify outcomes within sub-populations across multiple assessment periods; and
- Summary of expert opinion by interRAI members and their associates (Gray et al., 2009).

The first phase identified the key domains to be addressed by CAPs in palliative care through review of scientific and clinical practice publications. Information was gathered from at least three different global regions to ensure the CAPs are able to inform palliative care internationally and are not country specific. To represent the uniqueness of the Canadian context, resources were gathered in both French and English languages where available. In the second phase key informants and subject-matter experts were engaged to provide input on the components of the CAP through a series of consultations. Feedback was useful to ensure face, content, and construct validity of the CAPs and to ensure that the CAP contents were clinically relevant to clinicians across the care continuum. A 2010 meeting, involving Canadian and international experts, provided rigorous feedback for evaluation and revision to the CAPs. During phase three, triggers for the CAPs were developed using interRAI PC pilot data collected between 2006 and 2009 from CCAC's across Ontario. This process resulted in development of an interRAI PC CAP manual (Available from www.interrai.org) that outlines all eight interRAI PC CAPs.

4.3.1 Dyspnea CAP

The Dyspnea CAP helps clinicians recognize persons with a life limiting illness experiencing dyspnea when performing regular activity (Steel, Morris, & Leff, 2013a). The goals of care of focus on determining the severity of dyspnea symptoms and recognizing potential need for emergency intervention. Persons with a life limiting illness who trigger the Dyspnea CAP exhibit moderate or worse dyspnea at rest or when performing normal daily activities. Steel, Morris, & Leff (2013a) estimate that nearly 45% of palliative home care clients trigger the Dyspnea CAP of which almost half continue to trigger at follow-up. The Dyspnea CAP guidelines highlight strategies to identify onset and severity of dyspnea symptoms and to investigate possible causes of the symptoms. In addition, the Dyspnea CAP guidelines provide information on treatment options and education.

4.3.2 Delirium CAP

The Delirium CAP helps clinicians identify persons experiencing delirium in palliative care settings. The goals of care highlight the importance of identifying and treating any underlying causes, monitoring and addressing symptoms, preventing future complications, and maximizing quality of life (Steel, Inouye, Morris, Murphy, & Marcantonio, 2013b). Persons who trigger the Delirium CAP exhibit of one or more of the following symptoms that are different from the person's usual functioning: Easily distracted; Episodes of disorganized speech; Mental function varies over the course of the day; or Acute changes in mental status. Steel, Inouye, Morris, Murphy, & Marcantonio (2013b) estimate that less than 15% of palliative home care clients trigger the Delirium CAP. The Delirium CAP guidelines highlight key considerations and strategies for addressing symptoms of delirium.

4.3.3 Fatigue CAP

The Fatigue CAP is one of the most commonly triggered CAPs for persons with a life limiting illness. It identifies two groups whose QOL may be affected by symptoms of fatigue: (1) Persons who are currently experiencing severe fatigue, and (2) Those at risk of experiencing severe fatigue (Olsen, Steel, Ljunggren, Steel, & Smith, 2013). An estimated 43% of palliative home care clients experience severe fatigue and are unable to conduct some or all of their normal daily activities (Olsen, Steel, Ljunggren, Steel, & Smith, 2013). In contrast, persons at risk of experiencing severe fatigue exhibit two or more of the following characteristics: limited prognosis, recent fall, acid reflux, nausea, dry mouth, excessive sweating, thirst, memory problem, or exhibits signs of anxiety, depression, or activity withdrawal. Olsen, Steel, Ljunggren, Steel, & Smith, (2013) note up to 30% of the palliative home care population trigger at risk for fatigue. Fatigue CAP guidelines inform clinicians of issues specific to the trigger level group and suggest strategies to identify possible causes and to assist in symptom reduction.

4.3.4 Pressure Ulcer CAP

The Pressure Ulcer CAP (PU CAP) helps clinicians determine the level of risk of developing a pressure ulcer and educate about methods for prevention to reduce potential risk (Steel et al., 2013c). This CAP is the least likely of all eight interRAI PC CAPs to be triggered among palliative home care clients. The overall goals highlight the importance to treat existing pressure ulcers appropriately. The PU CAP triggers are based on presence of a pressure ulcer and on the presence of the following protective characteristics: absence of pain; absence of other skin ulcers; minimal care needed for personal hygiene; minimal assistance needed with bed mobility or transferring to the toilet; or bowel continent. If a person exhibits five or more protective factors and has a pressure ulcer then they would trigger the PU CAP as likely to improve. Steel et al. (2013c) found less than 5% of the palliative home care clients trigger the PU CAP as likely to improve, of which over 80% no longer have a pressure ulcer present at follow-up. Persons with four or fewer of the protective factors and a pressure ulcer present at the time of assessment trigger the PU CAP as difficult to improve. Steel et al. (2013c) estimate that of the 7% of palliative home care clients trigger as difficult to improve, of whom 56% no longer have a pressure ulcer at follow-up. The PU CAP guidelines address considerations for existing pressure ulcers, describe strategies for pressure ulcer management, and suggest approaches for prevention of pressure ulcers.

4.3.5 Mood Disturbance CAP

The Mood Disturbance CAP helps clinicians identify and address any immediate effects of depression or anxiety on the person’s health and wellbeing and to recognize underlying symptoms and conditions (Smith, Rabinowitz, Hirdes, Morris, Stewart, Constantino, & Steel, 2013). The goal of the Mood Disturbance CAP is to improve the person’s psychological well-being and support their engagement in the decision making process. Persons with a single mood symptom trigger the first level of the Mood Disturbance CAP while persons with multiple symptoms trigger at higher risk. Mood symptoms focus on feelings of anxiety and sadness, whether the person is expressing a wish to die at the time of assessment, and on the ability to find pleasure in usual activities. Smith, Rabinowitz, Hirdes, Morris, Stewart, Constantino, & Steel (2013) estimate that one third of palliative home care clients trigger the Mood Disturbance CAP of which an equal proportion trigger with a single mood symptom or multiple mood symptoms. Over half of the persons who trigger either level will no longer have the symptom(s) at follow-up (Smith, Rabinowitz, Hirdes, Morris, Stewart, Constantino, & Steel (2013). The Mood Disturbance CAP guidelines assist clinicians to identify best practice approaches to address the mood symptoms, determine the nature of the disorder, and to outline potential treatment and monitoring considerations.

4.3.6 Nutrition CAP

The Nutrition CAP identifies persons who are experiencing anxiety about not eating, could benefit from optimized energy and protein intake, or who may require intervention to alleviate hunger (Steel, Morris, Sorby, & Steel, 2013d). The goals of the Nutrition CAP focus on educating the person and the informal support network about nutrition specific issues and conditions. Persons who have a BMI less than 20 trigger the Nutrition CAP and are divided into two groups depending on whether they have recently lost weight. Steel, Morris, Sorby, & Steel, (2013d) estimate that 17% of palliative home care clients exhibited both low BMI and recent weight loss while 11% had low BMI but had not experienced recent weight loss. The Nutrition CAP guidelines focus on symptom management and provide information about food and fluid intake specific to prognosis.

4.3.7 Pain CAP

The Pain CAP, based on the Palliative Pain Index, combines multiple levels of pain ranging from no pain to severe, horrible, or excruciating pain (Won et al., 2010). The goals of the Pain CAP are to relieve suffering where possible, identify any underlying causes, optimize comfort and treatment efficacy, and closely monitor for any adverse events. Persons who trigger the Pain CAP at a high priority indicate presence of severe, horrible, or excruciating pain. Persons who trigger the Pain CAP at a medium priority exhibit mild to moderate pain with breakthrough pain. Won et al. (2013) estimate that about 20% of palliative home care clients trigger each Pain CAP group respectively. Guidelines for the Pain CAP focus in detail on assessment and management strategies.

4.3.8 Sleep Disturbance CAP

The Sleep Disturbance CAP helps clinicians determine and understand the nature of the sleep disturbance and identify any underlying causes (Ljunggren, Olson, Smith, Steel, Hirdes, & Morris, 2013). Goals of the Sleep Disturbance CAP are to reduce the sleep disturbance and maximize comfort and functioning. Two groups of persons may trigger the Sleep Disturbance CAP, those with a high potential to improve and those with a moderate potential to improve. Potential to improve is based on presence of a list of reversible issues. If the person exhibits difficulty sleeping and has two or more of the reversible issues as listed in the interRAI PC CAP manual, then they will trigger at a high potential to improve. Those who trigger with moderate potential to improve also have difficulty sleeping but exhibit one or no reversible issues. Ljunggren, Olson, Smith, Steel, Hirdes, & Morris (2013) found that 17% of persons trigger the Sleep Disturbance CAP with high potential to improve of which 78% did not have a sleep problem at follow-up. In addition, they note that of the 13% who triggered with moderate potential to improve, 48% did not have a sleep problem at follow-up.

4.4 Other Care Planning Tools

The current processes of care planning differ greatly by geographic region and by means. In Canada, a wide variety of tools are available, in addition to the interRAI PC, to inform the care planning process. In some regions, multiple assessment tools are used to inform the care planning process while in other regions, a single tool may be used. For example, on their website www.palliative.org, the Edmonton Regional Health Authority (ERHA) in Edmonton, Alberta, Canada lists 11 different assessment tools and guidelines developed by the Edmonton Zone Palliative Care Program (2013a) in addition to a list of references for other assessment tools that may be used. Some tools are symptom specific such as the Constipation Score (http://www.palliative.org/NewPC/proffesionals/tools/const_score.html), or the CAGE Questionnaire (Ewing, 1984), while others such as the Edmonton Symptom Assessment System-Revised (ESAS-r) (Watanabe et al., 2011), address multiple symptoms. During the care planning process, a clinician in the ERHA may use a variety of these tools, as they perceive necessary to identify the needs of the person with a life limiting illness. The tools used differ for each client. This may allow for shorter assessments when less information is perceived necessary by the clinician to inform their judgment during the care planning process. This can reduce the burden on the client as they may not need to spend as much time to be assessed. It allows the clinician increased freedom to choose what information they gather and the means in which to do so. However, when different assessment tools are used on a case-by-case basis, comparisons between persons with a life limiting illness, even among the same clinicians caseload, may be challenging. This style of care planning process, which may use a large variety of different assessments to complete one care plan for each person with a life limiting illness, is contrasted by the process conducted in Hamilton, Ontario, Canada where a case manager completes only the interRAI PC and the Palliative Performance Scale (PPS). In Hamilton, all persons with a life limiting illness are measured using the same tools allowing for comparison within the caseload and across the health region. Use of a standardized method of data collection creates a strong evidence base useful to inform regional policy as it allows for recognition of regional variation, benchmarking, and identification of population specific needs.

To understand the diversity in care planning tools available, an overview of some key tools used in various settings to assess the needs of persons receiving palliative care will be provided. The PPS, ESAS, ESAS-r, and the Liverpool Care Pathway (LCP) are well-known tools used in different contexts. A brief description of each tool is followed by comparison of its strengths and weaknesses in contrast to the interRAI PC.

4.4.1 Palliative Performance Scale (PPS)

The Palliative Performance Scale (PPS)[1] was developed by the Victoria Hospice Society, British Columbia as a variant of the Karnofsky Performance Scale (Crooks, Waller, Smith, & Hahn, 1991) to assess change in functional status and to measure the degree of decline across the illness trajectory (CCO, 2005a). The PPS measures overall performance to provide a 'best guess' estimation of prognosis (CCO, 2005b). The PPS is divided into 11 levels, organized into three stages: stable, transitional, and end-of-life. Levels, measured at 10% increments ranging from 100% to 0% where a higher score reflects better functioning and 0 represents death, have been found to be valid measure of survival (Morita, Tsunoda, Inoue, & Chihara, 1999; Younis et al., 2009). Harris et al. (2013) describe the range of the five domains of the PPS as follows: "ambulation (bed-bound to full), activity (unable to work to normal), self-care (completely dependent to completely independent), intake (mouth care only to full diet), and level of consciousness (drowsy or coma to fully alert)" (page 414). Scoring proceeds in this order so that the first categories (e.g., ambulation, activity) are given the greatest weights. In clinical settings, the PPS is gaining in popularity among clinicians (Fainsinger, Demoissac, Cole, Mead-Wood, & Lee, 2000) to aid in planning care (Barbera et al., 2010), and for communication (Anderson, Downing, Hill, Casorso, &

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[1] The PPS tool may be viewed at Palliative Performance Scale (PPSv2) version 2 [PDF] online.

Lerch, 1996; CCO, 2005b). It is short, quick to complete, and simple for clinicians to understand with minimal instruction. The PPS is used to estimate prognosis in homogeneous as well as minority populations (Harrold et al., 2005; Downing et al., 2007; Weng et al., 2009) and to assess needs for home care services (Anderson, Downing, Hill, Casorso, & Lerch, 1996; Ma et al., 2010). However, recent concerns have been raised that some PPS scores exhibit a high likelihood of overestimation of estimated prognosis (Selby et al., 2011).

Compared to the interRAI PC, the PPS form is much shorter, briefer and may be perceived as more user friendly due to its simplicity. It also provides a limited scope of information on the person with a life limiting illness and no information on their informal support network for clinicians. The PPS fails to inform clinicians of psychological, social, or spiritual issues important to person with a life limiting illness and does not address informal caregivers, loss and grief, end of life care, death management, nor advanced directives. The PPS is limited to functional and cognitive functioning of the person faced with a life limiting illness and provides minimal information for care planning in stark contrast to the over 280 items covering 75 key areas grouped into 17 domains captured by the interRAI PC. The interRAI PC contains the Changes in End Stage Signs and Symptoms (CHESS) Scale, which has been validated and shown to predict health instability in community and residential populations and shown to be a reliable predictor of estimated prognosis in nursing home and home care settings (Hirdes, Frijters, & Teare, 2003; Armstrong, Stolee, Hirdes, & Poss, 2010; Hjaltadóttir, Hallberg, Ekwall, & Nyberg, 2011; Tjam, et al., 2012).

4.4.2 Edmonton Symptom Assessment System (ESAS) and the Edmonton Symptom Assessment System Revised (ESAS-r)

The Edmonton Symptom Assessment System (ESAS) is a validated screening tool to screen to identify presence and severity of symptoms (Barbera et al., 2010). It is designed to identify if the person with a life limiting illness requires further more detailed assessment and/or possible intervention (Barbera et al., 2010). It focuses on nine symptoms common in palliative care: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and wellbeing (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). Like the PPS, the ESAS is limited to the person with a life limiting illness and does not include items on informal caregiver's situation or of caregiver distress. A tenth domain however does allow for persons to report an additional symptom of their choosing. This self-report subjective assessment may be used to identify changes frequently and can be used on a monthly, weekly, or daily basis depending on the person's changing care needs. Symptom distress is scored using a visual analogue scale where zero represents the absence of the symptom and ten represents the worst possible severity. Chang, Hwang, and Feuerman (2000) validated the ESAS against the Memorial Symptom Assessment Scale (MSAS), the Functional Assessment Cancer Therapy survey (FACT), and the Karnofsky Performance Status (KPS). In addition, a review by Watanabe, Nekolaichuk, Beaumont, Johnson, Myers, & Strasser (2011) lists over 10 studies that evaluated the reliability, validity, or sensitivity and/or specificity of the ESAS.

In a revised version of the ESAS, the ESAS-r[2], the visual analogue scale has been replaced with an 11-point numerical scale (Edmonton Zone Palliative Care Program, 2013b). In the ESAS-r, the person is required to circle the specific number on the same scale of zero to ten indicating symptom severity. The ESAS-r also includes definitions of key terminology reducing ambiguity and confusion found in the original version of the ESAS. The ESAS-r retains the original symptom items in a revised order. Watanabe, Nekolaichuk, Beaumont, Johnson, Myers, & Strasser (2011) found that the ESAS-r was easier for patients and clinicians to understand and complete and more user friendly.

If the person with a life limiting illness is unable or refuses to complete the ESAS or the ESAS-r, then it is possible for a member of their informal support network to complete it as a proxy. Nekolaichuk, Bruera, Spachynski, MacEachern, Hanson, & Maguire, (1999) found significant differences

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[2] The ESAS-r tool may be viewed at Edmonton System Assessment System Revised (ESAS-r) [PDF] online

in patient and physician/nurse proxy reporting using the ESAS. They found that physicians were more likely to rate symptom severity lower while nurse's ratings were closer. Moreover, they also found that these differences in ratings failed to improve over time and recommended further research was needed into proxy reporting. In contrast, Resnizky and Bentur (2007) found moderate to high correlation (0.458 fatigue ~ 0.787 shortness of breath) between informal caregiver proxy reporting and suggested that proxy reporting is reliable.

In contrast to all other tools, the ESAS and the ESAS-r may be completed directly by the person with a life limiting illness without any direction or in consultation with a health care professional. It is very quick to complete and recognized as user friendly. Unlike the interRAI PC that uses a trained assessor to gather information from multiple sources, the ESAS and the ESAS-r focus solely on self-report (or proxy report when necessary). This modular approach reduces the amount of assessment burden required as the client is able to report on their on perceptions without taking the time to complete objective measures or answer questions and interact with a clinician. In contrast to the simplicity in data collection of the ESAS and ESAS-r, the interRAI PC is much more time and labour intensive involving data gathering and triangulation of findings from multiples sources. The first source is to ask the person directly and to observe non-verbal cues such as facial expressions or body movements. In addition, the assessor then gathers information from persons who know the client (including family, friends, and other health care professionals) and consults available medical records. Using multiple sources of information beginning with the person enables the clinician to gain a comprehensive description of the individual person.

The interRAI PC includes all domains gathered by the ESAS and the ESAS-r with the exception of the opportunity to report an 'other' symptom. While the interRAI PC does not allow for any adjustments to the assessment forms on a local level, clinicians are able to write notes to be included with the assessment in the assessment record. The interRAI PC addresses five of the nine ESAS and the ESAS-r domains [pain, tiredness (fatigue), lack of appetite (nutrition), depression, and shortness of breath (dyspnea)]; with great depth through symptom specific interRAI PC CAPs. The ESAS and the ESAS-r gather self-report information but do not provide guidance to clinicians on how that information may be used to inform care planning. This differs greatly from the interRAI PC that is a 'complete symptom assessment' which encompasses a wide range of symptoms to provide that 'whole person' picture to inform care planning.

4.4.3 Liverpool Care Pathway for the Dying Patient (LCP)

The Liverpool Care Pathway for the dying patient (LCP)[3], developed in the UK for actively dying persons, aims to facilitate high quality end of life care and serve as a model of quality practice supporting care (Marie Curie Palliative care Institute, 2012). The LCP focuses on symptoms and care when the person is dying in last days and hours of life. The LCP provides guidance to clinicians on care planning domains including: comfort measures, anticipatory prescribing of medication, and discontinuation of inappropriate interventions (Watson, Lucas, Hoy, & Wells, 2009). It is comprised of three sections: Initial assessment (identification of key goals of care, addressing pain and symptom management, and review of appropriate pain medication regimen); Ongoing care (team approach using four-hour observation window for symptom identification and timely response); and Care after death (identify support and education needs for informal support network). The LCP emphasizes communication between the person, their informal support network and health care team, taking into special consideration the person's physical, psychosocial and spiritual needs. The LCP uses a standardized assessment strategy to facilitate and monitor treatments and evaluate person specific outcomes (Veerbeek et al., 2008).

The LCP provides detailed person specific information to inform care planning over a variety of domains. Like the interRAI PC, the LCP emphasizes a multidisciplinary team approach to care that

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[3] The LCP tool may be viewed at Liverpool Care Pathway [PDF] online

incorporates the person and their informal support network. However, in contrast to the interRAI PC, which can be used at any time during the illness trajectory from the point of diagnosis with a life-limiting illness, the LCP is specifically designed for persons who are dying. To be eligible for the interRAI PC, the person must be recognized as having a need that may benefit from a palliative approach, while eligibility for the LCP is more narrowly based on consensus by the health care team that the patient is dying. If deterioration has been occurring over a period of weeks to days, the LCP requires the person meet two of the following four criteria: bed-bound, semi-comatose, only able to take sips of fluid, or unable to take tablets (Watson, Lucas, Hoy, & Wells, 2009). While the LCP specifically applies to persons who are dying, it may not be appropriate to conduct the full interRAI PC at that time. The interRAI PC-H is a shorter assessment tool, appropriate for persons in the final stages at end-of-life. The interRAI PC fits the mandate of palliative care that recognizes the value for information exchange between the person with a life limiting illness, their informal support network, and care providers to occur as early as possible in the illness trajectory. The design of the LCP, and in particular eligibility requirements, may be more restrictive towards persons where prognosis is more clearly evident such as persons with advanced terminal cancer. The criteria used to identify those who are actively dying may not apply in the same way to the non-cancer population. In contrast, the interRAI PC is not disease specific and is easily used to assess all persons with a life limiting illness. It may be possible for the interRAI PC-H and the LCP to work together in a complementary fashion to inform clinicians of the person with a life limiting illness' needs across the illness trajectory however future research is needed. The interRAI PC, and more specifically use of the CHESS scale, may be useful to identify persons with a life limiting illness who may be nearing an actively dying phase and who may benefit from assessment using the LCP.

4.4.4 Summary Findings of Instruments Used in Care Planning

Implementation of a standardized comprehensive assessment tool in palliative care may lead to:

- Earlier identification;
- Systematic documentation;
- Enhanced communication;
- Evidence informed care planning; and
- Better management of symptoms (CCO, 2009).

This may decrease unnecessary ER visits, hospitalizations, and length of stay. To achieve these results, it is important that the screening and assessment tools to gather relevant person-specific information to ensure all domains important to the person with a life limiting illness are addressed. Of all the tools discussed, the interRAI PC is the most comprehensive covering more domains recognized by the CHPCA (Figure 2.8.) than the PPS, ESAS, and LCP. The clinical practice guidelines for quality palliative care, developed as a component of the National Consensus project in the United States identified eight areas paramount to quality whole person palliative care provision:

1. Structure and Processes of Care;
2. Physical Aspects of Care;
3. Psychological and Psychiatric Aspects of Care;
4. Social Aspects of Care;
5. Spiritual, Religious, and Existential Aspects of Care;
6. Cultural Aspects of Care;
7. Care of Imminently Dying; and
8. Ethical and Legal Aspects of Care. (NCP, 2013)

Of these common tools used to assess persons with a life limiting illness: the PPS, ESAS, ESAS-r, the LCP, and the interRAI PC, the interRAI PC is the only assessment instrument that addresses all of these aspects to care in-depth, for all persons with a life limiting illness regardless of estimated prognosis. The interRAI PC is the only tool which meets four essential components necessary for care planning: universality, coordinated care, a broad range of services, and provision of care regardless of setting (Picard, 2010). The interRAI PC assessment is appropriate to assess all persons with a life limiting illness regardless of disease diagnosis, trajectory, prognosis, or setting of care. The interRAI PC is the only tool to meet the definition of palliative care as defined by the WHO and provide both ‘impeccable assessment’ and support means for ‘early identification’ of need for palliative care for persons with a life limiting illness regardless of disease diagnosis or estimated prognosis.

Due to the finite amount of palliative care resources available, it is important to use a standardized comprehensive assessment to direct resources toward persons with a life limiting illness with the greatest needs. The PPS, ESAS, ESAS-r, and the LCP were all developed with a focus on persons diagnosed with cancer and have since begun to be tested for applicability to non-cancer populations. In contrast, the interRAI PC was developed as a ‘person specific’ comprehensive clinical assessment to examine the needs of any person with a life limiting illness without discrimination or bias based on disease diagnosis. The interRAI PC is the only tool which informs care planning throughout the disease trajectory based on identified and expressed preferences, values, goals, needs, and circumstances of the patient and their caregivers. In addition, only the interRAI PC is fully compatible with other interRAI instruments in widespread use in other sectors of the Canadian health care system.

5. Study Rationale and Methodological Overview of Research

5.1 Study Rationale

The WHO (2010) emphasizes the use of ‘early identification’ and ‘impeccable assessment’ to improve quality of life, and to prevent and relieve of suffering in palliative care. Through the use of high quality assessments, a standardized approach to palliative care can identify persons with a life limiting illness that may benefit from palliative care services early in the illness trajectory in a consistent manner. This enables care providers to identify issues pertinent to each individual situation, ensure the informal support network and formal care providers are matched with the skills to perform assigned duties, and to tailor a person-centered care plan that fits the needs of the person with a life limiting illness at the appropriate time in the desired setting. Evidence informed decision-making utilizing data gathered from standardized assessments facilitates higher quality of person-centered care by ‘leveling the playing field’ (Pereira & Bruera, 2001).

Standardized assessment and measurement through use of the interRAI PC provide systematic means to identify need at the individual person level and can be used at an aggregate level to create an evidence base to inform community, regional, and national standards and policies. Using evidence to inform care planning enables clinicians to understand with greater acuity the strengths, preferences and needs of the person. Leveraging of evidence from the interRAI PC will empower clinicians with knowledge to more accurately address and target resources to meet the needs of persons with a life limiting illness. Palliative care in Canada has been described as a ‘patchwork-quilt’ of services and programs provided inconsistently by care providers across regional jurisdictions (Williams et al., 2010). Access to palliative care in Canada is often based on “the luck of the draw” rather than basic entitlement (Carstairs, & Beaudoin, 2000, Part I A). It is “variable, fragmented, and financed through different mechanisms” (Romanow, 2002, page 182), and it leads to very different roles to be filled by various palliative care providers (Gaudette et al., 2002). As a result of unequal access to the patchwork of available palliative care services in Canada, less than one in eight Canadians who may benefit from palliative care are able to access care (Carstairs & Beaudoin, 2000). There is a lack of information from a population level on how systematically collected comprehensive person level evidence may be used to inform clinical decision making for persons with life limiting illness' in Canada. Using information collected in a standardized comprehensive manner across jurisdictions will allow for investigation of regional differences in accessibility.

5.2 Data Source

The interRAI PC is a standardized assessment instrument developed for persons with a life limiting illness residing in multiple care settings and included more than 280 items on demographic information; covering 75 key areas grouped into 17 unique domains (Steel et al., 2003; Smith et al., 2010). Assessments with the interRAI PC in home care settings in Ontario are completed by trained assessors and use a three-day observation period for most domains. Assessors consult multiple sources of information such as direct observation or communication with the person with a life limiting illness, the informal support network, and team of health care providers, and in consultation with available medical records, when completing the interRAI PC.

Data gathered from interRAI PC provide a comprehensive description of the individual care needs of palliative clients, which when combined with clinical judgment, is useful to inform the development and implementation of person specific care plans. The interRAI PC is considered both reliable and valid and the items contained within have excellent inter-rater and test-retest reliability for conducting population-based research (Steel et al., 2003; Hirdes et al., 2008). In a 12-country study, Hirdes et al. (2008) examined the psychometric properties and the reliability of five interRAI instruments including the interRAI PC. Using interRAI PC data gathered from the Czech Republic, Iceland, Norway, Spain, and the United States, Hirdes et al (2008) found strong evidence to support the inter-rater reliability of the interRAI PC. Although Hirdes et al. (2008) did not report the specific reliability of individual mood and dyspnea items, all items with weighted kappa's of less than 0.40 were not retained with the exception of measures of volatile symptoms like fever. Carpenter (2006) notes that each assessment instrument undergoes validity and reliability testing by a research and development team. Prior to use, the instruments undergo international research and development testing where the instruments are tested against proven scientific evidence and undergo testing against available gold standards (Carpenter, 2006). Hirdes et al. (2002) note that criterion validity has been established for numerous outcome scales including the CPS, ADL-H, and DRS. Specific to the development of the interRAI PC, Gray (2009) notes that the extensive field testing of the interRAI PC focused on item response rates, inter-rater reliability, and included convergent validity within the outcome scales.

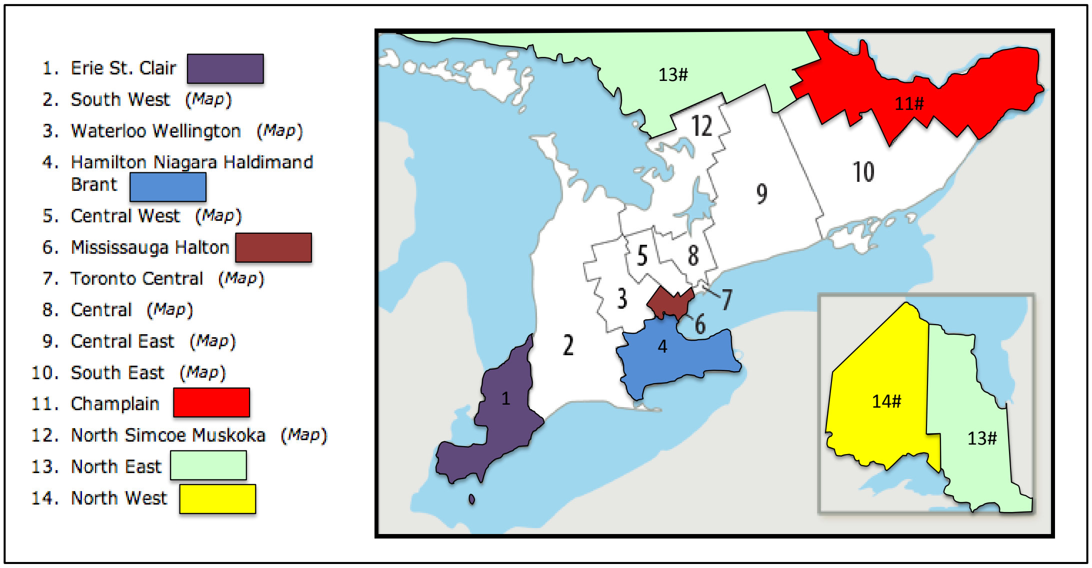
During the CAP development process of the interRAI PC, steps were taken to ensure face and content validity of the instrument, through widespread stakeholder consultation, evaluation of best-practice guidelines, and pilot testing with clients receiving palliative care services. Examination of specified outcomes at follow-up assessment will enable further understanding of the importance of triggering the Dyspnea CAP and to elucidate any increased risks for negative events.

A total of 7,168 interRAI PC assessments, collected between 2006 and 2011 were available for inclusion in the current analysis. A total of 399 assessments were excluded. Persons who resided in the community and were assessed to receive community based palliative homecare services were selected as the focus of these research studies as they comprised the vast majority of persons on whom the interRAI PC assessments were completed. Persons known not to reside in a private home/apartment/rented room at time of assessment (n=222) were excluded. Residential and living status at time of assessment for those excluded from the current analysis included: board and care (n=24), assisted living or semi-independent living (n=113), mental health residence such as a psychiatric group home (n=5), group home for persons with physical disability (n=2), setting for persons with intellectual disability (n=4), homeless (n=5), long-term care facility (n=3), hospice facility (n=63), acute care hospital (n=2) and other (n=1). As provincial variation exists in both health care structure and palliative care provision, analysis was limited to persons who resided in the province of Ontario. Persons who resided outside of the province of Ontario (n=38) were excluded from the analysis. Persons aged under 18 (n=8) or for whom age was missing (n=130) were also excluded from the analysis. Finally, assessments missing data for all eight CAPs were also excluded (n=6). Some cases were missing more than one of the above items therefore a final total of 6,769 baseline assessments and 1,000 follow-up assessments of unique persons were available for inclusion in the current analyses.

5.2.1.1 CCAC Pilot Data Location Descriptions

Data for the current study were gathered from six pilot sites located across the province of Ontario. As shown in Figure 5.1, these sites ranged from a primarily metropolitan urban district of the Mississauga Halton CCAC to more rural and geographically dispersed districts such as the North West CCAC. Representation from geographic regions from the South (Erie St. Clair) to the North (North West and North East) aimed to provide a more generalizable pilot dataset. Details of each CCAC follow.

Figure 5.1. Map of Community Care Access Center (CCAC) Districts that Piloted the interRAI PC, Ontario, Canada.



Original Source: OACCAC website. Retrieved from: http://www.ccac-ont.ca/Locator.aspx?EnterpriseID=15&LanguageID=1&MenuID=46

Note: Coloured areas denote CCAC's that provided pilot data.
White areas denote CCACs not involved in piloting the interRAI PC.
Note: Map was altered by addition of colours by thesis author (S.F.) from its original form.

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5.2.1.1.1 Champlain CCAC

The Champlain CCAC borders the North East and South East CCACs as well as the province of Quebec, and Vermont in the United States (Figure 5.1., Area #11). The Champlain CCAC provides care primarily in urban centers (approximately 75%) while also serving rural and remote populations covering almost 18,000 km^2. They serve over 53,000 clients every year with an average of 23,000 clients served daily (Champlain CCAC, 2011). The CCAC is comprised of one head office, nine branch offices, and twenty-two satellite offices. Approximately twenty percent of clients are non-native English speakers. The palliative program in the Champlain CCAC is partnered with Bruyere Continuing care and focuses on integrated approaches to end of life care provision. Palliative nurse practitioners are integrated within the palliative pain and symptom management consultation service to address the needs of both the palliative client and members of their informal support network. The palliative care team employs a circle of care philosophy to care comprised of a diverse care team including physicians, case managers, pain and symptom management specialists, advanced practice nurses and others as necessary on an individualized basis (Champlain CCAC Website, 2013). The Champlain CCAC regional palliative consultation team prioritizes caring, compassion, and expertise.

Data included in the pilot data were gathered, by approximately 20 case managers, for all palliative home care clients across all offices throughout the pilot window. Training of the case managers occurred over a 1-2 day period. All case managers received in person basic training. Identified champions received an extra half-day of intensive training. From initial discussion to staff training and initiation of the pilot took approximately six months and evolved from initial discussions during the Champlain CCAC amalgamation process. All case managers were registered nurses, a pre-requisite for membership on the palliative care team.

Referral to palliative care services and thereby eligible for analysis with the interRAI PC, clients must have been recognized as having an estimated prognosis of six months or less. Internal guidelines developed as a combination of best practice experiences and a literature search were established and used a gold standard question “Would you be surprised if they passed away in the next 6 months?” This would result in a designation code of ‘palliative’ and referral by the physician or community case manager to the palliative team. Once the person was referred, an interRAI PC assessment was completed. Data was collected using paper-based assessments, collected from 2006 to 2009. Data were de-identified then scanned and entered into the data repository at the University of Waterloo.

5.2.1.1.2 Erie St. Clair CCAC

The Erie St. Clair CCAC comprises the southernmost CCAC region in Ontario (Figure 5.1., Area #1). In 2012-2013, the Erie St. Clair CCAC provided care to over 37,000 client through access of care services and offered information and advice to thousands more (Erie St. Clair CCAC, 2013). The Erie St. Clair CCAC is divided into three districts: Windsor-Essex, Chatham-Kent, and Sarnia-Lambton. Data included in the pilot dataset were gathered from Windsor-Essex district, the most urban and ethnically diverse of the three regions.

The palliative program in Erie St. Clair is comprised of 8 full time care coordinators and 3 full time nurse practitioners and works closely with the Hospice of Windsor. Their palliative approach emphasizes the importance of an interdisciplinary approach to end of life care and actively integrates chaplains, social workers, and spiritual care providers into the care team of clinicians including the physician, nurse, and home care providers. At any given time, there may be over 600 persons receiving palliative care services and resources offered by the Erie St. Clair CCAC. The palliative care program has been provided for over four years in Windsor-Essex. The Erie St. Clair CCAC prioritizes the goals of the client when determining allocation of services and resources to meet need. Persons entering the palliative care program were initially assessed with either the RAI-HC (if coming from home care or not immediately recognized to require palliative care) or with the interRAI-PC (for those recognized to require palliative care services). Re-assessment was to be conducted every 3 to 6 months or as needed should a significant change in the client's needs occur. While estimated prognosis, based on the PPS score, nurse judgment, or physician referral are all tools used on an ad hoc basis to inform referral to palliative based services in the Erie St. Clair CCAC region, there is no clear means for persons to be referred to the palliative care program. In discussion with a key informant from the Erie St. Clair CCAC, it was made clear that if a client was actively receiving any kind of active curative care such as chemotherapy, they would not be eligible to receive palliative care support services. Data was collected from 2006 to 2008 using paper-based assessments, which were de-identified and then scanned and entered into the data repository at the University of Waterloo.

5.2.1.1.3 Hamilton-Norfolk-Haldimand-Brant CCAC

The Hamilton-Norfolk-Haldimand-Brant CCAC covers five regions including Hamilton, Haldimand-Norfolk, Niagara, Brant, and Burlington (Figure 5.1., Area #4). In 2011-2012, the Hamilton-Norfolk-Haldimand-Brant CCAC served 72,951 clients and members of their informal support network with an average of 794 high needs clients served per month (Hamilton-Norfolk-Haldimand-Brant CCAC, 2012). The Hamilton-Norfolk-Haldimand-Brant CCAC reported 7.5% of their expenditures were on palliative care clients (HNHB CCAC, 2013) down from 8.4% reported in 2011/2012 (Hamilton-Norfolk-Haldimand-Brant CCAC, 2012). Palliative care coordinators work with physicians and other service providers to address the physical, emotional and spiritual needs of the client and members of their informal support network and assist with admissions to hospice (Hamilton-Norfolk-Haldimand-Brant CCAC, 2013). The Hamilton-Norfolk-Haldimand-Brant CCAC is comprised of approximately 65% urban and 35% rural areas.

The Hamilton-Norfolk-Haldimand-Brant CCAC was the first site, which began to collect pilot data using the interRAI PC. Decisions to pilot the interRAI PC were an outcome for the palliative care integrated project collaborative from the Kingston group (J. Noble[4], personal communication, December 23, 2013). From 2006 to 2008 the original pilot data was gathered on all palliative home care clients accessing services from the Hamilton branch. In 2008, the pilot was extended to include all regions in the Hamilton-Norfolk-Haldimand-Brant CCAC. Eligibility for referral to the palliative care was based on

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[4] Janet Noble MSW, RSW, is the Director of Client Services for the Hamilton Branch of the Hamilton Niagara Haldimand Brant CCAC.

criteria sourced from Dr. Joanne Lynn, M.D.[5], a hospice physician and health services researcher, and current director of the Center on Elder Care and Advanced Illness for Altarum Institute[6]. Criteria for eligibility include that the assessor "would not be surprised if the person were to die within 12 months" or that the person "has pain and symptom issues that require palliative expertise including psycho-social care" (J. Noble, personal communication, December 23, 2013). Referral for the palliative care services may be determined by one of many sources including members of the person's clinical team, home care service provider, tertiary care specialist, family doctor, or primary care clinician. Clients may have been first assessed using the RAI-HC and then transferred to the palliative care team for follow-up assessment using the RAI-PC. At time of assessment, the care coordinator employed their judgment to determine whether the referred client exhibited need for palliative home care services on a case-by-case basis. The palliative care team typically consisted of 5 teams comprised of 16 care coordinators. All care coordinators received 1 day in class training and received follow-up refresher training as needed. Care coordinators included Registered Nurses, Social Workers, Occupational Therapists, Physiotherapists, Speech Language Pathologists, as well as relief staff when necessary. Data was collected from 2006 to 2010 using paper-based assessments. Assessments were de-identified, then scanned and entered into the data repository at the University of Waterloo.

5.2.1.1.4 Mississauga-Halton CCAC

The Mississauga-Halton CCAC prioritizes the delivery of quality integrated health care in the client's home (Mississauga Halton CCAC, 2013a). The Mississauga-Halton CCAC serves the sub areas of South Etobicoke, Oakville, Northwest and Southeast Mississauga, Halton Hills, and Milton (Figure 5.1., Area #6). In 2012-2013, the Mississauga Halton CCAC served more than 41,000 clients. Mississauga Halton

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[5] http://www.nlm.nih.gov/changingthefaceofmedicine/physicians/biography_208.html

[6] http://altarum.org/staff/joanne-lynn

CCAC is comprised of an ethnically diverse population with the immigrant population representing 43.2% in comparison to a 28.3% provincial average (Mississauga Halton CCAC, 2013a). In 2012/2013 the over 1,700 clients received palliative home care services representing a 6.2% increase in clients (Mississauga Halton CCAC. 2013a). Supporting clients to wish to die at home with dignity is one of the eight service specialties prioritized by the Mississauga Halton CCAC (Mississauga Halton CCAC, 2013b).

The interRAI PC was piloted by 10 case managers (9 registered nurses and 1 occupational therapist) on all home care clients with a prognosis of 12 months to live or less within the Mississauga-Halton CCAC catchment region. Clients were first assessed with the interRAI Contact Assessment for intake purposes. At that time they could be directly referred to the palliative team and receive the RAI-PC or they would be assessed with the RAI-HC if designated as a long-stay home care client and then transferred to the palliative team and assessed with the RAI-PC at a later date. Although anyone could refer clients to the palliative care team, eligibility for palliative care was based on an estimated prognosis of 12 months to live or less as designated by a physician or nurse practitioner. Assessors attended two-day in-person training on how to use the RAI-PC. Data collected from 2008 to 2011 using paper-based assessments were de-identified and transported to the University of Waterloo where they were scanned and entered into the data repository.

5.2.1.1.5 North East CCAC

The North East CCAC covers six regions; Cochrane, Algoma, Manitoulin/Sudbury, Timskaming, Nipissing, and Parry Sound (Figure 5.1., Area #13). In 2013, the North East CCAC served over 34,000 clients and over 15,500 clients per month (North East CCAC, 2013). A range of end-of-life care services including hospice palliative care, care directives, and bereavement support programs are offered to address physical, emotional, spiritual and practical needs of clients and members of their informal support networks (NorthEasthealthline.ca, 2013). Like the Champlain and Hamilton-Norfolk-Haldimand-Brant

CCAC, the North East CCAC also employs a circle of care approach to palliative care team service support. The circle of care is a person specific support network comprised of a variety of health care professionals working together to address the person's needs including physicians, advanced practice nurses, pain and symptom management consultants in addition to the CCAC care coordinator and others as required. Eligibility criteria for the palliative home care program were based on physician referral and community case manager expert judgment. Following initial assessment using the RAI Contact Assessment clients who were expected to die within three months were then referred to the palliative team and assessed with the interRAI PC. Eligibility criteria were flexible and not mandated. Referral policies may also have been affected by caseload intensity and demand

The Manitoulin/Sudbury region was selected as the focus of the interRAI PC pilot. It included a seventy percent urban and thirty percent rural client mix. Six registered nurse case managers who comprised the regional palliative team attended a two-day in person training workshop. Pilot data were collected from 2009 to 2011. Paper based assessments were completed, copied, and de-identified and then sent to the Nipissing University. Assessments were manually entered into an excel form which was then transferred to the University of Waterloo for entry into the data repository.

5.2.1.1.6 North West CCAC

The North West CCAC, covering 458, 010 km2 or 47% of the province of Ontario, is comprised of four districts: Kenora, Rainy River, Thunder Bay District, and Thunder Bay City (North West CCAC, 2013) (Figure 5.1., Area #14). In 2011-2012, the North West CCAC served 12,792 clients. The interRAI PC was piloted only in the Thunder Bay City district. In contrast to other CCAC's, the regional office in Thunder Bay employs only one end of life care coordinator. This care coordinator managed the end of life caseload of approximately 60~80 persons (but up to 120~130 during peak times) and completed all interRAI PC assessments for persons receiving palliative home care services. Referral for palliative care service was determined most often by the person's physician or home care case manager. Clients may be referred for palliative care services and assessed with the interRAI PC directly at the point of intake or may have received a previous RAI-HC assessment and be referred for palliative care services during a follow-up assessment. Data was collected from 2006 to 2010 using paper-based assessments. Assessments were de-identified, then scanned and entered into the data repository at the University of Waterloo.

5.2.2 Measures

interRAI instruments speak a common language. They share a core group of items that enable comparability between client groups or across care settings, and reduce the need for separate assessments and further documentation. Various scales representing different clinical and risk domains embedded within the interRAI PC considered in Chapters 6,7, and 8 include the Changes in Health, End-stage disease, and Signs and Symptoms (CHESS) scale (Hirdes, Frijters, & Teare, 2003); Cognitive Performance Scale (CPS) (Morris et al., 1994); the Activities of Daily Living Hierarchy (ADL-H) (Morris, Fries, & Morris, 1999); and the Pain Scale (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001). The CHESS scale, a measure of instability in health as a clinical outcome and predictor of mortality, ranges from 0 (no instability in health) to 6 (highly unstable health). Mental status is assessed using the CPS, a scale ranging from 0 (cognitively intact) to 6 (severe cognitive impairment). It has been validated against the Mini-Mental State Examination in both institutional and community settings (Morris et al., 1994; Landi et al., 2000). Physical functioning is measured using the ADL-H scale ranging from 0 (independent) to 6 (totally dependent). Items included in the ADL-H score include personal hygiene, toilet use, locomotion, and eating. The Pain Scale uses two items to measure pain and has scores ranging from 0 (no pain) to 4 (excruciating pain). The Pain Scale has been validated with the Visual Analogue Scale (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001).

The interRAI PC combines comprehensive, multidisciplinary evaluation of an individual's strengths, preferences, and needs with a series of Clinical Assessment Protocols (CAPs) to inform clinical decision-making as part of the care planning process (Martin, et al., 1999) and inform where more focused plans of care may be required. The interRAI PC includes eight Clinical Assessment Protocols (CAPs) in three domains: (1) Performance (Fatigue and Sleep Disturbance); (2) Clinical Complexity (Nutrition, Pressure Ulcers, Pain, and Dyspnea); and (3) Cognition and Mental Health (Mood Disturbance and Delirium). CAPs use algorithms calculated from responses collected on various items collected as part of the interRAI PC assessment. These CAPs do not require additional questions to be asked. The CAPs are designed to assist clinicians to probe in-depth into areas on specific aspects of person's function and quality of life, and to assess the person's potential for change. Each CAP addresses how the clinical issue may impact the life of the person with a life limiting illness; outlines the overall goals of care highlighting what is to be achieved through intervention; includes a targeting trigger identifying who is most likely to benefit from an intervention; and provides best practice care guidelines that inform an appropriate approach to the issue.

5.3 Proposed Research

This research addresses the importance of using standardized comprehensive evidence to inform care planning for persons with a life limiting illness, using information gathered from the interRAI PC and specifically through in-depth analysis focused on the interRAI PC CAPs. Three research chapters examine the clinical needs of palliative home care clients in Ontario, describe how clinical needs may vary by person and regional characteristics, and illustrate potential benefits using the interRAI PC CAPs may have to inform care planning. The interRAI PC was mandated for use across Ontario in September 2012, but to date only limited research has been done to examine the CAPs in the Canadian context. This thesis examines how the interRAI PC and its associated CAPs can provide information about needs and enable better care planning for persons with life limiting illness' among community dwelling persons receiving palliative home care services. Hierarchical triggering structure in the CAP distributions is presented.

Analyses for the three chapters are based on pilot data gathered between 2006 and 2011 using the interRAI PC assessment instrument. Community dwelling persons with a life limiting illness receiving palliative home care services in six geographic locations across Ontario, Canada, are included in the analysis. Persons with a life limiting illness residing in institutional or hospice facilities, or in jurisdictions outside of Ontario, were excluded. Chapters 6, 7, and 8 have been formatted as journal articles suitable for publication. Analyses are performed using SAS Version 9.2 with an alpha level of $p < 0.05$ for all statistical tests unless otherwise stated. The University of Waterloo's Office of Research Ethics granted ethics clearance for use of de-identified assessment data (ORE# 19424) November 29th, 2013.

5.3.1 Care Planning Needs of Ontario Palliative Home Care Clients Based on the interRAI Palliative Care (interRAI PC) Assessment Clinical Assessment Protocols (CAPs)

Chapter six provides an overview of the distributional properties of the interRAI PC CAPs adding to the current literature of the population level needs of persons with a life limiting illness receiving home care services. This chapter describes how data gathered from the interRAI PC CAPs may be used to inform clinicians during the care planning process for palliative home care clients in Ontario, Canada. This chapter is the first to examine how the CAPs may be used among a population of persons with a life limiting illness recognized to be nearing the end of life and requiring palliative home care services. Patterns in CAP triggering and variability in triggering rates among the eight interRAI PC CAPs are discussed. This is the first comprehensive study in Canada to use the interRAI PC CAPs to examine the care needs of a large diverse sample of palliative home care clients with multiple disease diagnoses across six regional jurisdictions (See Figure 5.1.). Specifically, the goals of this chapter are to: 1) examine distributional properties of the eight interRAI PC CAPs with special focus given to client age, sex, estimated prognosis, geographic location, and disease diagnosis (Cancer vs. No-Cancer Diagnosis) and 2) following methods used by Morris et al., (1999), identify a hierarchical structure in CAP triggering rates across the eight CAPs. Chapter six describes an overall profile of persons with a life limiting illness across Ontario who received palliative home care services and examines the value and depth of information available to be gained by utilization of evidence from the interRAI PC assessment instrument.

5.3.2 Changes in Dyspnea Symptoms Over Time Among Community Dwelling Persons with a Life Limiting Illness in Ontario, Canada

Chapter seven focuses on the interRAI PC Dyspnea CAP and describes the depth of information available to inform evidence based clinical decision-making during the care planning process. This chapter focuses on dyspnea as it is not only one of the most distressing symptoms at end of life, but is common among palliative home care clients and known to affect the QOL of both the person with a life limiting illness and the informal support network. Chapter seven employs cross-sectional and longitudinal methods to examine predictors of the Dyspnea CAP being triggered. Careful attention is given to the role of disease diagnosis and estimated prognosis. An extensive literature review focused on the epidemiology of dyspnea informed the rationale for variable selection and inclusion in all analyses. Specifically, the goals of chapter seven are to: 1) investigate the prevalence of dyspnea among persons who receive palliative home care services in Ontario, Canada; b) describe how those who experience dyspnea differ from those who do not experience dyspnea; and c) examine changes in dyspnea over time. Findings from this chapter seek to expand understanding on health and clinical characteristics as well as levels of health service utilization associated with dyspnea and focuses upon identification of predictive factors affecting development of new dyspnea and recovery from dyspnea over time. These findings may be clinically relevant to inform clinicians during care planning process and lead to more effective care.

5.3.3 A Cross-Sectional Examination of the Relationship Between Dyspnea and Distress Experienced Within the Caregiver-Client Unit of Care

Dyspnea, selected as the symptom of the focus of chapter seven, is widely recognized to be one of the most troubling symptoms for the person with a life limiting illness who experiences the symptom but also for their caregivers (Ng &von Gunten, 1998; Potter, Hami, Bryan, & Quigley, 2003; Dellon et al., 2010; Kroenke, Johns, Theobald, Wu, & Tu 2013). Chapter eight expands understanding of the negative characteristics associated with dyspnea for both the care recipient (person with a life limiting illness) and their informal caregiver emphasizing the importance for clinicians to prioritize care of dyspnea during the care planning process. There is a lack of palliative care research that examines the 'family unit', which includes both the person with a life limiting illness and their family caregivers together as an 'interactive system' (Mehta et al., 2009). The psychosocial wellbeing of persons at end of life and their caregivers are interrelated (Hodges, Humphris, & Macfarlane, 2005)) this chapter examines the relationship between presence of dyspnea and the presence of distress experienced by both the caregiver and care recipient by focusing on the caregiver-client unit of care.

As persons nearing the end of life experience multiple complex conditions and the main criteria to evaluate dyspnea is subjective it remains unclear how strong dyspnea is as a predictive factor affecting distress within the caregiver-client unit of care. Therefore, the current study examines the relationship between distress within the caregiver-client unit of care and dyspnea to investigate the role of dyspnea as an independent variable to predict distress experienced by the person or his/her caregivers. The specific objective of this study is to determine whether dyspnea is associated with distress in either the person receiving palliative care or members of their informal network. It is postulated that findings will emphasize the importance for clinicians to consider the caregiver-client unit of care when care planning for persons who are experiencing dyspnea.

6. Care Planning Needs of Ontario Palliative Home Care Clients Based on the interRAI Palliative Care (interRAI PC) Assessment Clinical Assessment Protocols (CAPs)

6.1 Introduction

Palliative care is a person-centered approach to care that prioritizes the highest level of pain and symptom management available to improve quality of life at the end of life for persons faced with a life limiting illness. Moreover, palliative care may enhance the health and well-being of the person's informal support network including family and caregivers. Palliative care may be "achieved through prevention and relief of suffering by means of early identification, comprehensive assessment, and treatment of pain and physical, psychosocial, or spiritual problems" (World Health Organization [WHO], 2010).

Standardized assessment provides a systematic way to identify need at the person level. Accumulation of assessments may create an evidence base to inform community, regional, and national standards and policies at an aggregate level. The interRAI Palliative Care (interRAI PC) assessment instrument is part of the larger interRAI suite of instruments. interRAI, an international collaborative of researchers, clinicians, and health professionals, share a united vision that implementation of standardized measurement systems and integration of comprehensive assessments into clinical practice may promote evidence informed decision making to improve care of vulnerable persons. The interRAI PC, designed for use among persons faced with a life limiting illness, is a standardized comprehensive assessment tool providing person-specific information to inform the care planning process. Moreover, information gathered from the interRAI PC enables tracking change over time, and may inform future development of a case mix system for persons receiving palliative care (Steel et al., 2003). The interRAI PC has been newly implemented in Ontario, Canada, joining other mandated interRAI instruments including the RAI-HC and MDS 2.0 (CHCA, 2008; Hirdes, Mitchell, Maxwell, & White, 2011).

The interRAI PC assists front line care providers to address aspects of physical and cognitive functioning, mental health and wellbeing, as well as social supports and end of life preferences. Uptake of evidence gathered from the interRAI PC into clinical decision-making facilitates interpersonal communication between clients and their care providers, and when appropriate their informal support network. Effective communication leads to higher quality of care at the person level through better targeting of care services to meet their needs at the right time in the right place.

The interRAI PC Clinical Assessment Protocols (CAPs) focus on specific aspects of person's function and quality of life and assess the needs, strengths, preferences, and potential for change of the person. Using algorithms embedded within the interRAI PC, the CAPs alert the assessor to specific problems and indicate either risk or potential for improvement, that should be addressed in the care plan (Carpenter, 2006). Each CAP contains 4 main components: issue statement, goals of care, triggers, and guidelines. The issue statement provides a clear rationale for why the specific CAP domain should be considered an important part of the palliative care services approach and examines the impact of the clinical issue on the person's life. The goals of care highlight the benefits of potential intervention and focus on what may be achieved through care (Brandeis, Berlowitz, Hossian, & Morris, 1995; Martin et al., 2009; Zhu et al., 2007; and Resnick et al., 1996). These vary by CAP but each may include: resolving the problem, reducing risk of deterioration or reducing side effects, or increasing the opportunity to improve or maintain function where possible. Targeting triggers identify which persons are most likely to benefit from intervention. Detailed technical information on the statistical code for the CAP triggers may be accessed via www.interRAI.org. Best practice care guidelines summarize appropriate responses to the issue. By outlining approaches to the problem clinicians are able to consider underlying issues and treatment alternatives when creating a person-specific plan of care. The CAP manual includes additional resources and reference materials enabling clinicians' quick access to detailed information on issues addressed by the CAPs.

The first suite of eight interRAI PC CAPs released in 2013 address three key domains: Performance- Fatigue CAP and Sleep Disturbance CAP; Clinical Complexity – Nutrition CAP, Pressure Ulcers CAP, Pain CAP, and Dyspnea CAP; and Cognition and Mental Health- Mood Disturbance CAP and Delirium CAP (Steel, et al., 2013e). These CAPs are distinct from other CAPs such as those accompanying the interRAI home care, long-term care, and mental health instruments, in that they specifically account for changing client needs as individuals progress towards death and recognize that clinicians may choose to whether to prioritize care planning to address the issue depending on the person's prognosis. The CAP's highlight, when appropriate, areas of need that may benefit from treatment/care even in the final stages of life. Mathias, Hirdes, and Pittman (2010) and Neufeld, Perlman, and Hirdes (2012) illustrated the benefits of the CAPs for both risk assessment and care planning in the community and institutional mental health settings. Neufeld, Freeman, Hirdes, and Joling (2014) highlighted the benefits for clinicians to use the CAPs to assist in identifying at-risk residents residing in long-term care facilities.

This is the first time to describe the strengths and limitations of the interRAI PC Clinical Assessment Protocols (CAPs) and illustrate its ability to identify persons at risk thereby providing valuable information during the care planning stage. Integration of evidence from the CAPs into the clinical decision making process clearly supports comprehensive assessment, as emphasized by the WHO (2010), be an integral component of quality palliative care. An overview of the CAPs development process will be provided and an examination of how the CAPs function in relation to physical, social, psychological, and clinical characteristics at an aggregate level will be shown. The detailed profile of home care clients diagnosed with a life limiting illness in six regions of Ontario assessed to receive palliative home care services will show the value and depth of information to be gained by utilization of the interRAI PC assessment instrument.

6.2 CAP development process

CAP development entailed a three phase multi-year process conducted by an international committee with members from nine countries, involved consideration of evidence from peer-reviewed literature; international best practice guidelines; and provided by a collective of national and international experts (Steel, 2013e). Phase one focused on an extensive literature review of international best practice guidelines for each CAP domain area, gathered from at least three global regions. These guidelines were used to identify and prioritize the CAP domain focus. If guidelines were unavailable then relevant peer-reviewed publications were identified. Phase two involved widespread consultation, focus groups, and formal in person reviews with subject-matter experts from around the world to gather feedback on the CAPs. Direct evaluation of the CAPS by clinicians was paramount to ensure face validity. Responses from both interRAI and outside experts supported that each CAPs captured accurate and clinically relevant information applicable to care providers. Recommendations during the consultation process were incorporated into the CAP frameworks. Phase three focused on creation of triggering algorithms created based on analysis of Canadian pilot data. The interRAI PC CAP manual was developed, detailing information on trigger rates; factors associated with triggering; and best practice guidelines (Steel et al. 2013e).

6.2.1 Data Source

The interRAI PC includes more than 280 items, covering 75 key areas, grouped into 17 key domains including demographic and intake information, medical diagnoses and conditions, physical and cognitive functioning, and psycho-social and emotional wellbeing (Steel, 2003). It may be employed in multiple care settings such as community-based, hospice, or residential care facility. Assessments, completed by trained assessors with professional backgrounds, including nursing and social work, consolidate information from direct observation, medical records, and communication with the person, their health team, and their informal support network. Information gathered from the interRAI PC assists clinicians in their evaluation of individual care needs. The breadth of information collected provides a comprehensive description of the person. Items contained in the interRAI PC have shown excellent inter-rater and test-retest reliability (Steel et al, 2003, Hirdes et al, 2008). Data gathered from interRAI PC assessments provide an evidence base, which when combined with clinical judgment, is useful to inform the development and implementation of care plans tailored to the unique needs of each person.

6.2.2 Clinical Assessment Protocols (CAPs)

The Dyspnea CAP and Delirium CAP both have binary triggers in comparison to the other six CAPs that have two triggering levels. The Dyspnea CAP identifies persons experiencing shortness of breath and highlights strategies to recognize the onset and severity of symptoms (Steel, Morris, & Leff, 2013a). Persons who are currently experiencing delirium trigger the Delirium CAP that highlights clinical strategies not only to identify and treat symptoms but also to prevent foreseeable complications and to improve quality of life (Steel, Inouye, Morris, Murphy, & Marcantonio, 2013b). The Fatigue CAP is the most frequently triggered. It differentiates the risk for persons currently or at risk to experience fatigue (medium risk-trigger level 1, high risk-trigger level 2) and outlines key considerations to address both causes and symptom reduction (Olsen, Steel, Ljunggren, Steel, & Smith, 2013). Based on the Pain Scale, the Pain CAP prioritizes persons experiencing pain (medium-trigger level 1, high-trigger level 2) and provides best practice guidelines for assessment and management strategies (Won et al., 2010). The Mood Disturbance CAP differentiates levels of risk of depression by symptom frequency (single-trigger level 1, multiple-trigger level 2) with a goal to improve psychological well-being (Smith, Rabinowitz, Hirdes, Morris, Stewart, Constantino, & Steel, 2013). It outlines best practice approaches that address the symptoms, investigate further the type of disorder, and lists key considerations for potential treatment and monitoring of the disorder. The Sleep CAP differentiates the potential to improve (moderate-trigger level 1 or high-trigger level 2) among persons experiencing a sleep disturbance. Based upon the presence of a list of reversible issues, the Sleep CAP focuses on strategies to reduce the disturbance, increase comfort, and improve functioning (Ljunggren, Olson, Smith, Steel, Hirdes, & Morris, 2013). The Nutrition CAP identifies persons who may benefit from education and interventions to optimize energy and protein intake, reduce anxiety about not eating, or who could benefit from interventions addressing hunger (Steel, Morris, Sorby, & Steel, 2013d). Trigger levels focus on persons with a low body mass index and differentiates levels based on absence (trigger level 1) or presence (trigger level 2) of weight loss. The Pressure Ulcers CAP emphasizes importance of appropriate treatment and identifies potential for improvement (moderate-trigger level 1, high-trigger level 2) for persons with pressure ulcers (Steel et al., 2013c).

6.2.3 Study Population

De-identified cross-sectional pilot data from 6,769 interRAI PC assessments gathered between 2006 and 2011 from palliative home care clients in Ontario, Canada were included for analysis. When follow-up assessments were available, only the first assessment was included. Sample characteristics of the study population are shown in Table 6.1. Age ranged greatly from 18 to 107 years with a mean age of 70.0 years (SD ±13.4 years), of whom more than 80% reported a diagnosis of cancer (n=5,875). The majority of persons had an estimated prognosis of greater than 6 weeks, with more than 40% (n=2,310) having an estimated prognosis of greater than six months at time of assessment. In contrast only 2% (n=110) had a prognosis of death being imminent.

Table 6.1. Sample Characteristics of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).

	Total Population % (N)
Age Groups	
18-44	4.3 (288)
45-64	29.9 (2,025)
65-74	25.4 (1,718)
75-84	28.7 (1,943)
85 +	11.7 (795)
Gender	
Male	49.1 (3,303)
Female	50.9 (3,418)
Estimated Prognosis	
Greater than 6 months	41.5 (2,310)
6 weeks to 6 months	48.1 (2,677)
Less than 6 weeks	8.4 (468)
Death Imminent	2.0 (110)
CCAC Site Location	
Site 1	4.0 (270)
Site 2	47.7 (4,581)
Site 3	14.6 (991)
Site 4	7.5 (510)
Site 5	2.1 (142)
Site 6	4.1 (275)
Diagnosis	
Have Cancer Diagnosis	86.8 (5,875)
Metastatic	40.0 (2,710)
Not Metastatic	46.8 (3,165)
Do not have Cancer	9.8 (666)
Diagnosis Unspecified	3.4 (228)

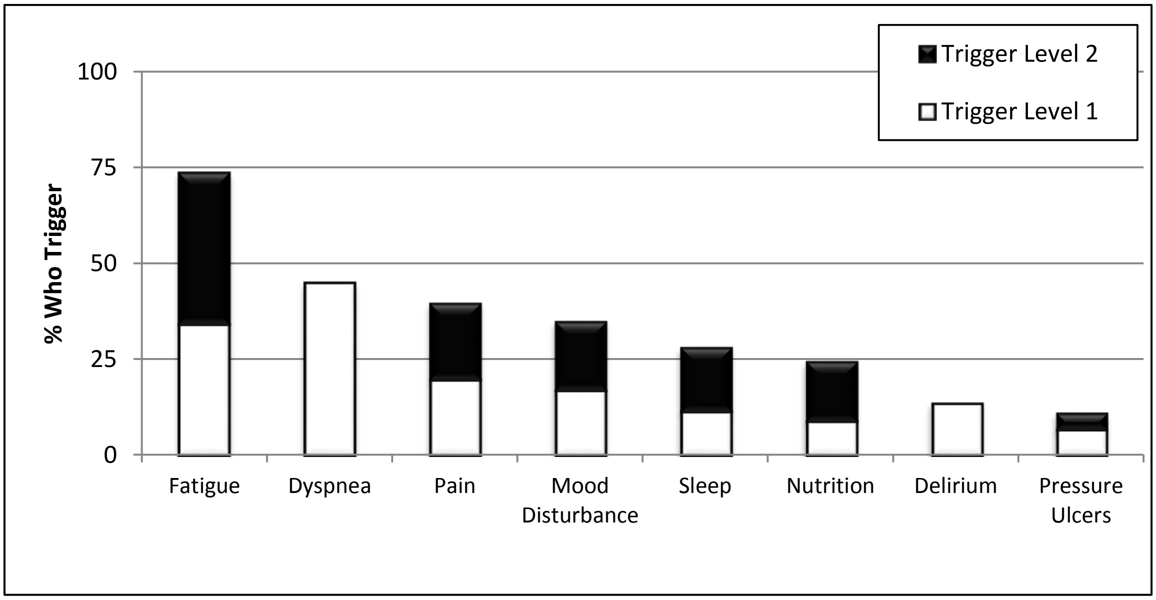
6.2.4 Analysis

The univariate distributional properties were examined for all eight interRAI PC CAPs and cross tabulations were used to examine the hierarchical triggering structure of the CAPs. Associated covariates including age, gender, estimated prognosis, geographic location, and disease diagnosis, were examined using chi-square to determine significant relationships. The hierarchical analysis also employed chi-square analysis to examine covariates among CAPs. All analyses were performed using SAS Version 9.2 with an alpha level of $p < 0.05$ for all statistical tests.

6.3 Results

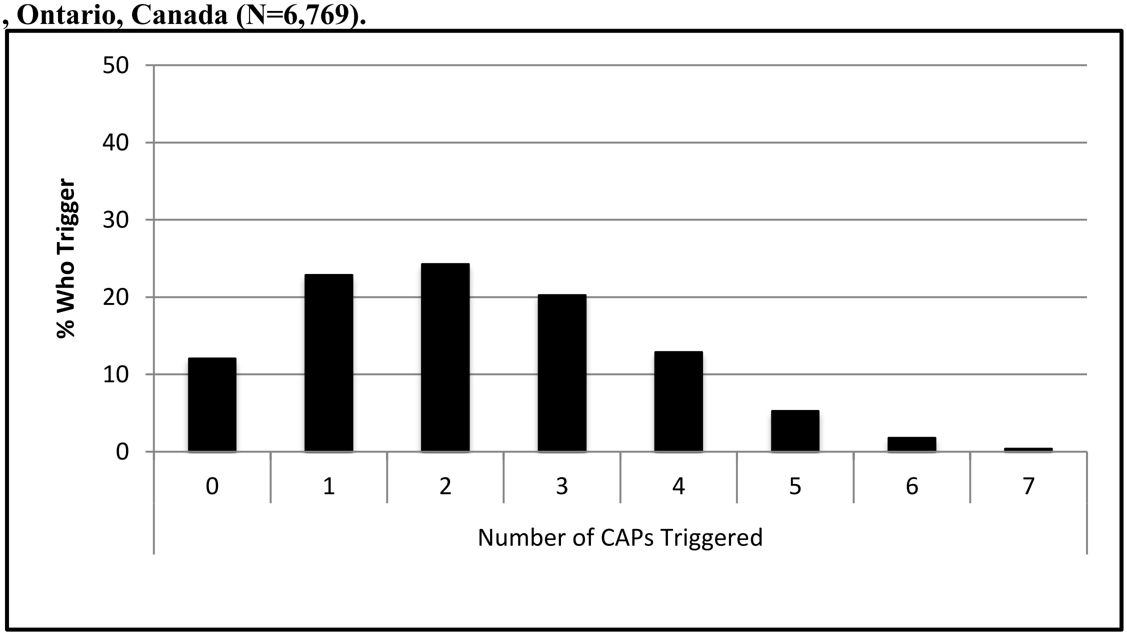
Each CAP contains individualized triggers occurring at different rates from 74% (Fatigue CAP) to less than 15% (Delirium and Pressure Ulcers CAPs) (Figure 6.1). Spearman's rank correlations suggested that the majority of CAPs were reasonably independent from each other. Modest correlations were evident between the Fatigue and Delirium CAPs (0.20) and Fatigue and Mood CAPs (0.26).

Figure 6.1. Triggering Rates by CAP of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).



Nearly 9 in 10 persons triggered at least one CAP (87.9%, n=5,950) and approximately two thirds triggered more than two CAPs (Figure 6.2.).

Figure 6.2. Number of CAPs Triggered by Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).



Variable distribution differs across the four clinical complexity CAPs (Table 6.2. and 6.3.). Dyspnea CAP and Pressure Ulcers CAP triggering rates increased with age but the Pain CAP triggering rate decreased with age. A curvilinear relationship was observed among persons who triggered the Nutrition CAP where the youngest (aged 18-44) and the oldest old (85+) age groups were more likely to trigger at level 1. Small gender differences were evident between CAPs. Males were more likely to trigger the Dyspnea CAP in contrast to females who were more likely to trigger the Nutrition CAP. Triggering of the clinical complexity CAPs increased as the length of estimated prognosis decreased. Persons over the age of 65 exhibited higher rates of persons who triggered the Pressure Ulcers CAP and were most likely to trigger as difficult to improve. With the exception of the Pain CAP where persons with a cancer diagnosis triggered most frequently, the clinical complexity CAPs were most often triggered by persons with only a non-cancer diagnosis.

Triggering rates differed by geographic location. CCAC Site 5 reported substantially lower rates of persons who triggered the Dyspnea CAP than other CCAC sites (23.6% for CCAC site 1 vs. range from 37.5% in CCAC site 2 to 46.75 in CCAC site 2). For the Nutrition CAP, although overall triggering prevalence were comparable across sites, persons from the CCAC Site 5 reported the highest triggering rates at level one but the lowest prevalence at level two. In contrast, CCAC Site 1 exhibited the lowest triggering rates for the Nutrition CAP at level one and the highest prevalence of Nutrition CAP triggering rates at level two.

Table 6.2. Distribution of Background Characteristics by Dyspnea and Nutrition Clinical Complexity CAPs of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).

	Dyspnea				Nutrition				
	Not Triggered %(N)	Trigger Level 1 %(N)	Chi-square (df)	p Value	Not Triggered %(N)	Trigger Level 1 %(N)	Trigger Level 2 %(N)	Chi-square (df)	p Value
Age Groups									
18-44	68.6 (192)	31.4 (88)	31.8 (4)	<.0001	76.4 (155)	12.3 (25)	11.3 (23)	28.4 (8)	0.0004
45-64	57.1 (1,140)	42.9 (858)			78.7 (1,044)	6.3 (84)	14.9 (198)		
65-74	54.4 (919)	45.6 (769)			76.5 (855)	8.4 (94)	15.1 (169)		
75-84	52.0 (994)	48.0 (919)			73.1 (882)	10.3 (124)	16.7 (201)		
85 +	54.0 (420)	45.9 (356)			71.9 (330)	12.2 (56)	15.9 (73)		
Gender									
Male	53.1 (1,727)	46.9 (1,526)	9.6 (1)	0.002	78.9 (1,645)	6.3 (132)	14.8 (308)	38.1 (2)	<.0001
Female	56.9 (1,908)	43.1 (1,446)			72.5 (1,591)	11.4 (251)	16.1 (353)		
Estimated Prognosis									
Death Imminent	37.4 (40)	62.6 (67)	105.2 (3)	<.0001	64.7 (33)	2.0 (1)	33.3 (17)	78.4 (6)	<.0001
Less than 6 weeks	43.8 (203)	56.3 (261)			65.2 (193)	6.8 (20)	28.0 (83)		
6 weeks to 6 months	53.4 (1,413)	46.6 (1,235)			73.5 (1,407)	9.2 (176)	17.3 (331)		
Greater than 6 months	63.7 (1,454)	36.3 (829)			79.4 (1,355)	9.4 (161)	11.2 (191)		
Geographic Location									
Site 1	62.6 (167)	37.5 (100)	41.5 (5)	<.0001	74.1 (172)	4.7 (11)	21.1 (49)	38.9 (10)	<.0001
Site 2	53.3 (2,389)	46.7 (2,091)			77.1 (1,945)	8.2 (208)	14.7 (371)		
Site 3	58.1 (574)	41.9 (414)			71.3 (627)	10.8 (95)	17.9 (157)		
Site 4	54.0 (273)	46.1 (233)			75.6 (272)	10.8 (39)	13.6 (49)		
Site 5	76.4 (107)	23.6 (33)			72.8 (75)	17.5 (18)	9.7 (10)		
Site 6	56.6 (155)	43.4 (119)			81.4 (175)	5.6 (12)	13.0 (28)		
Diagnosis									
Have Cancer Diagnosis	57.8 (2,295)	42.2 (1,678)	98.9 (3)	<.0001	76.1 (1,912)	8.71 (219)	15.2 (383)	39.5 (6)	<.0001
Have Cancer and Non-Cancer Diagnosis	56.5 (1,023)	43.5 (789)			77.8 (1,047)	6.76 (91)	15.5 (208)		
Have Non-Cancer Diagnosis Only	37.8 (245)	62.3 (404)			67.5 (241)	16.8 (60)	15.7 (56)		
Diagnosis unspecified	46.2 (103)	53.9 (119)			68.8 (66)	13.5 (13)	17.7 (17)		

Note: df denotes degrees of freedom

Table 6.3. Distribution of Background Characteristics by Pain and Pressure Ulcers Clinical Complexity CAPs of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).

	Pain					Pressure Ulcers				
	Not Triggered %(N)	Trigger Level 1 %(N)	Trigger Level 2 %(N)	Chi-square (df)	p Value	Not Triggered %(N)	Trigger Level 1 %(N)	Trigger Level 2 %(N)	Chi-square (df)	p Value
Age Groups										
18-44	47.4 (120)	20.6 (52)	32.0 (81)	156.7 (8)	<.0001	91.2 (239)	5.34 (14)	3.4 (9)	87.8 (8)	<.0001
45-64	51.9 (955)	23.1 (425)	25.0 (460)			91.6 (1,708)	3.9 (73)	4.5 (84)		
65-74	59.9 (948)	21.2 (336)	18.8 (298)			89.4 (1,414)	5.6 (88)	5.1 (80)		
75-84	67.4 (1,191)	16.2 (286)	16.3 (288)			88.3 (1,573)	8.0 (143)	3.7 (66)		
85 +	70.8 (499)	16.1 (113)	13.1 (92)			83.3 (600)	13.3 (96)	3.3 (24)		
Gender										
Male	59.5 (1,775)	19.9 (593)	20.6 (614)	2.8 (2)	0.25	88.6 (2,684)	6.7 (204)	4.7 (141)	2.7 (2)	0.26
Female	61.4 (1,913)	19.5 (608)	19.1 (594)			89.6 (2,811)	6.6 (208)	3.8 (120)		
Estimated Prognosis										
Death Imminent	51.5 (51)	24.2 (24)	24.2 (24)	53.2 (6)	<.0001	76.0 (73)	22.9 (22)	1.0 (1)	139.4 (6)	<.0001
Less than 6 weeks	50.5 (218)	23.6 (102)	25.9 (112)			80.0 (348)	15.9 (69)	4.1 (18)		
6 weeks to 6 months	57.3 (1,454)	22.1 (562)	20.6 (522)			87.9 (2,222)	7.5 (190)	4.6 (115)		
Greater than 6 months	65.2 (1,424)	18.2 (398)	16.6 (363)			92.7 (2,022)	3.5 (76)	3.8 (83)		
Geographic Location										
Site 1	50.2 (133)	23.8 (63)	26.1 (69)	195.2 (10)	<.0001	87.6 (232)	7.9 (21)	4.5 (12)	34.7 (10)	0.0001
Site 2	59.3 (2,382)	20.9 (838)	19.8 (795)			89.5 (3,653)	6.1 (248)	4.4 (181)		
Site 3	77.1 (745)	10.0 (97)	12.9 (125)			87.5 (853)	9.6 (94)	2.9 (28)		
Site 4	48.9 (244)	20.0 (100)	31.1 (155)			87.8 (430)	5.7 (28)	6.5 (32)		
Site 5	58.4 (80)	24.8 (34)	16.8 (23)			88.2 (119)	8.9 (12)	3.0 (4)		
Site 6	49.4 (129)	30.7 (80)	19.9 (52)			93.6 (247)	4.2 (11)	2.3 (6)		
Diagnosis										
Have Cancer Diagnosis	57.9 (2,124)	21.1 (774)	21.0 (772)	56.3 (6)	<.0001	91.0 (3,375)	4.5 (166)	4.6 (169)	215.9 (6)	<.0001
Have Cancer & Non-Cancer Diagnosis	61.7 (1,044)	18.5 (313)	19.8 (335)			90.0 (1,541)	6.3 (108)	3.7 (64)		
Have Non-Cancer Diagnosis Only	73.2 (429)	13.0 (76)	13.8 (81)			75.6 (445)	20.5 (121)	3.9 (23)		
Diagnosis unspecified	59.2 (116)	25.0 (49)	15.8 (31)			86.9 (173)	9.6 (19)	3.5 (7)		

Note: df denotes degrees of freedom

Males were more likely to trigger the Sleep Performance CAPs (Table 6.4.) Not only does the proportion who trigger the Fatigue CAP increase as length of estimated prognosis lessens, the number who trigger it at high risk nearly triples between those with an estimated prognosis of greater than six months compared to those where death is imminent. A similar pattern emerges for the Sleep CAP; however, it is much less frequently triggered than the Fatigue CAP. Geographic variation is pronounced among the performance CAPs. Prevalence of Fatigue CAP triggering ranged greatly by site. CCAC Site 3 stands out with lower rates for Fatigue CAP triggering (72% CCAC Site 3 compared to high of 84% CCAC Site 4) and the highest rate of triggering for the Sleep CAP (32% CCAC Site 3 compared to low of 24% CCAC Site 1).

Table 6.4. Distribution of Background Characteristics by Fatigue and Sleep Performance CAPs of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).

	Fatigue					Sleep				
	Not Triggered %(N)	Trigger Level 1 %(N)	Trigger Level 2 %(N)	Chi-square (df)	p Value	Not Triggered %(N)	Trigger Level 1 %(N)	Trigger Level 2 %(N)	Chi-square (df)	p Value
Age Groups										
18-44	31 (62)	40.0 (80)	29.0 (58)	23.2 (8)	0.003	62.8 (135)	12.1 (26)	25.1 (54)	74.7 (8)	<.0001
45-64	26.3 (396)	36.3 (547)	37.4 (564)			66.2 (1,055)	12.1 (192)	21.7 (346)		
65-74	27.5 (351)	31.8 (406)	40.7 (520)			73.6 (1,015)	11.5 (159)	14.9 (206)		
75-84	25.7 (364)	34.4 (487)	39.9 (565)			76.8 (1,187)	10.0 (154)	13.3 (205)		
85 +	24.5 (136)	30.6 (170)	44.9 (249)			74.5 (462)	13.1 (81)	12.4 (77)		
Gender										
Male	25.3 (607)	33.9 (815)	40.9 (982)	4.7 (2)	0.09	69.5 (1,813)	13.3 (346)	17.2 (449)	20.2 (2)	<.0001
Female	27.6 (693)	34.2 (860)	38.2 (960)			74.3 (2,014)	9.7 (263)	16.0 (433)		
Estimated Prognosis										
Death Imminent	2.5 (2)	8.9 (7)	88.6 (70)	856.8 (6)	<.0001	68.8 (53)	9.1 (7)	22.1 (17)	23.1 (6)	0.0008
Less than 6 weeks	3.8 (15)	25.3 (99)	70.8 (277)			75.3 (289)	5.0 (19)	19.8 (76)		
6 weeks to 6 months	14.1 (337)	41.9 (1,000)	44.0 (1,052)			71.5 (1,635)	11.2 (257)	17.3 (394)		
Greater than 6 months	45.6 (955)	27.9 (584)	26.6 (557)			72.0 (1,483)	12.5 (258)	15.5 (320)		
Geographic Location										
Site 1	19.5 (50)	35.2 (90)	45.3 (116)	202.3 (10)	<.0001	76.5 (199)	6.9 (18)	16.5 (43)	31.6 (10)	0.0005
Site 2	28.9 (868)	28.7 (860)	42.4 (1,273)			73.1 (2,499)	11.5 (393)	15.5 (529)		
Site 3	28.5 (262)	45.1 (415)	26.5 (244)			67.1 (633)	13.8 (130)	19.09 (180)		
Site 4	15.8 (70)	40.3 (178)	43.9 (194)			70.8 (312)	7.9 (35)	21.32 (94)		
Site 5	18.0 (20)	64.0 (71)	18.0 (20)			73.9 (68)	12.0 (11)	14.13 (13)		
Site 6	17.4 (39)	33.9 (76)	48.7 (109)			72.6 (143)	12.7 (25)	14.72 (29)		
Diagnosis										
Have Cancer Diagnosis	28.1 (823)	34.7 (1,016)	37.2 (1,090)	94.2 (6)	<.0001	73.6 (2,360)	11.3 (362)	15.1 (484)	19.8 (6)	0.003
Have Cancer and Non-Cancer Diagnosis	26.2 (375)	37.1 (530)	36.7 (525)			68.8 (1,038)	11.9 (180)	19.28 (291)		
Have Non-Cancer Diagnosis Only	17.2 (79)	24.8 (114)	58.0 (266)			71.2 (349)	9.8 (48)	18.98 (93)		
Diagnosis unspecified	23.4 (32)	21.9 (30)	54.7 (75)			71.8 (107)	14.8 (22)	13.4 (20)		

Note: df denotes degrees of freedom

Triggering rates of the cognition/mental health CAPs are shown in table 6.5. A general increase in Delirium CAP triggering is shown by age. Persons aged 85 or greater exhibited the highest triggering rate nearly double the rate of those aged 18-44. The inverse was generally seen for the Mood CAP where triggering frequency decreased with age with the exception for youngest age group. However, among those who triggered the Mood CAP, younger persons were more likely to trigger at a level two. The Delirium CAP is most commonly triggered by persons with shorter prognosis, with over two thirds triggering the Delirium CAP when death is imminent. In contrast, the Mood CAP was most commonly triggered by persons with an estimated prognosis of less than 6 weeks. Site variations in Delirium CAP triggering ranged greatly from 6.4% in the CCAC Site 5 (n=9) to over 20% in CCAC Site 1 (n=55) while the difference in Mood CAP triggering rates was less than 8% between CCACs (59.0%, n=134 in CCAC Site 6 to 66.9%, n=2,666 in CCAC Site 2). Those with a non-cancer diagnosis were more likely to trigger the Delirium CAP than those with cancer. Persons with a cancer and non-cancer diagnoses triggered the Mood CAP more frequently than those with only a cancer or only a non-cancer diagnosis.

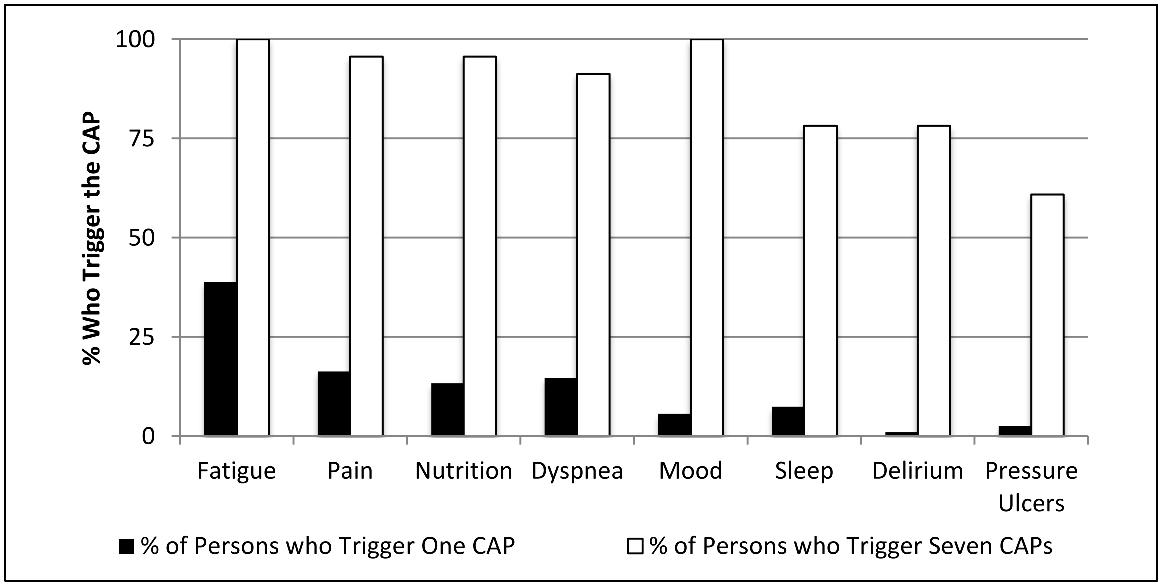
Table 6.5. Distribution of Background Characteristics by Delirium and Mood Cognition/Mental Health CAPs of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).

	Delirium				Mood				
	Not Triggered %(N)	Trigger Level 1 %(N)	Chi-square (df)	p Value	Not Triggered %(N)	Trigger Level 1 %(N)	Trigger Level 2 %(N)	Chi-square (df)	p Value
Age Groups									
18-44	91.3 (240)	8.8 (23)	12.9 (8)	0.02	63.4 (156)	14.2 (35)	22.4 (55)	45.2 (8)	<.0001
45-64	86.8 (1,601)	13.2 (244)			61.4 (1,105)	17.5 (315)	21.2 (381)		
65-74	86.1 (1,348)	13.9 (217)			63.8 (953)	18.0 (269)	18.2 (272)		
75-84	87.1 (1,540)	12.9 (228)			68.1 (1,161)	16.2 (276)	15.7 (267)		
85 +	83.1 (580)	16.9 (118)			71.7 (492)	16.0 (110)	12.2 (84)		
Gender									
Male	86.0 (2,567)	14.0 (417)	1.3 (2)	0.25	66.1 (1,904)	16.6 (479)	17.2 (496)	2.2 (2)	0.33
Female	87.0 (2,706)	13.0 (403)			64.3 (1,933)	17.4 (522)	18.3 (551)		
Estimated Prognosis									
Death Imminent	30.5 (25)	69.5 (57)	510.5 (6)	<.0001	65.1 (54)	19.3 (16)	15.7 (13)	73.3 (6)	<.0001
Less than 6 weeks	62.1 (267)	37.9 (163)			51.3 (205)	18.5 (74)	30.3 (121)		
6 weeks to 6 months	85.5 (2,171)	14.5 (368)			62.1 (1,492)	18.3 (440)	19.6 (470)		
Greater than 6 months	93.3 (2,036)	6.7 (146)			69.6 (1,490)	15.3 (328)	15.1 (324)		
Geographic Location									
Site 1	79.6 (214)	20.5 (55)	85.1 (10)	<.0001	62.3 (167)	15.3 (41)	22.4 (60)	34.9 (10)	0.0001
Site 2	89.1 (3,560)	10.9 (437)			66.9 (2,666)	17.2 (684)	16.0 (638)		
Site 3	81.6 (791)	18.5 (179)			62.0 (591)	15.3 (146)	22.8 (217)		
Site 4	80.9 (402)	19.1 (95)			62.9 (251)	18.3 (73)	18.8 (75)		
Site 5	93.6 (131)	6.4 (9)			61.1 (58)	17.9 (17)	21.1 (20)		
Site 6	79.3 (211)	20.7 (55)			59.0 (134)	19.4 (44)	21.6 (49)		
Diagnosis									
Have Cancer Diagnosis	88.0 (3,221)	12.0 (438)	42.5 (6)	<.0001	66.8 (2,336)	16.2 (566)	17.0 (595)	31.4 (6)	<.0001
Have Cancer and Non-Cancer Diagnosis	86.0 (1,482)	14.0 (241)			60.5 (1,017)	18.4 (309)	21.1 (355)		
Have Non-Cancer Diagnosis Only	78.1 (449)	21.9 (126)			67.5 (382)	18.7 (106)	13.8 (78)		
Diagnosis unspecified	86.3 (157)	13.7 (25)			70.6 (132)	12.8 (24)	16.6 (31)		

Note: df denotes degrees of freedom

Through examination of the count of triggered CAPs a hierarchical structure in CAP triggering emerged (Figure 6.3.). Fatigue is the most commonly triggered CAP, triggered by 38.9% of persons who triggered only one CAP to over 90% of persons who triggered three to five CAPs and 100% of persons to triggered six or more CAPs. Captured in the percentage of persons who trigger only one CAP, the Fatigue CAP, Pain CAP, Nutrition CAP, and Dyspnea CAP emerged as early-triggered CAPs. In contrast, the Delirium and Pressure Ulcer CAPs emerged as late-triggered CAPs. Consequently, persons who triggered only one CAP, they were most likely to trigger the Fatigue CAP, Pain CAP, Nutrition CAP, and Dyspnea CAP and were least likely to trigger the Delirium CAP and Pressure Ulcer CAP. Among those who triggered seven CAPs, all persons triggered the Fatigue CAP and Mood CAPs and over 90% triggered the Dyspnea CAP, Nutrition CAP, and Pain CAP. In contrast, the Sleep CAP, Delirium CAP, and Pressure Ulcers CAP were triggered less frequently triggered. When all but one CAP were triggered, the Sleep CAP, Delirium CAP, and Pressure Ulcers CAP remained least likely to be triggered.

Figure 6.3. Comparison of CAP Triggering Rates by Number of CAPs Triggered of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,769).



6.4 Discussion

Analyses of interRAI PC CAP triggering rates in Ontario, Canada illustrate the depth of information to be gained from the interRAI PC, a comprehensive standardized assessment instrument. Covering clinical complexity, performance, and mental health/cognition domains, the eight interRAI PC CAPs emphasize need for care planning in key areas of palliative care. The majority of persons triggered two or more CAPs reflecting high levels of clinical need within the palliative home care population. Variation in CAP triggering was evident based on the age, estimated prognosis, geographic location and diagnosis of the person. Older persons and those with a shorter estimated prognosis are most likely to trigger multiple CAPs.

As emphasized by the WHO, comprehensive assessment is an integral component of quality palliative care. White, McMullan, and Doyle (2009) found that two thirds of symptoms experienced by persons receiving palliative care services were not self-reported. Instead, the majority of symptoms were only detected through systematic questioning during assessment. As fatigue and dyspnea emerged as early-triggering CAPs, it is suggested that systematic questioning of these symptoms be prioritized during all clinical assessments. Treatment of symptoms at end of life can be effective and improve the QOL of the person and their informal support network (Lorenz, 2008). The increased health complexity of persons requiring palliative care necessitates individualized care planning. Decision making strategies informed by evidence from the interRAI PC CAPs assist clinicians to develop a person-centered care plan, identify areas of need, and prioritize treatment options.

Evidence of a hierarchical structure in CAP triggering may be useful to predict health complexity and change over time. For persons with multiple health concerns, the high frequency in Fatigue CAP, Dyspnea CAP, Pain CAP, Nutrition CAP, and Mood CAP triggering, warrant increased awareness. Fatigue CAP and Dyspnea CAP emerge as pervasive issues common among the overall palliative home care population. When persons seem relatively stable with few major health concerns, the hierarchical nature of CAP triggering suggests clinicians continue to investigate fatigue and dyspnea as potential areas of focus. In contrast, Delirium CAP and Pressure Ulcers CAP trigger at higher frequency for persons nearing end of life. The Delirium CAP and Pressure Ulcers CAP, late-triggering CAPs, rarely trigger in isolation and may highlight increased client need. The late-triggering of the Delirium CAP and Pressure Ulcers CAP suggest they are indicative of later stages of need in palliative care. Further investigation into the role of CAP triggering and symptom clusters is needed. The ability of the CAPs to identify symptoms also requires further assessment.

Consistent with previous research, the majority of persons in this study (86.8%, n=5875) reported a diagnosis of cancer. Seow, King, & Vaitonis, (2008) note that although persons with cancer receive 80-85% of palliative care services in Ontario they account for only one third of persons who die. Research used to inform current palliative care practice focuses almost exclusively on the needs of persons with a cancer diagnosis (McClement, 2006). "At the moment, there is only one model for palliative care in Canada: The cancer model" (S. Baxter, personal communication, March 1, 2010). Benefits of palliative care for persons with a cancer diagnosis and their informal support network during the rapid decline phase preceding death are well recognized, palliative care has been best known to benefit persons with cancer during these last few months of life (Shugarman, Lorenz, & Lynn, 2005; Lorenz, Shugarman, & Lynn, 2006). However, findings from this study stress increased need to broaden understanding of how persons without cancer receiving palliative care may differ. Disease diagnosis, more specifically the presence or absence of a cancer diagnosis, was a strong predictor of health characteristics and CAP triggering among persons at end of life. Persons reporting only a cancer diagnosis were more likely to trigger the Pain CAP. This may be expected, as there is increased awareness of the benefits of palliative care to address pain for persons with cancer and addressing uncontrolled pain is often a reason for referral. Therefore, persons with cancer who are experiencing challenges with pain may be more likely to be referred for palliative care services. In contrast, those reporting only non-cancer diagnoses such as heart failure, stroke, COPD, or dementia, were significantly more likely to trigger the Dyspnea CAP, Nutrition CAP, Pressure Ulcers CAP, Fatigue CAP, and Delirium CAP. This suggests that persons with non-cancer diagnoses who access palliative care services in Ontario, are more likely to exhibit increased health complexity and exhibit recognized need for person-specific tailoring of interventions to address multiple symptoms. Persons who reported both a cancer and non-cancer diagnosis were most likely to trigger the Mood and Sleep CAPs. For the Mood CAP, the prevalence of triggering with a single symptom was equally as high for those with non-cancer and cancer diagnosis and for those with non-cancer diagnosis only. However, those with both a cancer and non-cancer diagnosis were much more likely to trigger at a level 2. The level of psychosocial distress may comparable between persons with non-cancer and cancer diagnoses (Edmonds, 2001); however the present results suggest this burden may be amplified from additional disease diagnoses. This is also reflected in the CAP triggering hierarchical structure. Mood was not commonly triggered alone. However, when almost all CAPs were triggered, all persons triggered the Mood CAP. This suggests that triggering the Mood CAP may be related to increased symptom burden. It may also be possible that symptom characteristics such as length since onset, intensity, and frequency in relation to disease diagnosis may also affect the degree the symptoms impact on the person's health and QOL.

Palliative care needs to respond to the needs of persons for all ages. Findings from this study suggest that older persons are not only more complex and likely to exhibit the highest needs but that with the exception of the Pain CAP and Mood CAP, they trigger CAPs more frequently. Age-related barriers to palliative care referral, resource allocation, and service utilization in Canada have been reported elsewhere (Burt & Raine, 2006, Burge, Lawson, Critchley, & Maxwell, 2005; Burge, Lawson, Jonston, & Grunfeld, 2008; NELS ICE, 2008) and may be compounded by other challenges such as disease diagnosis, and geographic location of care (Freeman, Heckman, Naus, & Marston, 2013). Therefore, greater investigation into how age affects patterns in CAP triggering is warranted.

While the majority of CAPs were more likely to be triggered among older cohorts, two exceptions are the Mood CAP and Pain CAP where younger persons were most likely to trigger. A primary reason for these discrepancies may not be that mood and pain are less prevalent by age groups but instead that challenges exist for clinicians to recognize these symptoms (Proctor & Hirdes, 2000; Życzkowska, Szczerbińska, Jantzi, & Hirdes, 2007). Difficulties with mood and in particular symptoms of depression may also be under recognized in the older adult population due to their atypical presentation (Szczerbińska, Hirdes, & Życzkowska, 2012; Neufeld, Freeman, Joling, & Hirdes, 2014). Older adults are less likely to meet the DSM-IV-TR's diagnostic criteria resulting in failure to diagnose or more importantly failure to recognize the existence of a mood related problem. Mood disturbances and depression among older adults is often expressed as physical rather than psychological symptoms such as fatigue, weight loss, or gastro-intestinal problems in contrast to direct communications of feelings of sadness or expressions of depressed mood. This presents unique age-associated challenges for clinicians to recognize the signs of depression and mood disturbance in an older adult population.

The Pain CAP is commonly triggered for those aged 18-44. There are many possible explanations for this. First, younger persons experiencing severe pain or challenges in pain management may feel more confident to voice their concerns over pain management and therefore be referred more often than older adults who may be more hesitant to discuss pain symptoms (Bernabei et al., 1998). The ageist myth that older adults are used to pain and do not need treatment may also cause failure to refer. Older adults may be hesitant to express feelings of pain due to beliefs it is a natural part of the aging process (Bernabei et al., 1998). Rao (2004) notes that lack of recognition of pain symptoms and severity, as well as a lack of understanding of the benefits of pain treatment and management, exist for older persons. Cognitive impairment may affect the ability to communicate pain, challenge the clinician's ability to recognize signs that pain is present, and result in the underreporting of pain (Brazil, 2012). However, it may also reflect challenges for clinicians to recognize symptoms of pain among older adults. The prevalence of persons exhibiting cognitive impairment increases with age and thereby may result in elevated risk for under-recognition and under-treatment of pain for older adults.

It is commonly accepted that as persons near the end of life, the number of health issues and challenges also increases. CAP triggering rates differ greatly by age and estimated prognosis. The CAPs do not to provide a set treatment plan, but help guide the clinician to consider relevant issues, assist in prioritization of treatment feasibility, and to inform best practice guidelines for further information and guidance. In consultation with the person and when appropriate members of their informal support network, decisions on whether or not issues raised by the CAPs should be addressed should be made on a case-by-case basis. Wishes expressed by the person should be reflected when assessing treatment burden-benefit and determining whether or not to treat. It is important to remember that even in the final stages of life, persons may respond to and benefit from treatments that decrease symptom burden thereby improving QOL at the end of life.

6.5 Conclusion

Data gathered from the interRAI PC may inform understanding of the complex needs of palliative home care clients in Ontario. Patterns in CAP triggering suggest increased attention should be given to address the increasing complex needs of both older adults and of persons with a limited estimated prognosis. Future research should investigate variation by geographic location and further elucidate reasons for age-associated disparities in CAP triggering. Integration of evidence gathered from the interRAI PC CAPs into the care planning process may allow for higher quality of care through better tailoring of resources at address person-specific need.

7. Changes in Dyspnea Symptoms Over Time Among Community Dwelling Persons with a Life Limiting Illness in Ontario, Canada

7.1 Introduction

Dyspnea, also referred to as shortness of breath or breathlessness, is one of the most frequently reported and highly distressing symptoms affecting persons nearing end of life (Ng &von Gunten, 1998; Potter, Hami, Bryan, & Quigley 2003; Kroenke, Johns, Theobald, Wu, & Tu, 2013). It has been defined as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity” (American Thoracic Society (ATS), 1999, page 322). Persons may describe dyspnea in different ways including: ‘tightness in their chest’, ‘feelings of suffocation’, ‘air hunger’, increased difficulty to breath’, or ‘increased effort to breath’ (Wilkins, Dexter, & Heuer, 2009). Dyspnea affects multiple aspects of daily life from physical functioning to psychosocial well-being. It can cause anxiety and fear, which in turn increase the risk of social isolation and adverse outcomes (Bredin et al., 1999; Parshall et al., 2012). It is distressing for not only the person experiencing dyspnea, but also can cause intense feelings of anxiety and helplessness among the members of their informal support network (e.g. family, caregivers) (Booth, Silvester, & Todd, 2003). Gysels and Higginson (2009) note that dyspnea may be difficult for caregivers to cope with and serve as an ongoing threat to the ability to continue providing informal care. Some caregivers perceive the worst symptom to handle is dyspnea (Gysels &Higginson, 2009). Estimated prevalence rates for dyspnea vary greatly from 3 to 25% in the general population (Michelson & Hollrah, 1999) to 16 to 80% among persons with a life limiting illness (Ng &von Gunten 1998; Watson, Lucas, Hoy & Wells, 2009). In the last six weeks of life it is estimated that 70% of persons receiving palliative care experienced dyspnea and this increases to 90% during the active dying phase (Tarzian, 2000). Despite the high prevalence of dyspnea and the severity of distress it can cause, attention to dyspnea in the literature is lacking (Dudgeon & Rosenthal, 1996; Currow, Smith, Davidson, Newton, Agar, & Abernethy, 2010).

The philosophy underpinning most palliative care programs places priority on persons nearing end of life to receive the highest quality of care possible to relieve pain and distressing symptoms such as dyspnea. The World Health Organization (WHO) (2010) advocates that comprehensive assessment is essential to provision of person-centered care for the ‘total person’ or ‘whole self’. The goal of high quality of pain and symptom management is to improve the quality of living and dying for all persons faced with a life-limiting condition and to provide care and support for members of the persons informal support network. Palliative care services have been found to lead to improved survival, (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007) and increased satisfaction with care for both the persons faced with a life limiting illness and their informal support network (Kane, Bernstein, Wales, Leibowitz, & Kaplan, 1984) and with appropriate timing of referral, may lead to a reduction of unnecessary health care resource utilization (Tulskyc & Steinhauserc, 2007; Kamal, Currow, Ritchie, Bull, & Abernethy, 2012).

The subjective nature of dyspnea can make diagnosis of its underlying causes challenging for clinicians. The level of severity in dyspnea symptoms shows no clear relation to pulmonary functioning or disease status (Booth, Moosavi, & Higginson, 2008). Moreover, the complex multifaceted pathophysiology of dyspnea remains not fully understood, leaving its origins open to multiple interpretations. Dyspnea may result from interactions involving physiological, psychological, social, and environmental factors (American Thoracic Society, 1999). Currently, there is no clearly accepted ideal measurement scale for dyspnea for persons nearing end of life (Dorman, Byrne & Edwards, 2007) and no universally recognized evaluation criteria (Bruera, Sweeney, & Ripamonti, 2002). Viola et al, (2007) found the patient-rated visual analogue scale or the Borg scale were most commonly used measures of dyspnea. In a systematic review of measurement tools for dyspnea that identified 33 tools (11 breathlessness-specific, 18 disease specific and 4 unidimensional), Bausewein, Farquhar, Booth, Gysels, & Higginson (2007) found no measurement tool for dyspnea assessed all dimensions of the symptom. It is important that selection of the measurement tool for dyspnea consider both context and purpose (for example, to assess the overall severity of dyspnea, to assess the functional impairment caused by dyspnea, or to assess the quality of the dyspnea symptom) (Dorman, Byrne & Edwards, 2007).

Cancer Care Ontario recommends that identification of dyspnea, based on self-report by the person and where possible upon physical assessment, include consideration of the onset and frequency of the experience, absence/presence of anxiety, and level of difficulty breathing (Cancer Care Ontario, 2010). Self-report is important to assess the severity of the dyspnea and to determine any subjective effect it may have on the person's health status and QOL (Mahler et al., 2010). The consensus statement on the measurement of patient-reported dyspnea by the American College of Chest Physicians stated that clinicians should routinely ask and document patient self-reported frequency and intensity of dyspnea and that assessment of dyspnea investigate not only the distress but also meaning, and unmet needs that accompany the symptoms of dyspnea (Mahler et al., 2010).

Care planning for persons nearing end of life is not a one size fits all process. Across the dying trajectory, persons nearing end of life often experience a plethora of complex health issues. High quality palliative care to address distressing symptoms such as dyspnea depends on the clinician's ability to recognize and prioritize those symptoms. In the absence of detailed assessment, distressing symptoms, like dyspnea, may remain undetected (Homsi et al., 2006; White, McMullan, & Doyle, 2009). During the care planning process, it is useful for clinicians to combine clinical judgment with a comprehensive, standardized assessment to identify distressing symptoms affecting both the person with the life limiting illness and their informal support network (Morrison & Meier, 2004). Reliance on self-report is not adequate since White, McMullan, & Doyle (2009) found that nearly two thirds of all symptoms experienced at the end of life were not reported by patients. Among persons receiving palliative care, the number of symptoms detected using systematic assessment was ten times higher than those volunteered during the initial patient interview (White, McMullan, & Doyle, 2009). Therefore, comprehensive clinical assessment is a useful support to: inform the care planning process; support a person-driven goal setting process; and improve care team communication with the person and their informal support network.

The objectives of this chapter are to: a) investigate the prevalence of dyspnea among persons who receive palliative home care services in Ontario, Canada; b) describe how those who experience dyspnea differ from those who do not experience dyspnea; and c) examine changes in dyspnea over time. This chapter sheds light on health and clinical characteristics as well as levels of health service utilization associated with dyspnea and focuses upon identification of predictive factors affecting development of new dyspnea and recovery from dyspnea over time.

7.2 Methods

7.2.1 Study Population

The current study used de-identified interRAI Palliative Care (interRAI PC) assessment data, for 6,655 unique persons completed between 2006 and 2011 from adult palliative home care clients aged 18 years or older who resided in Ontario, Canada. Follow-up assessments were available for 959 persons.

7.2.2 Data Source

The interRAI PC is a comprehensive, standardized assessment instrument that addresses 17 key domains, including demographic/intake information, diagnoses, health conditions, physical and psychological functioning, and social and emotional well-being, based on 280 unique assessment items (Steel et al., 2003). In a pilot implementation, trained assessors, the majority being nurse case managers, completed the assessments based on information from various sources including: communication with and direct observation of the person; consultation with members of the informal support network (family, caregivers) when appropriate; discussions with the health team; and attention to personal health records.

Previous studies have shown the interRAI PC has excellent inter-rater and test-retest reliability (Steel et al., 2003, Hirdes et al., 2008). Initial field testing of the interRAI PC conducted by Steel et al., (2003) involved 144 persons in the USA and Europe, across multiple care settings including community, institutional, hospice, and acute care settings. All seven domains reported showed excellent inter-rater reliability with average kappa values ranging from 0.77 (preferences) to 0.95 (functional status) (Steel et al, 2003). Steel et al. (2003) found reliability for pain and other symptoms ranged from a low of 0.59 (change in sleep pattern) and 0.61 (other pain) to a high of 0.90 (diarrhea) and 0.91 (constipation).

In follow-up to reliability testing by Steel, Hirdes et al. (2008) conducted inter-rater reliability testing of the interRAI PC as part of an international multi-instrument reliability study of the suite of interRAI assessment instruments. Hirdes et al. (2008) found substantial overall instrument reliability of the interRAI PC (average weighted kappa reported was between 0.61 and 0.80 when interpreted using kappa values according to criteria outlined by Landis and Koch (1977)). The inter-rater reliability testing of the interRAI PC by Hirdes et al. (2008) involved 126 participants from 5 study sites across Europe and the United States. They found “almost perfect” strength of agreement based on Landis and Koch’s (1977) thresholds (Kappa statistic 0.81 – 1.00) for seven of the thirteen item domains and “substantial” strength of agreement for the remaining five.

7.2.3 Measure of Dyspnea

The interRAI PC measures four levels of dyspnea: Absence of symptom; absent at rest but present when performed moderate activities; absent at rest, but present when performed normal day-to-day activities; and present at rest. Trained assessors used client self-report to assess dyspnea. In the case that the client was unable to self-report whether or not they were experiencing dyspnea during assessment, assessors were instructed to review available clinical records and consult with the client’s health care team, family and informal caregivers (Smith et al., 2010). The interRAI PC also includes numerous other clinical measures that might be related to dyspnea (e.g., functional impairment), but does not require that those other clinical issues be causally attributed to dyspnea only.

The newly released interRAI PC Clinical Assessment Protocols (Steel et al., 2013e) include the Dyspnea CAP designed to assist clinicians to recognize persons with a life limiting illness experiencing dyspnea when performing regular activity (Steel, Morris, & Leff, 2013d). The two levels of the Dyspnea CAP: Trigger vs. not trigger, will be used in this chapter to indicate presence (trigger) and absence (did not trigger) of symptoms of dyspnea. Persons who trigger the Dyspnea CAP report dyspnea to either be present at rest or absent at rest but present when performing normal daily activities (Smith et al., 2010). Persons who do not trigger the Dyspnea CAP report dyspnea is absent or is only present when performing more strenuous than normal activities. Persons with a life limiting illness who trigger the Dyspnea CAP exhibit moderate or worse dyspnea at rest or when performing normal daily activities. The Dyspnea CAP also focuses on severe symptoms of dyspnea that may require potential need for emergency intervention. Steel, Morris, & Leff (2013a) estimate that nearly 45% of palliative home care clients trigger the Dyspnea CAP. The Dyspnea CAP guidelines provide strategies to identify the onset and severity of dyspnea symptoms and to investigate possible causes of the symptoms. In addition it provides information on treatment options and educational strategies.

7.2.4 Other Measures

Clinical summary scales, representing different clinical and risk domains embedded within the interRAI PC that are included in the present analysis are: the Changes in Health, End-stage disease, and Signs and Symptoms (CHESS) scale (Hirdes, Frijters, & Teare, 2003); the Cognitive Performance Scale (CPS) (Morris et al., 1994); the Activities of Daily Living Hierarchy (ADL-H) (Morris, Fries, & Morris, 1999); and the Pain Scale (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001). The CHESS scale measures health instability as a clinical outcome and predictor of mortality. It ranges from 0 (no instability in health) to 6 (highly unstable health). The CPS measures level of cognitive functioning using a scale ranging from 0 (cognitively intact) to 6 (severe cognitive impairment). It has been validated against the Mini-Mental State Examination in both institutional and community settings (Morris et al., 1994; Landi et al., 2000). The ADL-H measures physical functioning using a scale ranging from 0 (independent) to 6 (totally dependent). Items used to score the ADL-H include: personal hygiene, toilet transfer, locomotion, and eating (Morris, Fries, & Morris, 1999). The Pain Scale uses two items to measure pain and has scores ranging from 0 (no pain) to 4 (excruciating pain). The Pain Scale has been validated with the Visual Analogue Scale (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001).

7.2.5 Analysis

Analysis was performed in three phases. Phase one described the relationship between status of dyspnea and related factors at baseline assessment. Phase two examined health and service utilization characteristics and their associations with status of dyspnea at baseline and with change in status of dyspnea at time of follow-up assessment. Bivariate analyses were done using chi-square and t-tests depending on variable type to determine the significance of relationships with co-variates.

Phase three employed complete case logistic regression analysis to create two distinct profiles of risk and protective factors. Model A aimed to predict presence of a new dyspnea at follow-up among persons who did not experience dyspnea at baseline (predict triggering the Dyspnea CAP at follow up among persons who did not trigger the Dyspnea CAP at baseline assessment). Model B aimed to predict recovery from (absence of) dyspnea at follow-up among persons who exhibited dyspnea at baseline (predict not triggering the Dyspnea CAP at follow-up among persons who triggered the Dyspnea CAP at baseline assessment). The dependent variable for both models was presence or absence of dyspnea at time two. Persons included in Model A were restricted to those who did not experience dyspnea at baseline (did not trigger the Dyspnea CAP), while Model B was restricted to those who had dyspnea present at baseline (triggered the Dyspnea CAP). Model A was ordered descending to model the presence of the event occurring or the person having dyspnea. In contrast, Model B was not ordered descending so that it modeled the event not occurring or the person not having dyspnea. Logistic regression analysis was conducted using four stages for the analysis. In stage one, all variables that had emerged as significant in bivariate analysis or important as indicated in the literature review and available in the interRAI PC were included (See Appendix A). The second stage used model selection tool score and command best =10 were used to identify any unforeseen relationships among the list of variables used in stage one. The quantitative model selection tool score identified the best subsets of co-variates for each model from the total list of variables included for analysis. The best=10 command specified that only ten models be selected for display for each model size to allow increased flexibility for model identification. Finally, to minimize the chance that a better model was available, three automatic model selection techniques were used to search for any further models in the third phase. First, the forward automatic selection tool was used with an alpha of 0.1 for variable entry. Next, the backward automatic selection tool was used with an alpha of 0.1 for variable exit. Finally, the stepwise automatic selection tool was used with an alpha of 0.1 for both variable entry and exit criteria. A relaxed alpha level of 0.1 was selected to allow for inclusion of a larger range of variables. Stage three automatic model selection techniques did not elucidate additional models than had not already been considered during stages one and two. In the final fourth stage, the best model was selected and any potential unexplained alternatives to the best model were tested.

All analyses were performed using SAS Version 9.2 with an alpha level of $p < 0.05$ for all statistical tests unless otherwise noted above. Validity of the final logistic regression model was assessed using the Hosmer and Lemeshow Goodness-of-Fit test with a small statistic with a large p value indicating acceptable model fit (Hosmer and Lemeshow, 2013, p. 167); while the c-statistic was used to assess the discrimination strength of the model (Bewick, Check, & Ball, 2005).

7.3 Results

At baseline, nearly half of the population (44.9%, n=2,990) exhibited dyspnea compared to 55.1% (n=3,665) who did not exhibit dyspnea (Table 7.1.). With the exception of the oldest old, the prevalence of dyspnea increases with age. Males were more likely to experience dyspnea than females. The prevalence of dyspnea among persons whose death was imminent was nearly twice as high compared to those with an estimated prognoses of six months or greater (62.6% vs. 36.3%; p <0.0001). The prevalence of dyspnea also varied by CCAC site ranging from a low of 23.6% in Site 5 to a high of 46.7% in Site 2. Persons with a non-cancer diagnosis were more likely to exhibit dyspnea

Table 7.1. Sample Distributions and Presence of Dyspnea by Selected Demographic and Clinical Variables of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

	Independent Variable Distribution in Total Sample (%, N=6,655)	No Dyspnea at Baseline (55.1%, n=3,665)	Have Dyspnea at Baseline (44.9%, n=2,990)	Chi-square (df)	p value
Age Groups					
18-44	4.2 (280)	68.6 (192)	31.4 (88)	31.8 (4)	<0.0001
45-64	30.0 (1,998)	57.1 (1,140)	42.9 (858)		
65-74	25.4 (1,688)	54.4 (919)	45.6 (769)		
75-84	28.8 (1,913)	52.0 (994)	48.0 (919)		
85 +	11.7 (776)	54.1 (420)	45.9 (356)		
Gender					
Male	49.2 (3,253)	53.1 (1,727)	46.9 (1,526)	9.6 (1)	0.002
Female	50.8 (3,354)	56.9 (1,908)	43.1 (1,446)		
Estimated Prognosis					
Death Imminent	1.9 (107)	37.4 (40)	62.6 (67)	105.2 (3)	<0.0001
Less than 6 weeks	8.4 (464)	43.8 (203)	56.3 (261)		
6 weeks to 6 months	48.1 (2,648)	53.4 (1,413)	46.6 (1,235)		
Greater than 6 months	41.5 (2,283)	63.7 (1,454)	36.3 (829)		
Geographic Site					
1	4.0 (267)	62.6 (167)	37.5 (100)	41.5 (5)	<0.0001
2	67.3 (4,480)	53.3 (2,389)	46.7 (2,091)		
3	14.9 (988)	58.1 (574)	41.9 (414)		
4	7.6 (506)	54.0 (273)	46.1 (233)		
5	2.1 (140)	76.4 (107)	23.6 (33)		
6	4.1 (274)	56.6 (155)	43.4 (119)		
Diagnosis					
Have Cancer Diagnosis	59.7 (3,973)	57.8 (2,295)	42.2 (1,678)	98.9 (3)	<0.0001
Have Cancer and Non-Cancer Diagnosis	27.2 (1,812)	56.5 (1,023)	43.5 (789)		
Diagnosis unspecified	3.3 (221)	46.2 (102)	53.9 (119)		
Have Non-Cancer Diagnosis Only	9.8 (649)	37.8 (245)	62.3 (404)		

Note: df denotes degrees of freedom

Table 7.2. shows the prevalence of clinical and health characteristics by presence of dyspnea among the total population at baseline. Persons with dyspnea were more likely to exhibit functional impairment and moderate cognitive impairment compared to those who did not exhibit dyspnea. No significant differences were observed at baseline between prevalence of dyspnea and presence of depression or smoking status. Compared to those who did not exhibit signs of dyspnea at baseline, persons with dyspnea were more likely to experience fatigue ($p<0.0001$), difficulty clearing airway secretions ($p<0.0001$), weight loss ($p<0.0001$), edema ($p<0.0001$), urinary incontinence ($p=0.01$), and bloating ($p=0.003$). Bowel incontinence, acid reflux, nausea, and vomiting did not differ significantly by status of dyspnea.

Higher levels of health instability were also evident based on the distribution of the CHESS score among persons with dyspnea (Table 7.2.). This was not entirely surprising, since the presence of dyspnea is used in the calculation of CHESS and no persons with dyspnea present at baseline could score a zero on the CHESS scale. That being considered, significantly more persons with dyspnea experienced highly unstable health with a CHESS Score of 4 or greater compared to persons without dyspnea (47.7% vs. 26.9%, $p<0.0001$).

Table 7.2. Clinical and Health Characteristics by Status of Dyspnea at Baseline of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

	Total Population (%, N=6,655)	Status of Dyspnea at Baseline		Chi-square (df)	p value
		No Dyspnea (55.1%, n=3,665)	Have Dyspnea (44.9%, n=2,990)		
ADL Impairment					
No-minimal (ADL-H = 0)	51.5 (3,239)	57.1 (1,985)	44.5 (1,254)	99.7 (2)	<0.0001
Mild-moderate (ADL-H=1-2)	21.2 (1,334)	18.5 (642)	24.6 (692)		
Severe (ADL-H ≥3)	27.3 (1,720)	24.4 (848)	30.9 (872)		
Cognitive Impairment					
No-minimal (CPS = 0)	67.9 (4,272)	69.6 (2,416)	65.8 (1,856)	14.7 (2)	0.0006
Mild-moderate (CPS = 1-2)	24.3 (1,527)	22.4 (778)	26.6 (749)		
Severe (CPS ≥3)	7.9 (495)	8.1 (280)	7.6 (215)		
CHESS Scale					
0	4.6 (286)	8.4 (286)	0 (0)	703.2 (5)	<0.0001
1	12.0 (738)	17.7 (604)	4.9 (134)		
2	19.9 (1,229)	23.3 (794)	15.8 (435)		
3	27.3 (1,681)	23.8 (812)	31.6 (869)		
4	25.4 (1,567)	19.4 (661)	32.9 (906)		
5	10.7 (661)	7.5 (254)	14.8 (407)		
Depression Rating Scale					
0-2	90.9 (5,514)	91.5 (3,077)	90.2 (2,437)	3.2 (1)	0.07
3+	9.1 (550)	8.5 (285)	9.8 (265)		
Pain					
None/Less than daily pain	46.9 (2,912)	48.4 (1,666)	45.1 (1,246)	6.8 (1)	0.009
Experiences pain daily	53.1 (3,297)	51.6 (1,778)	54.9 (1,519)		
Presence of Pain					
No pain	30.7 (1,947)	32.2 (1,127)	28.9 (820)	11.1 (3)	0.01
Pain present with movement	10.3 (656)	10.6 (371)	10.0 (285)		
Pain present at res	2.5 (1,601)	2.6 (91)	2.4 (69)		
Pain present with movement and at rest	56.4 (35.8)	54.6 (1,911)	58.7 (1,668)		
Pain Scale					
No pain	27.7 (1,717)	28.9 (994)	26.2 (723)	9.8 (4)	0.04
Less than daily pain	19.3 (1,195)	19.5 (672)	18.9 (523)		
Daily pain but not severe	35.0 (2,174)	34.6 (1,191)	35.6 (983)		
Daily severe pain	13.1 (812)	12.5 (429)	13.9 (383)		
Daily excruciating pain	5.0 (311)	4.6 (158)	5.5 (153)		
Smoking					
Non-smoker (c7a = 0)	85.6 (5,516)	86.2 (3,047)	84.9 (2,469)	2.2 (1)	0.14
Smoker (C1a = 1,2)	14.4 (929)	13.8 (489)	15.1 (440)		
Sleep Problems					
Difficulty falling asleep					
No	69.9 (4,498)	73.2 (2,597)	65.8 (1,901)	40.9 (1)	<0.0001
Yes	30.1 (1,939)	26.8 (952)	34.2 (987)		
Too much sleep					
No	74.2 (4,761)	77.0 (2,729)	70.8 (2,032)	31.9 (1)	<0.0001
Yes	25.8 (1,567)	23.0 (817)	29.3 (840)		
Fatigue					
No	19.7 (1,290)	29.2 (1,056)	8.0 (234)	456.7 (1)	<0.0001
Yes	80.3 (5,253)	70.8 (2,566)	92.0 (2,687)		
Difficulty clearing airway secretions					

	No	85.4 (5,599)	91.6 (3,308)	77.7 (2,291)	251.9 (1)	<0.0001
	Yes	14.6 (959)	8.4 (302)	22.3 (657)		
Weight loss						
	No	54.0 (3,403)	57.8 (2,009)	49.4 (1,394)	45.0 (1)	<0.0001
	Yes	46.0 (2,897)	42.2 (1,466)	50.7 (1,431)		
Peripheral Edema						
	No	73.6 (4,840)	78.5 (2,848)	67.6 (1,992)	100.0 (1)	<0.0001
	Yes	26.4 (1,736)	21.5 (780)	32.4 (956)		
Urinary Incontinence						
	No	82.8 (5,446)	83.9 (3,040)	81.5 (2,406)	6.5 (1)	0.01
	Yes	17.2 (1,128)	16.1 (583)	18.5 (545)		
Bowel Incontinence						
	No	87.9 (5,709)	88.4 (3,165)	87.4 (2,544)	1.3 (1)	0.25
	Yes	12.1 (783)	11.6 (417)	12.6 (366)		
Acid Reflux						
	No	88.2 (5,795)	88.1 (3,189)	88.4 (2,606)	0.2 (1)	0.66
	Yes	11.8 (775)	12.0 (433)	11.6 (342)		
Bloating						
	No	80.9 (5,299)	82.2 (2,970)	79.3 (2,329)	8.7 (1)	0.003
	Yes	19.1 (1,250)	17.8 (643)	20.7 (607)		
Nausea						
	No	77.1 (5,045)	77.4 (2,789)	76.7 (2,256)	0.5 (1)	0.50
	Yes	22.9 (1,501)	22.6 (815)	23.3 (686)		
Vomiting						
	No	89.6 (5,858)	89.3 (3,214)	90.1 (2,644)	1.1 (1)	0.31
	Yes	10.4 (678)	10.7 (386)	10.0 (292)		

Note: df denotes degrees of freedom

Table 7.3. shows resource utilization of the total population stratified by presence of dyspnea at baseline. The majority of persons received assistance from a home nurse (76.1%, n=5,064), while approximately one third received assistance from a personal support worker (assistance with ADL and IADL tasks) (32.9%, n=2,190). One in four persons with dyspnea received oxygen therapy (27.2%, n=772) compared to less than one in twenty among persons not reporting dyspnea at baseline (4.8%, n=173). Overall, more than half reported a hospital stay in the past 90 days while less than one in four reported visiting the ER in the past 90 days. Persons with dyspnea were significantly more likely to report a hospital stay (p=0.0006) and more likely to report an ER visit (p=0.009) during the past 90 days. With the exception of receiving oxygen therapy, persons experiencing dyspnea at baseline were not more likely to receive assistance from formal care providers (home nurse, PSW, occupational therapy, and physiotherapy). In addition, no significant differences were evident by hours of informal care received.

Table 7.3. Health Resource Utilization Characteristics by Status of Dyspnea at Baseline of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

	Independent Variable Distribution in Total Sample	Population at Baseline		Chi-square (df)	P value
		No Dyspnea (55.1%, n=3,665)	Have Dyspnea (44.9%, n=2,990)		
Assistance from Formal Care Providers					
Receive assistance from Home Nurse					
No	23.9 (1,591)	20.0 (733)	28.7 (858)	68.4 (1)	<0.0001
Yes	76.1 (5,064)	80.0 (2,932)	71.3 (2,132)		
Receive assistance from Personal Support Worker					
No	67.1 (4,465)	67.0 (2,454)	67.3 (2,011)	0.1 (1)	0.80
Yes	32.9 (2,190)	33.0 (1,211)	32.7 (979)		
Receive assistance from Occupational Therapy					
No	83.0 (5,522)	83.3 (3,054)	82.5 (2,468)	0.7 (1)	0.40
Yes	17.0 (1,133)	16.7 (611)	17.5 (522)		
Receive assistance from Physical Therapy					
No	94.1 (6,265)	93.9 (3,441)	94.5 (2,824)	0.9 (1)	0.33
Yes	5.9 (390)	6.1 (224)	5.6 (166)		
Receive Oxygen Therapy					
No	85.4 (5,506)	95.2 (3,444)	72.8 (2,062)	641.0 (1)	<0.0001
Yes	14.7 (945)	4.8 (173)	27.2 (772)		
Hours of Informal Support (in last 3 days)					
0 - > 18 hours	53.7 (3,249)	53.2 (1,785)	54.3 (1,464)	2.4 (2)	0.30
18-35 hours	22.8 (1,379)	22.5 (757)	23.1 (622)		
36 +	23.5 (1,425)	24.3 (816)	22.6 (609)		
Have had a Hospital Stay in past 90 days					
No	44.9 (2,851)	46.8 (1,662)	42.5 (1,189)	11.8 (1)	0.0006
Yes	55.1 (3,495)	53.2 (1,887)	57.5 (1,608)		
Have visited ER in past 90 days					
No	79.6 (4,434)	80.8 (2,585)	77.9 (1,849)	6.8 (1)	0.009
Yes	20.5 (1,140)	19.2 (616)	22.1 (524)		

Note: df denotes degrees of freedom

Follow-up assessments were available for 959 persons (14.4%). Clinical and health characteristics reported at baseline by status of dyspnea at follow-up stratified by status of dyspnea at baseline are shown in Table 7.4. At follow-up, 47.1% (n=452) exhibited dyspnea compared to 52.9% (n=507) who did not. Of persons who did not experience dyspnea at baseline, 31.0% (n=169) reported new dyspnea symptoms at follow-up while 69.1% (n=377) continued not to experience dyspnea. Among persons who experienced dyspnea at baseline, 68.5% (n=283) continued to experience dyspnea at follow-up. In contrast, 31.5% (n=130) had recovered from dyspnea and no longer reported symptoms of dyspnea at follow-up.

Of persons who did not exhibit dyspnea at baseline, those who smoked at time of baseline assessment were more likely to exhibit a new dyspnea at follow-up (39.6% vs. 28.5%; p = 0.04). Moreover, of those who did not exhibit dyspnea at baseline, persons who experienced fatigue were more likely to develop new dyspnea symptoms (35.2% vs. 23.1%; p = 0.003) while persons who had urinary incontinence were less likely (21.0% vs. 32.2%; p=0.04). Among persons who experienced dyspnea at baseline, also having fatigue was predictive of continued dyspnea at follow-up. Persons with urinary incontinence were less likely to report continued dyspnea at follow-up (57.6% vs. 70.4%; p=0.04).

Table 7.4. Clinical and Health Characteristics by Status of Dyspnea at Baseline Stratified by Status of Dyspnea at Follow-up of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=959).

	No Dyspnea at Baseline (56.9%, n=546)					Have Dyspnea at Baseline (43.1%, n=413)				
	All persons with no dyspnea at baseline (56.9%, n=546)	No dyspnea at follow-up (69.2%, n=377)	New dyspnea at follow-up (31.0%, n=169)	Chi-square (df)	p Value	All persons with dyspnea at baseline (43.1%, n=413)	No dyspnea at follow-up (31.5%, n=130)	Continued dyspnea at follow-up (68.5%, n=283)	Chi-square (df)	p Value
ADL Impairment										
No-minimal (ADL-H = 0)	73.5 (380)	67.9 (258)	32.1 (122)	1.4 (2)	0.51	64.3 (247)	30.8 (76)	69.2 (171)	1.0 (2)	0.62
Mild-moderate (ADL-H=1-2)	12.2 (63)	71.4 (45)	28.6 (18)			20.1 (77)	36.4 (28)	63.6 (49)		
Severe (ADL-H ≥ 3)	14.3 (74)	74.3 (55)	25.7 (19)			15.6 (60)	30.0 (18)	70.0 (42)		
Cognitive Impairment										
No-minimal (CPS = 0)	73.3 (381)	68.5 (261)	31.5 (120)	0.8 (2)	0.66	78.7 (299)	30.4 (91)	69.6 (208)	2.0 (2)	0.36
Mild-moderate (CPS=1-2)	21.2 (110)	70.9 (78)	29.1 (32)			17.4 (66)	34.9 (23)	65.2 (43)		
Severe (CPS ≥ 3)	5.6 (29)	75.9 (22)	24.1 (7)			4.0 (15)	46.7 (7)	53.3 (8)		
Depression Rating Scale										
0-2	90.0 (451)	69.2 (312)	30.8 (139)	0.2 (1)	0.68	88.5 (316)	31.0 (98)	69.0 (218)	0.2 (1)	0.68
3+	10.0 (50)	72.0 (36)	28.0 (14)			11.5 (41)	34.2 (14)	65.9 (27)		
Pain										
Less than daily	47.2 (239)	71.1 (170)	28.9 (69)	0.4 (1)	0.53	40.9 (150)	28.7 (43)	71.3 (107)	1.2 (1)	0.27
Daily pain	52.8 (267)	68.5 (183)	31.5 (84)			59.1 (217)	34.1 (74)	65.9 (143)		
Smoking										
Non-Smoker	82.6 (431)	71.5 (308)	28.5 (123)	4.3 (1)	0.04	80.1 (322)	31.7 (102)	68.3 (220)	0.1 (1)	0.77
Smoker	17.4 (91)	60.4 (55)	39.6 (36)			19.9 (80)	30.0 (24)	70.0 (56)		
Fatigue										
No	36.9 (199)	76.9 (153)	23.1 (46)	8.6 (1)	0.003	12.5 (50)	44.0 (22)	56 (28)	4.3 (1)	0.04
Yes	63.2 (341)	64.8 (221)	35.2 (120)			87.5 (349)	29.5 (103)	70.5 (246)		
Difficulty clearing airway secretions										
No	92.7 (498)	70.1 (349)	29.9 (149)	3.2 (1)	0.08	81.2 (328)	31.4 (103)	68.6 (225)	0.2 (1)	0.64
Yes	7.3 (39)	56.4 (22)	43.6 (17)			18.8 (76)	34.2 (26)	65.8 (50)		
Weight loss										
No	60.6 (315)	72.7 (229)	27.3 (86)	3.2 (1)	0.08	60.0 (228)	33.8 (77)	66.2 (151)	0.5 (1)	0.47
Yes	39.4 (205)	65.4 (134)	34.6 (71)			40.0 (152)	30.3 (46)	69.7 (106)		

Peripheral Edema											
	No	80.0 (432)	71.0 (307)	28.9 (125)	3.3 (1)	0.07	71.7 (291)	33.3 (97)	66.7 (194)	1.2 (1)	0.28
	Yes	20.0 (108)	62.0 (67)	38.0 (41)			28.3 (115)	27.8 (32)	72.2 (83)		
Bladder Incontinence											
	No	85.0 (459)	67.8 (311)	32.2 (148)	4.1 (1)	0.04	83.9 (344)	29.7 (102)	70.4 (242)	4.2 (1)	0.04
	Yes	15.0 (81)	79.0 (64)	21.0 (17)			16.1 (66)	42.4 (28)	57.6 (38)		
Bowel Incontinence											
	No	90.1 (480)	68.3 (328)	31.7 (152)	0.3 (1)	0.61	91.7 (373)	31.6 (118)	68.4 (255)	0.4 (1)	0.53
	Yes	9.9 (53)	71.7 (38)	28.3 (15)			8.4 (34)	26.5 (9)	73.5 (25)		
Sleep Problems											
Difficulty falling asleep											
	No	71.0 (377)	70.8 (267)	29.2 (110)	1.8 (1)	0.18	64.7 (256)	32.4 (83)	67.6 (173)	0.04 (1)	0.84
	Yes	29.0 (154)	64.9 (100)	35.1 (54)			35.4 (140)	31.4 (44)	68.6 (96)		
Too much sleep											
	No	79.4 (416)	70.2 (292)	29.8 (124)	0.3 (1)	0.60	73.9 (291)	33.0 (96)	67.0 (195)	0.8 (1)	0.36
	Yes	20.6 (108)	67.6 (73)	32.4 (35)			26.1 (103)	28.2 (29)	71.8 (74)		
Acid Reflux											
	No	87.6 (474)	69.2 (328)	30.8 (146)	0.01 (1)	0.93	88.0 (358)	32.1 (115)	67.9 (243)	0.3 (1)	0.62
	Yes	12.4 (67)	68.7 (46)	31.3 (21)			12.0 (49)	28.6 (14)	71.4 (35)		
Bloating											
	No	85.5 (461)	68.8 (317)	31.2 (144)	0.1 (1)	0.76	84.7 (343)	31.2 (107)	68.8 (236)	0.03 (1)	0.87
	Yes	14.5 (78)	70.5 (55)	29.5 (23)			15.3 (62)	32.3 (20)	67.7 (42)		
Nausea											
	No	78.2 (422)	68.5 (289)	31.5 (133)	0.6 (1)	0.46	76.3 (312)	30.1 (94)	69.9 (218)	1.7 (1)	0.20
	Yes	21.9 (118)	72.0 (85)	28.0 (33)			23.7 (97)	37.1 (36)	62.9 (61)		
Vomiting											
	No	92.2 (495)	68.9 (341)	31.1 (154)	0.4 (1)	0.51	89.9 (364)	30.2 (110)	69.8 (254)	3.2 (1)	0.07
	Yes	7.8 (42)	73.8 (31)	26.2 (11)			10.1 (41)	43.9 (18)	56.1 (23)		

Note: df denotes degrees of freedom

Table 7.5. summarizes assistance received from formal care providers as well as hours of informal support by status of dyspnea at baseline stratified by status of dyspnea at follow-up. Among persons who did not exhibit dyspnea at baseline, persons who did not receive assistance from a home nurse were more likely to experience a new dyspnea at follow-up. Prevalence of assistance from other formal care providers for the both populations was not significantly different with the exception of receiving oxygen therapy. One in five persons with dyspnea received oxygen therapy at baseline compared to one in twenty persons for those who did not report dyspnea at baseline. Among persons who did not exhibit dyspnea at baseline, those receiving oxygen therapy were significantly more likely to be experiencing a new dyspnea at follow-up (62.5% vs. 29.5%, p=0.0006).

Table 7.5. Health Resource Utilization Characteristics by Status of Dyspnea at Baseline Stratified by Status of Dyspnea at Follow-up of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=959).

	Clients Did Not Exhibit Dyspnea at Baseline					Client Exhibited Dyspnea at Baseline				
	All persons with no dyspnea at baseline (56.9%, n=546)	No dyspnea at follow-up (69.2%, n=377)	New dyspnea at follow-up (31.0%, n=169)	Chi-square (df)	p Value	All persons with dyspnea at baseline (43.1%, n=413)	No dyspnea at follow-up (31.5%, n=130)	Continued dyspnea at follow-up (68.5%, n=283)	Chi-square (df)	p Value
Assistance from Formal Care Providers										
Receive assistance from Home Nurse										
No	23.3 (127)	61.4 (78)	38.6 (49)	4.5 (1)	0.03	34.6 (143)	25.9 (37)	74.1 (106)	3.2 (1)	0.72
Yes	76.7 (419)	71.4 (299)	28.6 (120)			65.4 (270)	34.4 (93)	65.6 (177)		
Receive assistance from Personal Support Worker										
No	69.8 (381)	67.5 (257)	32.6 (124)	1.5 (1)	0.07	70.5 (291)	28.9 (84)	71.1 (207)	3.1 (1)	0.08
Yes	30.2 (165)	72.7 (120)	27.3 (45)			29.5 (122)	37.7 (46)	62.3 (76)		
Receive assistance from Occupational Therapy										
No	87.7 (479)	68.1 (326)	31.9 (153)	1.8 (1)	0.18	84.5 (349)	29.8 (104)	70.2 (245)	2.9 (1)	0.09
Yes	12.3 (67)	76.1 (51)	23.9 (16)			15.5 (64)	40.6 (26)	59.4 (38)		
Receive assistance from Physical Therapy										
No	91.8 (501)	69.3 (347)	30.7 (154)	0.1 (1)	0.72	93.7 (387)	31.8 (123)	68.2 (264)	0.3 (1)	0.61
Yes	8.2 (45)	66.7 (30)	33.3 (15)			6.3 (26)	26.9 (7)	73.1 (19)		
Receive Oxygen Therapy										
No	95.6 (518)	70.5 (365)	29.5 (153)	11.7 (1)	0.0006	80.7 (314)	33.4 (105)	66.6 (209)	1.8 (1)	0.18
Yes	4.4 (24)	37.5 (9)	62.5 (15)			19.3 (75)	25.3 (19)	74.7 (56)		
Hours Informal Support (in last 3 days)										
0 - > 18 hours	62.2 (306)	67.0 (205)	33.0 (101)	3.4 (2)	0.19	63.5 (223)	31.4 (70)	68.6 (153)	0.2 (2)	0.93
18-35 hours	19.5 (96)	71.9 (69)	28.1 (27)			18.2 (64)	32.8 (21)	67.2 (43)		
36 +	18.3 (90)	76.7 (69)	23.3 (21)			18.2 (64)	29.7 (19)	70.3 (45)		
Hospital Stay in past 90 days										
No	46.8 (249)	69.5 (173)	30.5 (76)	0.02 (1)	0.9	44.3 (167)	34.1 (57)	65.9 (110)	0.6 (1)	0.45
Yes	53.2 (283)	67.0 (198)	30.0 (85)			55.7 (210)	30.5 (64)	69.5 (146)		
Visited ER in past 90 days										
No	80.6 (381)	71.9 (274)	28.1 (107)	0.7 (1)	0.39	77.1 (232)	33.2 (77)	66.8 (155)	0.2 (1)	0.64
Yes	19.5 (92)	67.4 (62)	32.6 (30)			22.9 (69)	36.2 (25)	63.8 (44)		

Note: df denotes degrees of freedom

Model A (Table 7.6.) used logistic regression analyses to examine risk and protective factors for exhibiting new dyspnea symptoms at follow-up assessment. Consistent with bivariate analysis, presence of fatigue (OR 2.32; 95% CI 1.51-3.56) and receipt of oxygen therapy (OR 4.51; 95% CI 1.87-10.91) emerged as strong risk factors predicting development of a new dyspnea at follow-up. Interestingly, persons experiencing urinary incontinence were less likely to develop a new dyspnea (OR 0.51; 95% CI 0.28-0.96). In contrast, receiving assistance from a home nurse, which was significant at the bivariate level, was no longer significant in the multivariate model. Females were less likely to develop new dyspnea symptoms compared to males (OR 0.65; 95% CI 0.44 – 0.96). Age was not significant in the logistic regression model. A c statistic of 0.65 indicates moderate predictive strength of Model A. Acceptable fit for Model A is indicated by a relatively small Hosmer and Lemeshow statistic along with a large p value (6.89; p=0.55).

Logistic regression analysis described in Model B (Table 7.7.) examined risk and protective factors among those who exhibited signs of dyspnea at baseline for recovering from dyspnea and no longer exhibiting signs of dyspnea at time of follow-up assessment. Persons experiencing fatigue were less likely to recover from dyspnea (OR 0.48; 95% CI 0.26 – 0.88). In contrast, persons who received support from a personal support worker were more likely to recover from dyspnea (OR 1.71; 95% CI 1.06 – 2.74). Neither age nor gender was significant in the regression analysis. A c statistic of 0.59 indicates weaker predictive strength of this model compared with Model A. Acceptable fit for Model B is indicated by a relatively small Hosmer and Lemeshow statistic along with a large p value (2.64; p=0.95).

Presence/absence of a cancer diagnosis, CCAC site, and assessment interval (in days) between baseline and follow-up assessment were forced into the models but there were no significant associations for these variables. Accordingly, they were then removed from the final models.

Table 7.6. Final Multiple Logistic Regression Model for Development of New Dyspnea at Follow-up Assessment Among Persons Who Did Not Exhibit Dyspnea at Time of Baseline Assessment, Ontario Palliative Home Care Clients 2006-2011, Ontario, Canada (N=959).

Independent Variable	Parameter estimate (SE)	Adjusted odds ratio (95% CI)	*p* value
Age (10 year increments)	0.08 (0.08)	1.08 (0.93 - 1.25)	0.31
Gender (Ref = Male)			
Female	-0.43 (0.20)	0.65 (0.44 - 0.96)	0.03
Bladder Incontinence (Ref = Continent)			
Bladder incontinent	-0.68 (0.31)	0.51 (0.28 - 0.94)	0.03
Fatigue (Ref = No fatigue)			
Have fatigue	0.84 (0.22)	2.32 (1.51 - 3.56)	0.0001
Oxygen Therapy (Ref = Do not receive oxygen therapy)			
Receive oxygen therapy	1.51 (0.45)	4.51 (1.87 - 10.91)	0.0008

Note: C statistic 0.65

Table 7.7. Final Multiple Logistic Regression Model for Recovery From Dyspnea at Follow-up Assessment Among Persons Who Did Not Exhibit Dyspnea at Time of Baseline Assessment, Ontario Palliative Home Care Clients 2006-2011, Ontario, Canada (N=959).

Independent Variable	Parameter estimate (SE)	Adjusted odds ratio (95% CI)	*p* value
Age (10 year increments)	0.02 (0.08)	1.02 (0.86 - 1.20)	0.86
Gender (Ref = Male)			
Female	0.14 (0.22)	1.16 (0.75 - 1.78)	0.51
Fatigue (Ref = No fatigue)			
Have fatigue	-0.75 (0.32)	0.48 (0.26 - 0.88)	0.02
Personal Support Worker (Ref = Do not receive support)			
Receive support from a personal support worker	0.53 (0.24)	1.71 (1.06 - 2.74)	0.03

Note: C statistic 0.59

7.4 Discussion

Dyspnea is reported to be a highly distressing symptom for both the person and caregivers (Booth, Silvester, & Todd, 2003), suggesting it should be of major concern. Although dyspnea affects nearly half of the palliative home care sample in this study it is not inevitable. The overall prevalence of dyspnea remained the same over time; however a large proportion of persons exhibited change over time. Dyspnea CAP triggering rates clearly show that not only do some persons get worse and develop symptoms of dyspnea over time, but that a substantial portion of persons exhibit the potential to improve in symptoms over time. Of persons with dyspnea at baseline, 1 in 3 developed a new dyspnea by time of follow-up. In contrast, 1 in 4 persons with dyspnea were able to recover from their symptoms. The high number of persons changing in status of dyspnea over time suggests it would be useful to seek out risk factors that may be modifiable.

Dyspnea was less common among persons with cancer diagnoses compared to those with other reported disease diagnoses. This has been supported in previous findings that persons with non-cancer diagnoses who receive palliative home care services such as those with diagnoses including stroke, Alzheimer's disease or other dementia, or Parkinson's disease (Freeman & Hirdes, forthcoming) exhibit higher levels of health complexity compared to the general palliative population. Increased health complexity and uncontrolled symptom prevalence may be a driving factor for referral to palliative care for persons with non-cancer diagnoses.

The higher prevalence rates for dyspnea among those with shorter prognosis for survival found in the cross-sectional results were not evident in longitudinal analysis. This may be due to multiple factors, the most important of which is mortality. Follow-up assessments were available for less than 20% of the baseline population. High mortality levels evident among palliative end of life populations may contribute to this reduced sample size. However, it may also represent the nature of a pilot dataset where data collection windows may not have allowed ample time to elapse for a follow-up assessment to be warranted. Persons in the sample may still be alive and residing in the community, but not yet have received a follow-up assessment. Alternatively, some persons nearing the end of life are not able to remain in the community due to increased level of caregiver distress or unavailability of a caregiver. These persons may transition to community hospice or long-term care facilities for more intensive support and therefore would not be represented in this dataset. The Alzheimer's Society of Canada (2011) notes that most persons with Alzheimer's disease nearing end of life receive care from a LTCF due to the heavy burden placed on their caregivers and informal support network. Future analyses may examine the role of prognosis and time to death to be investigated with larger sample sizes now that Ontario has mandated the interRAI PC for use across the province. However, at the time of writing of this thesis, data available after implementation were not available. Furthermore, future data linkages between the interRAI HC, MDS 2.0, and interRAI PC assessment instruments would allow for greater depth of understanding through linking and tracking of person specific need over time across the continuum of care.

Persons with increased levels of functional or moderate cognitive impairment were more likely to exhibit dyspnea at baseline. However, neither functional status nor cognitive impairment was significantly associated with changes in status of dyspnea over time in both bivariate and multivariate analyses. This suggests that the relationships of cognitive and functional impairment with dyspnea may be related to other factors such as prognosis. This is also evident among various health characteristics including difficulty clearing airway secretions, weight loss, edema, bloating, difficulty falling asleep, and too much sleep. All of these characteristics were significantly more common among persons with dyspnea at baseline; however they were not significantly associated with changes in dyspnea over time. It is possible that the lack of significant findings was a result of sample size limitations.

At baseline, differences in the prevalence of dyspnea were evident by site at the bivariate level, but not at the multivariate level. Due to varying sample sizes between CCAC's and limitations in the availability of follow-up data in various regions, it was not possible to fully investigate regional differences at this time. Future investigations should examine whether variations in the prevalence of dyspnea is due to differences in regional referral processes and disparities in service availability or whether it is due to underlying risk factors in the total population (for example, long-term exposure to high levels of environmental pollutants).

At baseline, persons who smoked were not more likely to exhibit signs of dyspnea. However, at follow-up, among those who did not exhibit signs of dyspnea at baseline, persons who smoked were more likely to exhibit new dyspnea. This supports previous findings by Dudgeon and Lertzman (1998) that smoking is significantly associated with dyspnea among an end of life population. Therefore, it remains important for clinicians to discuss smoking cessation options during the care planning process.

As expected, fatigue was strongly associated with dyspnea and emerged as a strong factor at the bivariate and multivariate levels for both development of a new dyspnea and recovery from dyspnea over time. Experiencing fatigue increases the risk for persons to develop a new dyspnea over time. In addition, persons who experience fatigue are less likely to recover from dyspnea. Among those exhibiting both fatigue and dyspnea at baseline, over 70 percent were likely to continue to exhibit dyspnea. Like dyspnea, fatigue has been shown to interfere with ADLs and result in decreased quality of life (Richardson, 1995; Crow, & Hammond, 1996). Although fatigue is experienced by the majority of persons faced with a life limiting illness and is one of the most frequently reported physical concerns reported, it should not be perceived as ‘normal’ or ‘untreatable’ (Kristjanson, 2006). Attention to fatigue during the care planning process with a person-centered individualized focus may have a double benefit. Symptoms of dyspnea and fatigue share common characteristics such as variation in severity by time of day or by activity being performed. Incorporation of non-pharmacological therapies such as energy expenditure planning or energy conservation and restoration strategies into the care plan may address fatigue and dyspnea together as a multidimensional construct and maximize potential benefits. Prioritization of activities to be completed when energy levels are highest, ensuring adequate rest and nutrition, and reducing stress may reduce or prevent fatigue (Radbruch, et al., 2008; NHS Lothian, 2010) and thereby reduce the risk to develop a new dyspnea over time or promote recovery from dyspnea. As some causes of fatigue may be modifiable, it is plausible that amelioration of fatigue may in turn reduce symptoms of dyspnea. Education during the care planning process is fundamental to assist the person to recognize aspects of dyspnea or fatigue they can control and to introduce strategies such as planned periods of rest, delegation of activities to others, increased physical activity where appropriate.

Receipt of home care assistance from a personal support worker (PSW) emerged as an important predictor of recovery from dyspnea in multivariate analyses. PSW home care supports services primarily target ADL and IADL tasks including: assistance with bathing hygiene, mobility, or toileting as well as meal preparation and housework. Previous studies note the relationship between allocation of PSW support in Ontario, Canada to respond to worsening symptoms and increased functional impairment (Seow, Barbera, Howell, & Sydney, 2010a). Receipt of more than 7 hours of PSW services per week has been shown to reduce demand for hospital based services with lower odds of hospital admissions, ER visits before death, and of dying in a hospital (Seow, Barbera, Howell, & Sydney, 2010b). In contrast, although our study found persons with dyspnea were more likely to report a hospitalization and visiting the ER in the past 90 days at baseline, persons with dyspnea were not more or less likely to experience a hospitalization nor visit the ER at follow-up assessment. Our findings support that allocation of PSW support results in increased potential for symptom improvements among persons with dyspnea. As PSW's focus on support with ADLs and IADL activities, persons with dyspnea who receive PSW assistance may no longer be performing strenuous physical activities such as bathing or performing regular house duties such as vacuuming or meal preparation thereby reducing opportunities to experience dyspnea during exertion. Communication during the care planning process and allocation of services to reduce or prevent dyspnea is important. Recognition of tasks that trigger episodes of dyspnea and matching of PSW supports may enable better targeting of PSW services to support persons at the end of life. Receipt of support from a PSW was associated with higher improvement rates of dyspnea over time suggesting that the symptoms of dyspnea may be modifiable through the provision of additional services or clinical interventions. Future randomized clinical trials would be beneficial to test this further.

A finding unique to this study is the significant relationship between urinary incontinence and lower prevalence of dyspnea. Developing a new dyspnea or continued experiencing of dyspnea over time were more common among persons who are urinary continent. Previous studies have noted an increased risk for dyspnea among persons who are incontinent among populations of persons with COPD (Hirayama, Binns, Lee, and Senjyu, 2005) and adults with cystic fibrosis (White, Stiller, and Roney, 2000). Both studies linked the association for increased prevalence of dyspnea and urinary incontinence to coughing. Urge urinary incontinence may result from increased stress and intra-abdominal pressure, caused by repeated coughing (Hirayama, Binns, Lee, and Senjyu, 2005). In contrast, McGrother et al. (2005) found dyspnea was associated with higher risk for stress incontinence at the bivariate level. In multivariate analysis, McGrother et al. (2005) found that dyspnea was only associated with stress incontinence in the cross sectional model and was not associated with stress incontinence in longitudinal analysis. Instead multivariate findings found consistent associations with physical non-respiratory characteristics, obesity, and disease diagnoses (McGrother et al., 2005). None of these studies focused on an end of life population. Persons nearing end of life with dyspnea may not experience coughing to the same extent someone may with chronic lung disease in its earlier stages.

Consultation with expert palliative care clinicians currently practicing in the palliative home care field raised alternative potential confounding factors including pharmaceuticals, urinary retention, dehydration, or other physiological contributing factors (N. Dahlen[7], personal communication, November

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29, 2013; J. Fergusen[8], personal communication, November 28, 2013; M. Henderson-Betkus[9], personal communication, November 28, 2013) which may be indicated by urinary continence. First, urinary continence can be suggestive of urinary retention or dehydration. Urinary retention is a common problem affecting person at the end of life that in addition to urinary continence can present numerous ways including confusion, restlessness, or agitation (Watson, 2005). Dehydration may lead to decreased urine output that may be mistaken by clinicians as urinary continence. Other potential confounding factors with urinary continence include: bowel incontinence, cachexia, edema, and insufficient fluids. These were examined, but no associations were found between these characteristics and dyspnea at the bivariate and multi-variate levels. Other suggested factors that may contribute to the relationship between urinary continence and increased risk for dyspnea include metabolic abnormalities, neuromechanical and metabolic imbalances, and kidney failure. The relationship between dyspnea and urinary incontinence has not been widely addressed among persons nearing end of life. Further investigation is warranted to determine whether these findings are spurious resulting from having examined a large number of potential independent variables by replicating these analyses in another sample to confirm the role of bladder continence as a risk factor for dyspnea.

7.5 Summary

Dyspnea is not inevitable as persons receiving palliative care progress in the illness trajectory towards death. Findings from this study describe risk factors to develop a new dyspnea and to recover from dyspnea over time may be useful to inform and prioritize care planning strategies. As dyspnea is one of the most distressing symptoms and commonly experienced among persons at the end of life,

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resource allocation that addresses fatigue should be prioritized. Prevention strategies for development of dyspnea over time need to further elucidate the role of urinary continence as a risk factor. Allocation of PSW supports to meet client need may assist to support recovery from dyspnea over time.

8. A Cross-Sectional Examination of the Relationship between Dyspnea and Distress Experienced Within the Caregiver-Client Unit of Care

8.1 Introduction

Dyspnea is one of the most troubling symptoms for both persons with a life limiting illness who experience the symptom and for their caregivers (Ng &von Gunten, 1998; Potter, Hami, Bryan, & Quigley, 2003; Dellon et al., 2010; Kroenke, Johns, Theobald, Wu, & Tu 2013). Dyspnea, highly prevalent among persons nearing end of life, often increases in severity as the person progresses towards death (Booth, Moosavi, & Higginson, 2008). Dyspnea may trigger an intense fear of suffocation, which causes high levels of distress (Australian Government National Health and Medical Research Council, 2006, p. 109). Dyspnea directly affects the person's functional ability and mobility and can cause anxiety thereby increasing the risk of social isolation (Bredin, et al., 1999; Parshall et al., 2012). It can incite a cycle of panic and distress where the symptoms of dyspnea cause anxiety. The increased level of anxiety may then elevate the symptoms of dyspnea thereby further increasing the psychological distress (Australian Government National Health and Medical Research Council, 2006, p. 109). Conversely, it may also be possible that anxiety incites the cycle of dyspnea, panic and distress, such that anxiety is the cause of dyspnea (Lankan et al., 2008).

Informal caregivers play an essential role in community-based care and support for persons nearing end of the life. In Canada, over 8 million persons provided care to a family member or friend who had a long-term health condition, disability, or age-related problem in 2012 (Statistics Canada, 2013). Even from the point of diagnosis with a life limiting illness, the lives of members of the persons informal support network including family, friends, caregivers, or co-workers may be affected (CHPCA, 2005). CHPCA notes that each death substantially affects the immediate health and well-being of an average of five other persons or over 1.25 million Canadians annually (CHPCA, 2012).

Informal care enables vulnerable persons who wish to stay at home to remain in the community longer (Canadian Caregiver Coalition, 2012). Yet, it is not without cost. Approximately half of informal caregivers caring for their spouses or children experience distress (Statistics Canada, 2013). Providing informal care for a person nearing the end of life often involves an extensive range of complex and strenuous duties . The increased level of assistance necessary to provide care affects the physical, financial, and psychological health and wellbeing of the informal caregiver (Fletcher, Fast, & Eales, 2011). Informal caregivers may be unprepared for the complex health and psychosocial needs of persons nearing the end of life.

Caring for a person with dyspnea has been linked to high levels of distress, unmet needs, and fewer reported positive benefits experienced by caregivers during caregiving activities (Malik, Gysels, & Higginson, 2013). Dyspnea has been linked to anxiety and feelings of helplessness among caregivers (Goodridge, Duggleby, Gjevre, & Rennie, 2008; Booth, Silvester, & Todd, 2003). Dyspnea may be difficult for caregivers to cope with and serves as an ongoing threat to the ability to continue providing informal care (Gysels and Higginson, 2009). As the disease progresses and the prevalence and frequency of dyspnea increase (Solano, Gomes, & Higginson, 2006) caregivers may experience increased feelings of distress and helplessness (Booth, Silvester, & Todd, 2003). In a study of caregivers of patients dying of cystic fibrosis, Dellon et al. (2010) found over half (52%) of patients reported dyspnea to be the most distressing symptoms while 100% of caregivers reported dyspnea to be distressing during the final week of life.

Palliative care aims to provide the highest quality of pain and symptom management not only to the persons nearing the end of life but also advocates for the provision of support and care to those family, friends, and other informal network members affected by the persons illness. Expanding the unit and focus of care from the quality of living and dying for the person faced with a life limiting illness to include his or her family, friends, and caregivers (informal support network) is a cornerstone of the palliative care philosophy. The World Health Organization (WHO; 2010) takes the view that palliative care should prioritize self-determination for the 'total person' and care for the 'whole self' while simultaneously recognizing the need for a multidisciplinary team approach which also addressed the needs of family members and friends enabling them to function as a support system. This involves helping informal caregivers to cope throughout the illness trajectory and during bereavement. Palliative care services have been found to lead to increased satisfaction with care for not only the person faced with a life limiting illness, but also for their informal caregivers (Kane, Bernstein, Wales, Leibowitz, & Kaplan, 1984). In addition, palliative home care programs have been shown to improve overall scores for QOL, reduce physical symptoms such as dyspnea, reduce psychological distress such as depression or anxiety, and improve accessibility to formal care services (Melin-Johansson, Axelsson, Gaston-Johansson, & Danielson, 2010).

Previous research has shown mutuality in distress experienced by the caregiver and the care recipient (client). Caregiver and client physical and psychosocial wellbeing at end of life are interrelated (Hodges, Humphris, & Macfarlane, 2005). Anxiety disorders exhibited by caregivers may be associated with anxiety experienced by the client and vice-versa (Bambauer et al., 2006). Moreover, depression is also a common distressing symptom for a number of caregivers and clients. Lankan et al (2008) note that up to one third of caregivers of persons with advanced respiratory disease may exhibit risk for depression while in a meta-analysis of depression among cancer patients, Krebber et al (2014) found the mean prevalence of depression ranged from 8% to 24%. Dyspnea has also been associated with increased levels of distress by both the person faced with a life limiting illness and their informal caregivers. Gysels, Bausewein, and Higginson (2007) suggest that caregivers are equally as distressed by dyspnea as is the person experiencing it. Malik, Gysels, and Higginson (2013) note that interventions to address dyspnea experienced by persons with a life limiting illness must also address the needs of the caregivers. The physical and psychological suffering experienced by the client has been shown to affect the psychological health and wellbeing of the caregiver both during the illness trajectory and following during the bereavement period.

Care planning for persons with a life limiting illness can be complex and involve issues at a time when added sensitivity, patience, and understanding are needed. High quality palliative care recognizes the impact that caregiving and bereavement may have on members of the informal support network and aims to address the needs of the caregiver across the illness trajectory and during bereavement. This includes access to caregiver-focused resources, counseling, and education in addition to collaboration with and support from health professionals to assist with care related duties. It involves informed tradeoffs to achieve a burden/benefit balance, which should aim to meet the needs of both the client and caregiver when determining the plan of care. This applies specifically to the allocation or non-allocation of interventions, treatments, or supports when considering estimated prognosis, the impact on QOL, and goals of care for all members of the care unit. When caring for a person nearing the end of life, these challenges are magnified due to the expanded unit of care focus of palliative care to address the needs of the person during the illness trajectory and the needs of their informal support network during and following the death of the person.

It is well recognized that a large number of persons would prefer to die at home; however, the feasibility of a home death is heavily dependent upon the availability and efforts of informal caregivers (Canadian Caregiver Coalition, 2012). Informal caregivers are needed to enable and support persons nearing end of life to remain in the community at achieve a home death (Gomes & Higgins, 2006). The level of informed decision-making and perceived choice to provide community based palliative care for the client vary greatly, and can have a substantial impact on caregiver health and well-being (Stajduhar & Davies, 2005). Therefore, caregivers' needs should be considered of fundamental importance during the care planning decision-making process. Following, it is important to have a better understanding of how individual person-specific characteristics increase the likelihood for the caregiver and client (members of the care unit) to experience distress.

Previous research by Hirdes et al. (2012) used pilot data from the interRAI PC to investigate predictors of caregiver distress among an earlier sub-sample of the current sample palliative home care population. Bivariate associations showed increased risk for caregiver distress for a large group of client demographic and caregiver characteristics, clinical indicators, and health service indicators (Hirdes et al., 2012). Moreover, multivariate logistic regression analyses found that a combination of a subset of client, caregiver, and service use/provider characteristics significant at the bivariate level was strongly predictive of caregiver distress. Hirdes et al., (2012) did not focus on distress as experienced by the caregiver-client care unit. Distress experienced by the client was not included as part the dependent variable. Instead, their research focused solely on caregiver distress. In their bivariate analysis, dyspnea was shown to be a significant indicator of caregiver distress (OR 1.27; SD 1.04-1.55); however, this variable was not included as an independent variable in the final multiple logistic regression model (Hirdes et al., 2012). The Changes in Health and End Stage Signs and Symptoms (CHESS) Scale, a measure of health instability (Hirdes, Frijters, & Teare, 2003), was included in the final regression analysis. Since dyspnea is included in the CHESS scale, its predictive strength as an independent variable was not presented.

Due to the multiple conditions experienced by persons nearing end of life and the subjective evaluation of dyspnea, it remains unclear how strong dyspnea is as a predictive factor affecting distress within the caregiver and client care unit. Therefore, the current study examined the relationship between distress within the caregiver and client unit and dyspnea. In contrast to previous work by Hirdes et al., (2012) which used caregiver distress only as the dependent variable of focus, current analysis aimed to elucidate the role of dyspnea as an independent variable to predict distress experienced by the person or his/her caregivers. The specific objective of this study was to determine whether dyspnea is associated with distress in either the person receiving palliative care or members of their informal network among a sample population of persons receiving palliative home care services in Ontario, Canada.

8.2 Methods

8.2.1 Data Source

This cross sectional analysis focused on de-identified interRAI PC assessment data gathered from 6,655 unique palliative home care clients. Pilot data were collected from 2006 to 2011 across six regional CCAC jurisdictions in Ontario, Canada.

The interRAI PC is a comprehensive standardized assessment instrument, now mandated for use for all palliative home care clients assessed to receive care across all regional jurisdictions in Ontario, Canada. The interRAI PC provides a comprehensive picture of clients heath and clinical characteristics encompassing physical, mental, and social domains as well as important information regarding demographic, health service utilization, and care preferences. It gathers a breadth of information on client mood, life-completion, and self-reported spirituality. In addition, the section on informal supports collects information describing the informal caregiving network including primary and secondary caregiver's relationship to the client, hours and type of care provided. Trained assessors completed assessments using information from the direct observation and discussion with the client, members of their health care team, and informal support network as well as consideration of available medical records, as part of regular clinical practice. The strength of inter-rater and test-retest reliability of the interRAI PC (Steel et al., 2003, Hirdes et al., 2008) has been described previously (see Chapter 7).

8.2.2 Measures of Distress

The interRAI PC collects information on caregiver distress based on three items: a) Informal helper is unable to continue caring activities; b) Primary informal helper expresses feelings of distress, anger, or depression; and c) Family or close friends report feeling overwhelmed by the person's illness. The rate of caregiver distress, calculated based on the presence of one or more of these three items, was present in one quarter of caregivers (25.2%, n=1,580).

Three self-reported mood items embedded within the interRAI PC were used to evaluate three dimensions of the clients' state of mood including a) Anhedonia (little interest or pleasure in things normally enjoyed; b) Anxiety (anxious, restless, or uneasy); and c) Dysphoria (sad, depressed, or hopeless). Together, in the current analysis, self-report of one or more of these variables indicated self-reported distress. One or more signs of self-reported distress was exhibited by 44.9% of clients (n=2,571).

The Depression Rating Scale (DRS) has been shown to be an effective assessor-rated scale to indicate potential signs of depression. It is calculated from seven mood and behaviour items embedded within the interRAI PC. Each item is rated 0 (not exhibited in the last 30 days); 1 (exhibited up to five days a week) or 2 (exhibited daily or almost daily) and then added to comprise a summative score ranging from 0 indicating no depression to a maximum score of 14. The DRS has been validated against the Hamilton Depression Rating Scale and the Cornell Scale for Depression in Dementia and shown to have greater sensitivity and specificity when compared to the 15-item Geriatric Depression Scale among a long-term care population (Burrows, Morris, Simon, Hirdes, & Phillips, 2000). More recently the validity and reliability was demonstrated in a palliative home care population (Fisher, Seow, Brazil, Smith, & Guthrie, 2014c). While a score of 3 is associated with major or minor depressive disorders (Burrows et al., 2000), a lower threshold score of 1 was used in the current analysis to indicate presence of any depressive symptom. A DRS score of 1 or greater was reported by 30.0% of clients (n=1,816).

A measure of overall client distress was derived from a score of one or more on the DRS and/or presence of self-reported distress. Overall client distress was reported by 47.6% of clients (n=2,957). A global measure of distress affecting either the palliative care client or his/her caregivers (referred to here collectively as the "care unit") was calculated using presence of any of the three indicators of caregiver distress or presence of any of the three client self-rated mood items or a DRS score by the client of one or higher. Care unit distress was present among 53.0% of client/caregiver units (n=3,491).

8.2.3 Analysis

Cross-sectional analyses to elucidate the relationship between dyspnea and care unit distress were performed in three phases. Phase one provided an overview of the bi-variate relationship between presence of dyspnea and defining distress characteristics of the caregiver, client, and care unit. Phase two examined the bi-variate relationship between client specific characteristics and their prevalence associated with status of care unit distress. These analyses used chi-square and odds ratios to determine the significance and strength of relationships between co-variates.

Phase three employed complete case logistic regression analysis to investigate the strength of dyspnea as a risk factor for care unit distress (Models 1-4). The dependent variable for all models was presence or absence of care unit distress. The 'descending' statement was used to order the event to occurring; meaning care unit distress was present. As the purpose of this chapter was to investigate the role of dyspnea in relationship to care unit distress, regression analysis did not focus on all possible factors affecting care unit distress. Model 1 examined the role of dyspnea as an independent predictor of care unit distress. Model 2 controlled for basic unmodifiable client characteristics. Based on previous research predicting caregiver distress among a palliative home care population (Hirdes et al, 2012), a comparative model (Model 3) was run to control for co-variates recognized as important. Model 4 combined variables from Model 2 and Model 3 to examine the predictive strength of dyspnea as a risk factor for care unit distress. As the role of dyspnea as an independent risk factor for care unit distress was the focus of this chapter, automatic model selection techniques focused on predicting care unit distress were not employed to confirm the above analyses. Final model analysis compared the predictive model strength for care unit distress including dyspnea to previous findings predicting caregiver distress by Hirdes et al. (2012).

All analyses were performed using SAS Version 9.2 with an alpha level of $p < 0.05$ for all statistical tests. Validity of the logistic regression models were assessed using the Hosmer and Lemeshow Goodness-of-Fit test where a small statistic with a large p value indicated acceptable model fit (Hosmer & Lemeshow, 2013, p. 167). The c statistics was used in the current analysis to assess the discrimination strength of the logistic regression model (Bewick, Cheek, & Ball, 2005) and as a basis to compare the different models fitted to predict care unit distress (Peng, Lee, & Ingersoll, 2002).

8.3 Results

Sample characteristics are shown in Table 8.1. The majority of palliative home care clients were aged 65 or greater of whom nearly two thirds were married (64.5%). Two in five clients reported a prognosis of greater than six months (41.5%, n=2,283) while death was expected within six weeks of assessment for one in ten clients (10.3%, n=571). The vast majority (86.9%, n=5,785) reported a diagnosis of cancer, of whom approximately one third simultaneously reported non-cancer diagnoses (n=1,812). Dyspnea was a commonly occurring symptom reported present when performing activities for 45.9% (n=3,054) of clients and present at rest for 17.4% (n=1,155) of clients.

Table 8.1. Sample Characteristics of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

	Total Population (N=6,655)
Age Groups	
18-44	4.2 (280)
45-64	30.0 (1,998)
65-74	25.4 (1,688)
75-84	28.8 (1,913)
85 +	11.7 (776)
Gender	
Male	49.2 (3,253)
Female	50.8 (3,354)
Marital Status	
Not married	35.6 (2,292)
Married/partner	64.5 (4,155)
Estimated Prognosis	
Death is imminent	1.9 (107)
Less than 6 weeks	8.4 (464)
6 weeks to 6 months	48.1 (2,648)
Greater than 6 months	41.5 (2,283)
Geographic Site	
1	4.0 (267)
2	67.3 (4,480)
3	14.9 (988)
4	7.6 (506)
5	2.1 (140)
6	4.1 (274)
Diagnosis	
Reported cancer diagnosis only	59.7 (3,973)
Reported non-cancer diagnosis only	9.8 (649)
Reported both cancer and non-cancer diagnosis	27.2 (1,812)
Diagnosis unspecified	3.3 (221)
Functional Ability	
No-minimal impairment (ADL-H = 0)	51.5 (3,239)
Mild-moderate impairment (ADL-H = 1-2)	21.2 (1,334)
Severe impairment (ADL-H ≥3)	27.3 (1,720)
Cognitive Ability	
No-minimal impairment (CPS = 0)	67.9 (4,272)
Mild-moderate impairment (CPS = 1-2)	24.3 (1,527)
Severe impairment (CPS ≥3)	7.9 (495)
Dyspnea	
No dyspnea	36.8 (2,446)
Present when performing activities	45.9 (3,054)
Present at rest	17.4 (1,155)

Table 8.2. shows sample characteristics of informal caregivers of clients receiving palliative home care services. Nearly all clients reported having a primary caregiver (n=6,530, 98.1%) while 71.8% reported having a secondary caregiver (n=4,779). Primary caregivers were most likely to be spouses/partners of the client (58.6%, n=3,823) followed by their adult children (29.1%, n=1,897). Other primary caregivers including siblings of the client, other relatives, friends, and neighbours were reported by 12.4% of respondents (n=810). Secondary caregivers were most likely to be adult children of the client (52.0%, n=3,492), followed by other primary caregivers (16.7%, n=1,109). Few spouses of clients reported being secondary caregivers (1.5%, n=178). Over three quarters of informal caregivers provided ADL care during the last 3 days (78.8%, n=4,483). Almost all informal caregivers provided IADL care during the last 3 days (96.4%, n=5,546). Approximately half of informal caregivers reported providing less than 18 hours of care assisting with IADL and ADL support over the past three days (53.7%, n=3,249). In comparison, 22.8% reported providing between 18 and 35 hours of care (n=1,379) and 23.5% (n=1,425) reported providing 36 hours or more of care. The majority of clients reported having a strong and supportive relationship with their family (95.7%, n=6,277).

Table 8.2. Characteristics of Informal Caregivers of Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

	Prevalence Total Population at Baseline (N=6,655)
Primary Caregiver Relationship to Client	
Child	29.1 (1,897)
Spouse/Partner	58.6 (3,823)
Other	12.4 (810)
Did not report having a primary caregiver	1.9 (125)
Secondary Caregiver Relationship to Client	
Child	52.0 (3,492)
Spouse/Partner	1.5 (178)
Other	16.7 (1,109)
Did not report having a secondary caregiver	28.2 (1,876)
Informal Caregiver Provides ADL care	
No	21.2 (1,209)
Yes	78.8 (4,483)
Informal Caregiver Provides IADL care	
No	3.7 (210)
Yes	96.4 (5,546)
Caregiver Resides with Client	
No	18.6 (1,080)
Yes	81.4 (4,736)
Hours of Informal Care Provided (in past 3 days)	
>18	53.7 (3,249)
18-35	22.8 (1,379)
<36	23.5 (1,425)
Strong and Supportive Relationship with Family	
No	4.3 (280)
Yes	95.7 (6,277)

Psychosocial characteristics indicating distress of the client, informal caregiver, and care unit are shown in Table 8.3. Nearly half of clients exhibited signs of distress (47.5%, n=2,857). Clients experiencing symptoms of dyspnea were more likely to also exhibit overall signs of distress (p <0.001), more likely to report one or more signs of self-reported distress (p<0.0001), and more likely to be at risk for depression indicated by increased DRS scores at all levels scoring one or higher (p=0.002) compared to persons who did not experience dyspnea. A common pattern was evident for individual client self-report mood items (anhedonia, anxiety, and dysphoria) that consistently showed that the signs of depression were more common among persons exhibiting dyspnea than persons who did not exhibit dyspnea. One in four caregivers exhibited signs of distress (25.2%, n=1,580). Caregivers of clients experiencing dyspnea were more likely to exhibit distress (p=0.005). Less than 10% of caregivers reported feeling unable to continue their caregiving activities (n=577), while 14.7% reported feelings of distress, anger, or depression (n=934) and 18.5% reported feeling overwhelmed by the person's illness (n=1,166). Similar to the pattern exhibited for client self-reported distress, the prevalence of all individual informal caregiver distress items showed increased prevalence of distress when caring for a client exhibiting dyspnea. However, the increased prevalence of informal helpers unable to continue caring activities was not statistically significant. When indicators of caregiver distress and client distress were combined, over half of the caregiver-client units exhibited distress (53.0%, n=3,491). Clients who exhibited dyspnea were more likely to also exhibit signs of combined distress than persons without dyspnea (p <0.0001).

Table 8.3. Bivariate Associations of Indicators of Client and Caregiver Distress by Status of Dyspnea Among Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

	Total Population	Status of Dyspnea			Chi-square (df)	p value
		No Dyspnea	Dyspnea Present when Performing Activities	Dyspnea Present at Rest		
Client Status						
Client exhibits overall distress (Self-reported depression and/or DRS 1+)						
No	53.5 (3,152)	56.9 (1,219)	50.6 (1,446)	48.3 (487)	27.6 (2)	<0.0001
Yes	47.5 (2,857)	43.1 (925)	49.4 (1,410)	51.7 (522)		
Client exhibits signs of self-reported distress						
No	55.1 (3,152)	59.6 (1,219)	53.0 (1,446)	51.2 (487)	27.7 (2)	<0.0001
Yes	44.9 (2,571)	40.4 (825)	47.0 (1,281)	48.8 (465)		
Little interest in things						
No	78.1 (4,417)	82.1 (1,658)	76.7 (2,071)	73.7 (688)	32.7 (2)	<0.0001
Yes	21.9 (1,238)	17.9 (362)	23.3 (630)	26.3 (246)		
Anxious/uneasy						
No	68.5 (3,926)	74.2 (1,525)	65.5 (1,785)	64.8 (616)	48.6 (2)	<0.0001
Yes	31.5 (1,806)	25.8 (530)	34.5 (942)	35.2 (334)		
Sad/hopeless						
No	70.1 (3,999)	73.0 (1,495)	68.2 (1,852)	69.4 (652)	13.0 (2)	0.002
Yes	29.9 (1,703)	27.0 (553)	31.8 (863)	30.6 (287)		
Depression Rating Scale						
0	70.1 (4,248)	72.9 (1,586)	68.2 (1,978)	69.3 (684)	20.8 (6)	0.002
1-2	20.9 (1,266)	19.2 (417)	22.5 (653)	19.9 (196)		
3-5	6.8 (415)	6.3 (138)	7.0 (202)	7.6 (75)		
6 +	2.2 (135)	1.7 (36)	2.3 (67)	3.2 (32)		
Informal Caregiver Status						
Caregiver exhibits signs of distress						
No	74.8 (4,693)	75.8 (1,733)	75.5 (2,201)	70.9 (759)	10.8 (2)	0.005
Yes	25.2 (1,580)	24.2 (552)	24.6 (716)	29.1 (312)		
Informal helper is unable to continue in caring activities						
No	90.1 (5,752)	91.3 (2,107)	91.0 (2,672)	89.8 (973)	1.8 (2)	0.40
Yes	9.1 (577)	8.8 (202)	9.0 (265)	10.2 (110)		
Primary informal helper expresses feelings of distress, anger, or depression						
No	85.3 (5,404)	84.9 (1,963)	86.5 (2,541)	82.6 (189)	9.6 (2)	0.008
Yes	14.7 (934)	15.1 (348)	13.5 (397)	17.4 (189)		
Family or close friends report feeling overwhelmed by persons illness						
No	81.6 (5,154)	82.6 (1,906)	81.7 (2,401)	78.8 (847)	7.2 (2)	0.03
Yes	18.5 (1,166)	17.4 (401)	18.3 (537)	21.2 (228)		
Combined Care Unit Distress						
Distress exhibited by either/both Caregiver and Client						
No	47.1 (3,102)	51.6 (1,244)	44.8 (1,360)	43.5 (498)	31.6 (2)	<0.0001
Yes	53.0 (3,491)	48.5 (1,169)	55.2 (1,675)	56.5 (647)		

Table 8.4. describes the bivariate associations between client demographic characteristics and status of distress within the care unit. Distress within the care unit was significantly associated with client age, prognosis, CCAC site location, diagnosis, and status of dyspnea ($p<0.0001$). Clear age differences emerged as both the prevalence and risk for care unit distress were significantly higher for the younger clients in comparison to the oldest old ($p<0.0001$). No differences were evident by client gender or marital status. Care unit distress is most commonly reported by persons with an estimated prognosis of less than six weeks (69.5%, n=321) in contrast to clients with a prognosis of greater than six months (48.8%, n=1,112) who reported the lowest rate of care unit distress. Clients with an estimated prognosis of less than six weeks were at highest risk for distress within the care unit (OR 2.38; 95% CI 1.92-2.96) followed by those with a prognosis of greater than six weeks and less than six months (OR 1.43; 95% CI 1.27-1.60) compared to clients with a prognosis of greater than six months to live. Clients who reported both a cancer and non-cancer diagnosis were most likely to exhibit care unit distress (59.1%, n=1,065 $p<0.0001$), followed by persons with only a non-cancer diagnosis (54.2%, n=347). Persons with dyspnea were more likely to exhibit signs of unit distress than clients who did not have dyspnea ($p<0.0001$). Persons who reported dyspnea present at rest were at a slightly higher risk to exhibit unit distress (OR 1.38; 95% CI 1.2-1.59) than those who reported dyspnea present when performing activities (OR 1.31; 95% CI 1.18-1.46) when compared to persons who did not experience dyspnea.

Table 8.4. Bivariate Associations of Client Demographic Characteristics by Status of Distress Within the Caregiver/ Client Unit Among Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

	Neither Exhibit Signs of Distress (47.1% n=3,102)	Either/Both Caregiver or Client Exhibit Signs of Distress (53.0%, n=3,491)	Chi-square (df)	p value	Unadjusted Odds Ratio
Age Groups					
18-44	40.0 (110)	60.0 (165)	25.1 (4)	<0.0001	1.66 (1.25-2.19)
45-64	43.9 (870)	56.1 (1,111)			1.41 (1.19-1.67)
65-74	47.3 (792)	52.7 (882)			1.23 (1.04-1.46)
75-84	48.9 (928)	51.1 (969)			1.15 (0.98-1.36)
85 +	52.5 (402)	47.5 (364)			ref
Gender					
Male	47.6 (1,533)	52.4 (1,687)	0.8 (1)	0.38	ref
Female	46.5 (1,547)	53.5 (1,778)			1.04 (0.95-1.15)
Marital Status					
Not Married	47.9 (1,086)	52.1 (1,182)	1.6 (1)	0.21	ref
Married/Partner	46.2 (1,904)	53.8 (2,214)			1.07 (0.96-1.18)
Estimated Prognosis					
Greater than 6 months	51.2 (1,165)	48.8 (1,112)	81.6 (3)	<0.0001	ref
6 weeks to 6 months	42.4 (1,117)	57.6 (1,519)			1.43 (1.27-1.60)
Less than 6 weeks	30.5 (141)	69.5 (321)			2.38 (1.92-2.96)
Death Imminent	47.6 (49)	52.4 (54)			1.16 (0.78-1.71)
Geographic Site					
1	42.1 (112)	57.9 (154)	68.3 (5)	<0.0001	1.03 (0.73-1.44)
2	50.4 (2,228)	49.6 (2,196)			0.74 (0.57-0.94)
3	39.7 (391)	60.3 (595)			1.13 (0.87-1.49)
4	42.4 (214)	57.6 (291)			1.01 (0.75-1.36)
5	29.0 (40)	71.0 (98)			1.83 (1.18-2.83)
6	42.7 (117)	57.3 (157)			ref
Diagnosis					
Report cancer diagnosis only	49.7 (1,955)	50.3 (1,978)	42.8 (3)	<0.0001	ref
Report non-Cancer diagnosis only	45.8 (293)	54.2 (347)			1.17 (0.99-1.38)
Report cancer and non-cancer diagnosis	40.9 (737)	59.1 (1,065)			1.43 (1.28-1.60)
Diagnosis unspecified	53.7 (117)	46.3 (101)			0.85 (0.65-1.12)
ADL Impairment					
No-minimal (ADL-H=0)	52.5 (1,690)	47.5 (1,528)	80.0 (2)	<0.0001	ref
Mild-moderate (ADL-H=1-2)	43.5 (578)	56.5 (752)			1.44 (1.27-1.64)
Severe (ADL-H ≥ 3)	39.9 (678)	60.1 (1,020)			1.66 (1.48-1.88)
Cognitive Impairment					
No-minimal (CPS = 0)	52.1 (2,212)	47.9 (2,031)	136.0 (2)	<0.0001	ref
Mild-moderate (CPS = 1-2)	35.2 (535)	64.8 (983)			2.00 (1.77-2.26)
Severe (CPS ≥ 3)	41.1 (202)	58.9 (290)			1.56 (1.29-1.89)
Dyspnea					
No dyspnea	51.6 (1,244)	48.5 (1,169)	32.6 (2)	<0.0001	ref
Present when performing activities	44.8 (1,360)	55.2 (1,675)			1.31 (1.18-1.46)
Present at rest	43.5 (498)	56.5 (647)			1.38 (1.2-1.59)

Note: df denotes degrees of freedom

Logistic regression models for care unit distress are shown in Tables 8.5.-8.8. When only dyspnea was included in Model 1 (Table 8.5.), a significant relationship with care unit distress was evident showing that persons with dyspnea were at increased risk for care unit distress (OR 1.18; 95% CI 1.07-1.30n; p=0.001). Dyspnea remained significantly associated with care unit distress (OR 1.18; 95% CI 1.06-1.32; p=0.003) when controlling for client level characteristics including age, gender, diagnosis, and prognosis (Model 2, Table 8.6.). However, the odds ratio for dyspnea did not change substantially when controlling for client level variables. Dyspnea remained significant in multivariate analysis (Model 3, Table 8.7.) when controlling for key clinical characteristics (OR 1.14; 95% CI 1.02-1.27; p=0.02), but did not show an increase in predictive strength. In Model 4 (Table 8.8.), which included both client and clinical characteristics, dyspnea continued to be significantly associated with care unit distress (OR 1.21; 95% CI 1.07-1.36; p=0.002). Acceptable fit for Model 4. is indicated by a relatively small Hosmer and Lemeshow statistic accompanied by a large p value (6.23; p=0.62). A c statistic of 0.65 in Model 4 indicated stronger predictive strength than in Models 1-3, which had smaller c statistics.

Table 8.5. Model 1-Logistic Regression Model of Dyspnea as an Independent Variable to Predict Presence of Distress Within the Caregiver/Client Unit Among Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

Independent variable	Parameter estimate (SE)	Adjusted odds ratio (95% CI)	p value
Dyspnea (Ref = None)			
Have dyspnea	0.16 (0.05)	1.18 (1.07-1.30)	0.001

C statistic = 0.52

Table 8.6. Model 2- Multiple Logistic Regression Model Using Client Characteristics to Predict Presence of Distress Within the Caregiver/Client Unit Among Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

Independent variable	Parameter estimate (SE)	Adjusted odds ratio (95% CI)	p value
Dyspnea (Ref = None)			
Have Dyspnea	0.17 (0.06)	1.18 (1.06-1.32)	0.003
Age	-0.11 (0.2)	0.90 (0.86-0.93)	<0.0001
Gender (Ref = Male)			
Female	0.07 (0.06)	1.07 (0.96-1.19)	0.23
Diagnosis (Ref = Do not have cancer)			
Have Cancer	0.002 (0.09)	1.00 (0.85-1.18)	0.98
Estimated Prognosis (Ref = Greater than six months)			
Six weeks to six months	0.02 (0.06)	1.44 (1.29-1.62)	0.81
Less than six weeks	0.54 (0.92)	2.44 (1.96-3.03)	<0.0001
Death imminent	-0.2 (0.16)	1.16 (0.78-1.73)	0.18

C statistic = 0.58

Table 8.7. Model 3- Multiple Logistic Regression Model Using Clinical Characteristics to Predict Presence of Distress Within the Caregiver/Client Unit Among Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

Independent variable	Parameter estimate (SE)	Adjusted odds ratio (95% CI)	p value
Dyspnea (Ref = None)			
Have dyspnea	0.13 (0.06)	1.14 (1.02-1.27)	0.02
Functional Ability (Ref = No-minimal impairment (ADL-H = 0))			
Mild-moderate impairment (ADL-H = 1-2)	0.19 (0.07)	1.21 (1.06-1.40)	0.007
Severe impairment (ADL-H >3)	0.33 (0.07)	1.40 (1.20-1.62)	<0.0001
Cognitive Ability (Ref = No-minimal impairment (CPS = 0))			
Mild-moderate impairment (CPS = 1-2)	0.60 (0.07)	1.83 (1.60-2.07)	<0.0001
Severe impairment (CPS >3)	0.17 (0.11)	1.18 (0.95-1.48)	0.14
Hours of Informal Care Provided in Last 3 Days (Ref = <18)			
18-38 hours	0.09 (0.07)	1.10 (0.95-1.27)	0.21
36 hours +	0.13 (0.06)	1.14 (1.02-1.27)	0.02

C statistic = 0.62

Table 8.8. Model 4- Final Multiple Logistic Regression Model Using Client and Clinical Characteristics to Predict Presence of Distress Within the Caregiver/Client Unit Among Clients Receiving Palliative Home Care Services 2006-2011, Ontario, Canada (N=6,655).

Independent variable	Parameter estimate (SE)	Adjusted odds ratio (95% CI)	p value
Dyspnea (Ref = None)			
Have dyspnea	0.19 (0.61)	1.21 (1.07-1.36)	0.002
Age (10 year increments)	-1.15 (0.23)	0.87 (0.83-0.91)	<0.0001
Gender (Ref = Male)			
Female	0.07 (0.06)	1.08 (0.96-1.21)	0.22
Diagnosis (Ref = Do not have cancer)			
Have cancer	0.19 (0.10)	1.21 (1.00-1.46)	0.05
Estimated Prognosis (Ref = Greater than six months)			
Six weeks to six months	0.19 (0.14)	0.64 (0.39-1.04)	0.07
Less than six weeks	0.24 (0.08)	1.90 (1.47-2.44)	<0.0001
Death imminent	0.06 (0.11)	1.22 (1.07-1.38)	0.003
Functional Ability (Ref = No-minimal impairment) (ADL-H = 0)			
Mild-moderate impairment (ADL-H =1, 2)	0.28 (0.08)	1.33 (1.14-1.55)	0.0003
Severe impairment (ADL-H >3)	0.37 (0.09)	1.45 (1.22-1.72)	<0.0001
Cognitive Ability (Ref = No-minimal impairment) (CPS = 0)			
Mild-moderate impairment (CPS =1, 2)	0.61 (0.07)	1.85 (1.60-2.13)	<0.0001
Severe impairment (CPS >3)	0.36 (0.13)	1.44 (1.12-1.85)	0.004
Hours of Informal Care Provided in Last 3 Days (Ref = <18)			
18-36 hours	0.45 (0.08)	1.57 (1.34-1.83)	<0.0001
More than 36 hours	-0.05 (0.08)	0.95 (0.81-1.11)	0.53
Geographic Location (Ref = Site 2)			
Site 1	0.19 (0.14)	1.20 (0.92-1.58)	0.17
Site 3	0.24 (0.08)	1.27 (1.08-1.48)	0.004
Site 4	0.06 (0.11)	1.06 (0.86-1.32)	0.57
Site 5	0.86 (0.22)	2.37 (1.56-3.61)	<0.0001
Site 6	-0.09 (0.14)	0.91 (0.69-1.21)	0.53

C statistic = 0.65

8.4 Discussion

Distress within the care unit is a major problem affecting over half of the palliative home care population. Findings from this study show that client, caregiver, and care unit distress are all significantly associated with the presence of dyspnea: All measures of distress are increasingly prevalent when the client is experiencing dyspnea. It is important that clinicians recognize that dyspnea affects all members of the care unit and that care provided to address symptoms of dyspnea may have a double benefit to both the client and the caregiver. During the care planning process clinicians should reflect on the presence of distress within the care unit and design interventions and allocate resources which address the needs of the client and caregiver as a collective unit (Mehta et al., 2009). Chapter seven models predicting which clients exhibit elevated risk to develop a new dyspnea over time and predicting those who exhibit highest potential to recover from dyspnea, provide insight into potential areas for interventions to address dyspnea. Following, care planning and targeted intervention strategies to treat dyspnea may not only address symptoms of dyspnea for the client but may also reduce distress within the care unit.

The philosophy of palliative care encourages clinicians to look at the ‘whole person’ when addressing symptoms like dyspnea and to extend the focus of care to the ‘whole care unit’. Treatments for dyspnea should be part of a greater plan of care to address multiple factors recognizing the needs of the person and their caregiver. Care planning to address complexity of symptoms experienced by persons nearing the end of life necessitates a multidimensional response to improve QOL and wellbeing for caregivers and clients. Dyspnea remains a significant predictor of care unit distress in multivariate analyses a finding that supports prioritization of resource allocation to address symptoms of dyspnea. As dyspnea is a recurring issue, analyses indicate increased need for clinicians to prioritize identification of factors that may trigger an exacerbation.

The interRAI Palliative Care Dyspnea Clinical Assessment Protocol (CAP) informs organization of clinical observations in a systematic manner to identify factors that influence clinical and other outcomes. The interRAI PC Dyspnea CAP identifies when symptoms of dyspnea, which may or may not have been previously prioritized, require further investigation by the clinician. The interRAI CAPs have been found to assist in the prevention of further decline, reduction of unnecessary hospital or emergency room visits, and assist to delay or prevent admission to LTC (Carpenter, 2006). Integrating use of the Dyspnea CAP into the clinical decision making process provides clinicians with best practice guidelines important to address specifically in the context of persons nearing the end of life. Most importantly, the Dyspnea CAP contains a summary of best practice guidelines useful to assist clinicians to reflect on potential underlying issues to consider during the care planning phase. Findings from the current study emphasize the importance care planning to address dyspnea have not only for the client but also for the caregiver.

Although dyspnea remained a significant predictor of care unit distress in multivariate analysis it was not the strongest predictor. In comparison to the predictive strength of multivariate analysis by Hirdes et al. (2012) indicated by a c-statistic of 0.75, Model 4, the comparable model in the current study using dyspnea as an independent variable in contrast to the CHESS score, showed slightly weaker predictive strength with a c-statistic of 0.65. The continued strength of association of dyspnea in all models suggests that dyspnea remains a predictive characteristic, yet the smaller odds ratio indicates dyspnea may not be the most important or strongest characteristic driving care unit distress. Oi-Ling, Man-Wah, and Kam-Hung (2005) also found dyspnea to be highly distressing in the last week of life, but not the strongest distressing symptom. They noted this might be attributed to increased recognition and treatment of dyspnea as well as the availability of clinical practice guidelines (Oi-Ling et al., 2005).

Clients were more likely to report self-reported distress than exhibit signs of depression as captured in the DRS. This supports previous findings by Krebber et al. (2014) who also note the discrepancy between higher rates of self-reported distress compared to lower rates of diagnosed clinical depression may be a result of overestimation during self-report or under recognition by diagnostic interview. This emphasizes the importance that open conversations between clinicians and clients may have to inform the clinician and to assist them to gain a fuller picture of distress as felt by the person. Caregivers were more likely to feel overwhelmed by the situation than to report being unable to care. Being unable to continue caring activities may suggest other issues not captured within the interRAI PC or correlated in other items within the multivariate analysis.

Clients who reported multiple diagnoses including cancer were at highest risk to experience care unit distress. It may be that experiences of the caregiver and client with dyspnea differ based on unique circumstances experienced specific to the disease diagnosis. Findings from a qualitative study comparing lived experiences with dyspnea among persons with cancer, COPD, and other diseases found marked differences in person's perceptions of the causes of dyspnea (Gysels & Higginson, 2011). Persons with COPD were more likely to perceive dyspnea as self-inflicted, which they had brought on through their own actions, and thereby were more likely to feel guilt associated with symptoms of dyspnea (Gysels & Higginson, 2011). In contrast, persons with cancer were likely to perceive episodes of dyspnea as characteristic of their illness and a reminder of their own mortality (Gysels & Higginson, 2011). Mehta et al (2010) found that past caregiving experiences influenced the means in which caregivers addressed or perceived their current situation. As the disease trajectories and frequency of exacerbations with dyspnea differ greatly by disease diagnosis and estimated prognosis, it is possible that experiences with episodes of dyspnea may lead to cumulative fear and distress. Limitations in sample size for numerous non-cancer diagnoses inhibit the ability of the current analysis to investigate further the role of disease diagnosis. However it is an area where further examination with a larger sample size is needed.

A limitation of the current chapter is the use of cross-sectional data. Cross-sectional data prevents inference of a causal relationship between dyspnea and distress within the care unit. Therefore longitudinal studies with larger sample sizes are required to improve understanding of the temporal order between dyspnea and care unit distress. A systematic review by Gysels, Bausewein, and Higginson (2007) investigating experiences of dyspnea found that of 19 studies examining dyspnea and COPD identified internationally, four studies examined the patient's experience of care, one examined care from the informal caregivers perspective, and one examined care from a health professional perspective. They also noted limitations in sample size and lack of quantitative research limit current understanding about the relationship between the symptoms of dyspnea as a predictor of the distress faced by persons and their caregivers as they near the end of life. Although current dataset challenges limit the ability to conduct longitudinal analysis this dataset is one of the largest non-administrative datasets currently available in Canada. Challenges to sample size are a problem common in palliative care. A scan of recently published full article research abstracts in three prominent palliative care journals revealed that only 2 published studies (5%, n=2/44) consisted of sample sizes greater than 1000[10]. Nonetheless, findings from this study establish the importance for clinicians to address dyspnea within the care unit.

The Dyspnea CAP provides a summary of guidelines clinicians may consider when addressing dyspnea during the care planning process. For the client, these include determining the onset and severity of the dyspnea symptoms as well as investigating the cause (Steel, Morris, and Leff, 2013a). The Dyspnea CAP outlines general treatment strategies including positioning, medication options, and breathing exercises as well as the importance on educating the client and caregiver. Clients and caregivers may not understand the multiple of triggers for dyspnea and be equipped with the necessary treatment and management strategies. Clinicians should discuss with clients and caregivers of the role of prescription medications and the importance of adherence to manage everyday symptoms and

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[10] Articles included in this scan were accessed from:

- The Journal of Palliative Care–Spring 2013, Autumn 2013; Available at http://www.criugm.qc.ca/journalofpalliativecare/index.html;
- The Journal of Palliative Medicine—Jan. 2014, Feb. 2014; Available at http://www.liebertpub.com/overview/journal-of-palliative-medicine/41/; and
- The BMJ of Palliative and Supportive Care—Feb. 2014, Mar. 2014; Available at http://spcare.bmj.com

exacerbations. Clients and caregivers should work together with the clinician to create a management plan and discuss anticipated events that may occur as the person nears death.

For community based palliative home care clients, informal caregivers often shoulder the majority of responsibility for care (Taube, 2005). Without adequate support, the magnitude and intensity of care provision necessary to keep the client at home in the community as they progress along the illness trajectory may overwhelm the client with a life limiting illness and his/her caregivers. Therefore, the care plan must include educational interventions to support and inform not only the person with a life limiting illness but also their informal support network with respect to current and projected expectations of need, level of care to be required, and availability of formal support services (Taube, 2005).

8.5 Summary

Distress within the care unit experienced by caregivers and clients should be a priority focus for clinicians when care planning to meets the needs of clients nearing the end of life. To provide optimal palliative care, the clinician must communicate available treatment and management options tailored to meet the specific needs of both the client and their informal caregiver. This must be done in a manner that empowers both clients and caregivers with the knowledge needed to determine whether treatments offered will cause added burden or assist to alleviate distress.

The interRAI Dyspnea CAP may be an effective resource not only to identify persons experiencing dyspnea who may require further attention from clinicians (as discussed in chapter seven), but also as a resource to empower clinicians with best practice guidelines to address issues of distress within the caregiver/client unit. Awareness of the needs of both caregiver and client are paramount to provision of high quality care palliative care. As the Mood CAP already addresses issues specific to distress experienced by the person with a life limiting illness, development of a specific interRAI PC CAP dedicated to caregiver distress is warranted. Results from this chapter illustrate clear associations between presence of dyspnea and increased client, caregiver, and care unit distress. Effective palliative care should address the symptom of dyspnea to improve the health and QOL of both the client and the caregiver.

9. Summary

The widely recognized benefits of palliative care including improved survival, (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007) increased satisfaction with care by clients and caregivers (Kane, Bernstein, Wales, Leibowitz, & Kaplan, 1984) and reduction of unnecessary health care resource utilization (Tulskyc & Steinhauserc, 2007; Kamal, Currow, Ritchie, Bull, & Abernethy, 2012), are all dependent upon the clinicians ability to recognize and prioritize client need, to craft a person-centered plan of care, and then to allocate appropriate palliative care resources to meet the needs of the client. As advocated by the WHO (2010), incorporation of comprehensive clinical assessment by clinicians is a critical aspect of the decision making process to support an evidence-informed, person-centered approach to care planning. The focus of this thesis has been to demonstrate the potential use of the interRAI Palliative Care assessment instrument (interRAI PC) and its associated Clinical Assessment Protocols (interRAI PC CAPs) to inform individualized care plan development for persons with life limiting illnesses. Chapter six of this thesis gave an overview of the set of eight interRAI PC CAPs and provided description of the CAP development process. The interRAI PC CAPs do not to provide clinicians with an automated plan of treatment. Instead, they help the clinician to consider relevant issues, to evaluate and integrate these issues into their clinical decision making process and to inform best practice guidelines for further guidance. While clinicians may be aware of a multitude of health issues facing the client, the interRAI PC CAPs may trigger in areas previously not recognized by the clinician. The interRAI PC CAPs may also confirm observations by the clinician and be used as further evidence to confirm their clinical evaluation and best judgment.

When any of the eight interRAI PC CAPs are triggered, clinicians in consultation with the person and, when appropriate, members of their informal support network can make informed, collaborative decisions on whether or not issues raised by the CAPs should be addressed further. CAPs are frequently triggered by community-based palliative care clients – two thirds of those assessed triggered two or more

CAPs. Unique distributional characteristics of each CAP were presented in chapter six and a hierarchical triggering structure was described. This evidence may be useful to predict levels of health complexity and change over time. CAPs triggered at high rates such as fatigue, dyspnea, and pain warrant increased attention by clinicians for the majority of palliative home care clients. Even among clients who are relatively stable, the CAP hierarchical triggering structure suggests that clinicians will encounter fatigue and dyspnea as clinical issues affecting their clients. In contrast, CAPs that trigger later in the dying process (e.g., Delirium CAP and Pressure Ulcer CAP) rarely trigger in isolation. These persons tend to have multiple clinical problems affecting their quality of life. When clinicians observe a client who triggers CAPs that tend to occur later in the dying trajectory, they may encounter more complex clinical needs requiring more in-depth attention as part of the care planning process.

The eight interRAI PC CAPs released in 2013 point to needs that may require further clinical attention across the disease trajectory. The interRAI PC CAPs address three key domains: Performance (i.e., Fatigue CAP and Sleep Disturbance CAP); Clinical Complexity (i.e., Nutrition CAP, Pressure Ulcers CAP, Pain CAP, and Dyspnea CAP); and Cognition and Mental Health (i.e., Mood Disturbance CAP and Delirium CAP) (Steel, et al., 2013e). In this dissertation, the Dyspnea CAP was selected for a more detailed examination, for two reasons. First, next to the Fatigue CAP, the Dyspnea CAP is the most commonly triggered CAP affecting nearly half of the current sample palliative home care population. Second, dyspnea is reported in the literature to be one of the most distressing symptoms affecting both the client and their informal caregiver (Ng &von Gunten, 1998; Potter, Hami, Bryan, & Quigley, 2003; Dellon et al., 2010; Kroenke, Johns, Theobald, Wu, & Tu 2013).

Although specific estimates of prevalence rates of dyspnea among the end of life population differ greatly, it is consistently reported to be one of the most common symptoms affecting persons nearing the end of life (Ng &von Gunten, 1998; Potter, Hami, Bryan, & Quigley, 2003; Dellon et al., 2010; Kroenke, Johns, Theobald, Wu, & Tu 2013). With prevalence rates as high as 95% for individuals with COPD, 70% for persons with cancer, 85% for persons with cardiac failure and motor neuron disease (Solano, Gomez, & Higgenson, 2006; Oliver, 2005) it is an issue clinicians must recognize and address when caring for persons nearing end of life. Chapter seven of this thesis characterized the prevalence of dyspnea among a sample of community dwelling palliative home care population in Ontario, Canada. Consistent with these previous studies, dyspnea was highly prevalent affecting nearly half of the palliative home care population at baseline (44.9% at baseline, 47.1% at follow-up). However, results reported in chapter seven demonstrate clearly that there is a strong relationship between dyspnea and prognosis as well as other clinical factors. Therefore, any effort to characterize rates of dyspnea across populations must take into account important covariates like proximity to death for those estimates to be meaningful and comparable. The interRAI PC assessment instrument provides the necessary data elements to support such comparisons.

In many cases, dyspnea can be preventable or modifiable such that it is not an inevitable part of the dying process. Although the prevalence of dyspnea over time was comparable, longitudinal analysis in chapter seven show that the experiences with dyspnea change over time for many persons. Chapter seven showed that person-level characteristics, some of which are potentially amenable to change, affect the risk for dyspnea over time. Among persons who exhibited dyspnea at initial assessment, approximately one third had recovered and no longer exhibited symptoms of dyspnea at the time of follow-up assessment. Bivariate and logistic regression analyses showed that persons experiencing fatigue and those receiving assistance from a personal support worker at baseline were more likely to recover from dyspnea by follow-up. It is not known whether this reflects an improvement in status resulting from clinical intervention (i.e., more PSW time leading to improved respiratory function) or a “regression to the mean” effect of persons who were more seriously impaired at the start of service delivery improving either spontaneously or as a result of good quality palliative care. Further analysis in chapter seven showed that among clients who did not exhibit dyspnea at baseline, approximately one third of persons had developed new dyspnea symptoms at follow-up. Logistic regression analyses showed that female clients and those with bladder incontinence were less likely to develop new dyspnea while those experiencing fatigue at baseline were more likely to develop new dyspnea by time of follow-up. As shown by the literature review section of this thesis dealing with the pathophysiology of dyspnea and possible risk factors (Michelson & Hollrah, 1999; Kristjanson, 2006; Booth, Moosavi, & Higginson, 2008; McCusker et al., 2009; Wilkins, Dexter, & Heuer, 2009; Porter & Kaplan, 2012), dyspnea is a complex clinical problem; however, there are reasonable treatment options (Bredin, et al., 1999; Sorenson, 2000; Jennings, 2002; Booth, Moosavi, & Higginson, 2008; Cancer Care Ontario, 2010; Parshall et al., 2012) and clinical strategies available to address the symptoms of dyspnea (Corner, Plant, A'hern, & Bailey, 1996; Kristjanson, 2006; Booth 2008). Findings from chapter seven suggest in addition to directly addressing the cause and symptom of dyspnea itself, addressing issues of fatigue, and PSW service allocation may also have positive effects over time. This suggests that a multidisciplinary approach to care addressing multiple triggered CAPs would be a good strategy for responding to the dyspnea CAP (and other triggered CAPs).

A hallmark of the palliative care philosophy is its aim to provide the highest quality of care and support for both the persons nearing the end of life and informal caregivers. Caring for a person with dyspnea has been linked to high levels of distress, unmet needs, fewer reported positive benefits experienced during caregiving activities, and feelings of anxiety, depression and helplessness (Booth, Silvester, & Todd, 2003; Goodridge, Duggleby, Gjevre, & Rennie, 2008; Malik, Gysels, & Higginson, 2013). This evidence is supported by findings in chapter eight of this thesis. High quality palliative care has shown potential to increase satisfaction with care, improve global quality of life for client and their caregiver, reduce physical symptoms like dyspnea, decrease signs of depression or anxiety, and improve access to health care resources (Kane, Bernstein, Wales, Leibowitz, & Kaplan, 1984; Melin-Johansson, Axelsson, Gaston-Johansson, & Danielson, 2010). Chapter eight examined the association between presence of dyspnea and distress experienced by members of the caregiver-client unit of care and showed that distress was a major problem affecting over half of the caregiver-client units of care. Dyspnea was shown to be associated with a higher prevalence of distress in the client and for the caregiver. Therefore, clinicians should prioritize recognition of and interventions for symptoms of dyspnea in order address psychosocial aspects of QOL in addition to the basic medical concerns posed by dyspnea. The interRAI Dyspnea CAP is a valuable resource to assist clinicians to create a management plan. The best practice guideline information available from the interRAI PC Dyspnea CAP guidelines can be a quick and effective resource for identifying strategies that may reduce the impact of dyspnea on the person and his/her caregiver(s). Being aware of and responding to the needs of both caregiver and client are basic tenets of high quality care palliative care

Although palliative care is offered in almost every sector of the Canadian health care system, including acute care, complex continuing care, long-term care, and home care (Dudgeon et al., 2007), it remains an uninsured service under the Canada Health Act (CHA). At the federal level, Canada does not yet have legislation mandating provincial provision of palliative care for persons nearing the end of life. The Ontario Association of Community Care Access Centers (OACCAC) (2003) recognized palliative care lacked "coordination, integration, and consistency" that resulted in great difficulty for clients and their caregivers to navigate palliative care services in Ontario. To address this on a provincial level, OACCAC mandated the use of the interRAI PC assessment instrument for all persons receiving palliative home care services across all CCACs in Ontario, Canada by 2012.

There are multiple strategies which may be employed to encourage or improve uptake of information from the interRAI PC CAPs by clinicians. One strategy may be to mandate that clinicians address all triggered CAPs in the subsequent care plan, as is the strategy currently employed in the long-term care sector in Ontario (J.P. Hirdes[11], personal communication, April 22, 2014). Although this would ensure information from the CAPs are integrated into the decision making process, it may inadvertently inflate the volume of work done in response to the interRAI PC if clinicians feel they must document a detailed plan of action for every triggered CAP as an administrative requirement. . This strategy may not be recommended for the interRAI PC as persons nearing end of life may refuse a treatment perceived as too burdensome (e.g. a person may refuse to increased medication to treat pain if it meant they would become drowsy and less aware, inhibiting their ability to communicate in a perceived meaningful way with family). Alternatively, information on triggered CAPs may be made available directly to the clinician as an integral part of their outcome report, as is the case in the OACCAC data reporting system software for the RAI HC CAPs (J.P. Hirdes, personal communication, April 22, 2014). Here, information would be made immediately available to clinicians and they would then be given the flexibility on whether or not to address the CAP. If this strategy is applied to the interRAI PC and the palliative homecare population it may be recommended that clinicians report reasons surrounding the decision to address or not address issues specific to triggered CAPs. Integrating the CAPs into regular clinical practice and recording the information for easy access over time may allow for clinicians to examine results of their care planning activities during follow-up assessments. There are numerous strengths of the interRAI PC assessment instrument and the large database amassed as a result of the pilot implementation phase. First, as has been previously discussed, the interRAI PC is part of an integrated suite of assessment instruments, which have shown excellent inter-rater and test-retest reliability (Steel et al., 2003, Hirdes et al., 2008). As part of the interRAI suite, the interRAI PC contains items common to other interRAI instruments, and more specifically the RAI-HC and the MDS 2.0 that are currently used in the majority of provinces/territories in Canada. This allows health authorities using multiple interRAI

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[11] Dr. John P. Hirdes is Professor in the School of Public Health and Health Systems, University of Waterloo, Canada and Ontario Home Care Research and Knowledge Exchange Chair.

assessment instruments to integrate them into a continuous care reporting symptom. Now that the interRAI PC assessment instrument has been mandated in Ontario, the OACCAC will be able to link and track clients as they transition across the various points in the health care (e.g., from receiving general home care and assessment with the RAI-HC to receiving palliative care and assessment with the interRAI PC). Second, the interRAI PC is a multi-dimensional comprehensive standardized assessment instrument that provides the clinician with a detailed picture of their client. CHPCA recognizes the multifaceted role palliative care may take to improve the health and wellbeing of persons nearing end of life as summarized in eight key domains of issues associated with illness and bereavement, shown in the CHPCA domains of palliative care (Figure 2.8). Consistent with efforts to address the needs of the ‘whole person’, the interRAI PC addresses 17 unique domains (Steel et al., 2003). With the exception of the loss and grief domain that includes bereavement planning, mourning and grief, all other domains (psychological, social, spiritual, practical, end-of-life care, disease management, and patient family characteristics) recognized by the CHPCA are included in the interRAI PC assessment instrument. Third, data in the pilot implementation were gathered by trained assessors (mostly nurse case managers) who completed the assessments as a part of their regular clinical practice. Data were gathered from all available sources including conversation with and direct observation of the person, interviews with informal caregivers, consultation with members of their health care team including doctors, nurses, and other professionals, and examination of available medical records. Finally, the breadth of data gathered will allow for greater generalizability to the palliative home care population in Ontario Canada. The data used in this thesis were gathered from six CCACs, representing urban, rural, and mixed geographic regions, northern and southern health regions, and areas with high, low, and mixed ethnic diversity. The duration of the pilot also allowed some opportunity for repeat assessments to be collected enabling some opportunity for longitudinal analysis as shown in chapter seven.

Conversely, limitations of the interRAI PC must also be recognized. First, with over 280 items, the amount of time to complete the assessment can be burdensome to not only the assessor, but more specifically the person. Especially among an end of life population, likely to be experiencing fatigue, having a conversation about their situation and needs can be exhausting. In this case, clinicians may need to complete the assessment in multiple visits or may need to rely more on reporting from family, other formal health care providers (e.g. Family physician or PSW) and available health records. It is also imperative to avoid using redundant assessments as screening tools because these would unnecessarily increase the level of burden when the information is already capture din the interRAI PC. Next, it is important to recognize that while assessments are completed by trained assessors, their clinical expertise and communication styles may vary from person to person. This can lead to challenges for clinicians to assess subpopulations of persons nearing the end of life such as persons who are unable to communicate due to cognitive impairment. Additional follow-up training may be required to ensure clinicians are able to obtain the necessary information to create a comprehensive understanding of the person and his/her needs. Finally, to date, there has been a lack of studies examining the sensitivity of change of the interRAI PC measures. With growth in the number of available follow-up assessments, future studies will be able to investigate this with greater precision.

Future research should be undertaken to provide further evidence on the validity of the interRAI PC and the interRAI PC CAPs. One such validity study might employ comparison of the well accepted scales (e.g. ESAS) with results from the interRAI PC. Validity studies to examine CAPs specifically should also be completed. A potential validity study focused on the Dyspnea CAP could measure dyspnea using the interRAI PC and compare it to other methods. Clients could complete dyspnea focused instruments such as the UCSD Shortness of Breath Questionnaire (SOBQ), the Borg Scale, and/or the Visual Analogue Scale. Research by Eakin, Sassi-Dambron, Ries, and Kaplan (1995) showed high reliability and validity of the SOBQ and Baseline Dyspnea Index among a wide range of dyspnea measures. Results of these tests could be used to provide evidence for the validity of the dyspnea measure. Tests would be completed by an independent clinician prior to interRAI PC assessment with a trained assessor. Care in the planning of these assessments would need to account for assessment burden on the patient. Completing multiple assessments on dyspnea would enable comparative measurements of both context and frequency of the symptom of dyspnea to be ascertained independently to determine the validity of the interRAI Dyspnea CAP. It would also be useful to examine whether the subjective measures of the interRAI PC (e.g. dyspnea) relate to concurrent objective clinical tests of the domain of interest (e.g. pulmonary function testing).

Although the interRAI PC instrument has numerous strengths as a comprehensive assessment instrument characterizing the needs of palliative home care clients in Ontario, Canada, limitations of the current research must also be recognized. Missing data was perhaps the largest challenge faced when conducting the current analyses. During the pilot implementation phase, some reasons for this became apparent and were addressed immediately while other issues have been addressed since full implementation. First, it became evident that some clinicians did not feel comfortable discussing end of life issues such as estimated prognosis (missing17.3%, n=1,153). To address these issues during the pilot phase, follow-up training and education was provided to emphasize the importance of gathering this information and completing the full assessment as well as provision of strategies and techniques on how to have conversations on sensitive topics. The initial pilot collected data using a paper-based teleform assessment form. Assessors were required to mark bubbles using a black pen or marker. Some assessors chose to slash bubbles instead of accurately colouring in the bubbles creating challenges when scanning teleform assessment and coding data electronically. This required manual correction to correct unreadable bubbles for assessments already completed. Managers at sites where this occurred were contacted and reminded of proper assessment marking procedures. Additionally, in the paper based assessment, diagnoses were written into boxes manually by clinicians. When scanning these boxes it was challenging to recognize the handwriting of some assessors. In this case, manual correction was completed. However, disease diagnosis information could not be clearly ascertained for 3.3% of cases (n=221). The de-identified nature of the assessments prohibited follow-up by researchers with clinicians at that time to determine accurate diagnosis information. Therefore, to address those with missing disease diagnoses, a separate variable of diagnosis unspecified was used in the analyses. These errors were corrected following completion of the pilot as now data is directly entered in a computer system. Formalized reporting systems (e.g., the Home Care Reporting System managed by the Canadian Institute for Health Information) include standardized data quality checks to address issues of missing data, out of range values and logical inconsistencies in assessment records (e.g., date related errors). As the interRAI PC has become adopted as a provincial standard in Ontario one would expect that the new OACCAC managed reporting system will have a positive impact on overall data quality. Drop down menus and entry of ICD codes for disease diagnoses incorporated into the computerized entry system can also improve the accuracy of these variables. In order to submit an interRAI PC assessment, new software should require all items to be answered and preclude incomplete assessments to be uploaded into the database system at the point of assessment.

During statistical analysis, regression analysis in chapter seven and chapter eight were the most affected by the challenges related to missing data. The option chosen to address missing data in this thesis was to run regression analysis assuming complete cases (i.e., the records included in the regression analysis were those having no missing data for any variables included in the analysis). The SAS software defaults to complete case regression analysis and eliminates all records that have missing data for any of the variables included in regression analysis coding. In a complete case analysis, as the number of variables entered into the model increased, the cumulative impact of missing data in the current study reduced the number of records included in the each regression model analysis. This inhibited the ability to use the automatic model selection technique SCORE to its fullest confirm and to compare selected models or to inform of alternate models.

Although single and multiple imputation strategies exist as alternative options to address missing data, they were not used in this thesis. Recent studies using the same interRAI PC dataset found that multiple imputation did not yield significantly different results from the complete case analysis (Fisher, Seow, Brazil, Freeman, Smith, & Guthrie, 2014a; Fisher, Seow, Cohen, Declercq, Freeman, Guthrie, 2014b). For this reason, and because complete case analysis is most frequently used (and reported on) in epidemiological research analysis (van der Heijden, Donders, Stijnen, & Moons, 2006), this method was used in this thesis. As it is recognized that employing complete case analysis may increase the possibility that results of the regression analyses may be biased (Sterne, et al., 2009) future research is needed to confirm current regression analysis findings.

Although the current dataset had challenges limiting the ability to conduct longitudinal analysis it should be recognized that the current dataset is one of the largest currently available with a sample size of 6,655 unique persons receiving palliative care of whom 1,000 have a follow-up assessment. A scan of abstracts of recently published full article research abstracts in three prominent palliative care journals[12]: The Journal of Palliative Care; The Journal of Palliative Medicine; and the BMJ of Palliative and Supportive Care revealed that less than 5% of published studies (n=2/44) consisted of sample sizes greater than 1000. Moreover, about three quarters of published studies used sample sizes less than 500 (n=34/44).

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[12] Articles included in this scan were accessed from:

- The Journal of Palliative Care--Spring 2013, Autumn 2013; Available at http://www.criugm.qc.ca/journalofpalliativecare/index.html;
- The Journal of Palliative Medicine—Jan. 2014, Feb. 2014; Available at http://www.liebertpub.com/overview/journal-of-palliative-medicine/41/; and
- The BMJ of Palliative and Supportive Care—Feb. 2014, Mar. 2014; Available at http://spcare.bmj.com

The prospects for future research using information gathered from the interRAI PC are bountiful, as the size of the current dataset will continue to grow in the years to come. Even in its pilot stage beginnings, the breath of information from the over 280 items combined with the large sample size of 6,655 are unprecedented making this dataset one of the richest and most comprehensive data sources of health and clinical information on persons receiving palliative home care in Canada. Further integration of the interRAI PC into clinical practice in Ontario, and expansion to other jurisdictions across Canada, will enable expanded tracking of Canadians as they navigate across the care continuum. This will open up new and exciting opportunities for longitudinal research. Because the interRAI suite of instruments contain a core set of items it will soon be possible to examine how the health needs of persons change as they transition through levels of care over time and near the end of life. Data gathered from the interRAI PC during this pilot and now ongoing since its integration into daily clinical practice, may inform greater understanding of the complex needs of palliative home care clients in Ontario.

Patterns in CAP triggering suggest increased attention should be given to address the accumulative complex needs of both older adults and of persons with a limited estimated prognosis. Future research should investigate variations by geographic location and further elucidate reasons for age-associated disparities in CAP triggering. Integration of evidence gathered from the interRAI PC CAPs into the care planning process may allow for higher quality of care through better tailoring of resources at address person-specific need. Additional investigation may use the interRAI PC CAPs and their hierarchical triggering structure to investigate further symptom clusters which may be associated with the CAPs. Findings from this study showed that symptoms of dyspnea often occur with fatigue and are clearly associated with distress within the unit of care. Further investigation into the association with care unit distress and other CAPs is merited. Moreover, these findings suggest need for future intervention studies to examine clinical decision making strategies affecting the choice to address or not address triggered CAP related issues, to elucidate which aspects of the CAPs clinicians find beneficial and select to integrate into the plan of care, in addition to the need to examine outcomes associated with integration of evidence from the interRAI PC CAPs.

A finding unique raised in chapter seven was the significant relationship between urinary incontinence and lower prevalence of dyspnea. Persons with urinary incontinence were less likely to develop a new dyspnea or to continue experiencing dyspnea over time. This raises important questions regarding the role of bladder continence as a risk factor for dyspnea or whether it is simply a concurrent indicator of some other underlying clinical problem. Literature is greatly lacking in this area and no studies to date have investigated this question. Consultation with experts in the field suggests further research may investigate potential confounding medical conditions, effects of reduced bladder output from dehydration, or underreporting.

The present thesis provided some evidence that the receipt of palliative home care assistance from a PSW was associated with recovery from dyspnea in chapter seven. Future research could employ an intervention study design to examine whether this change is caused by access to PSW services or whether some other explanatory factor is responsible. It may be possible that PSW services may help to reduce events that trigger episodes of dyspnea, but this warrants further investigation. Further research should investigate whether matching of PSW supports to address identified and person-specific tasks that trigger episodes of dyspnea result in symptom improvements among persons with dyspnea.

Current analysis shows that a clear relationship exists between distress among caregivers and care recipients and the symptoms of dyspnea. This raises two important implications for the interRAI PC. First, due to the important interrelationship recognized in the current thesis and by a study by Hirdes et al., (2008), the development of a specific interRAI PC CAP dedicated to caregiver distress (the mood CAP deals with the client's distress) should be a priority for interRAI. Second, as recognized in chapter eight, the interRAI PC does not address the areas of grief and bereavement for the caregiver. It may be useful for future research to focus on development of a triggering algorithm that alerts clinicians when caregivers may be at elevated risk for complicated grief and bereavement.

Implications from this thesis illustrate potential benefits using the interRAI PC CAPs to provide an evidence base important to inform care planning activities. At the clinical level, when one or more interRAI PC CAPs are triggered clinicians should take notice. The interRAI PC CAPs not only identify important problems that require further investigation by the clinician, they identify problem areas that may be amenable to intervention. More specifically, the interRAI PC CAPs only trigger when there is a potential to improve or recover from the problem or there is an ability to prevent or slow further decline. In the case of the interRAI Dyspnea CAP, findings from the current study show that symptoms of dyspnea are not an inevitable part of the illness trajectory near the end of life. These findings are of value to the general population as well, providing hope that 1 in 3 persons with dyspnea may recover over time and raising awareness that an equal number of persons without dyspnea may develop dyspnea over time. They reinforce the need for clinicians to have open dialogue with the client and their caregivers during the care planning process. The next logical step building on the findings from this thesis would be to develop a study examining client outcomes when clinicians care plan to address issues identified by the interRAI PC CAPs.

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Figure 2.2. Cancer Illness Trajectory of Death.	Lynn, J. & Adamson, D.M. (2003) Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. Washington: Rand Health, pp. 11.	Copyright permission not required for noncommercial purposes
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Figure 2.7. CHPCA Square of Care.	Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., … West, P. (2004). In: A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, Ottawa, Canada, pp. 112.	Copyright Permission Granted Monday January 27th, 2014 from Sharon Baxter, Executive Director of the Canadian Hospice Palliative Care Association (CHPCA).
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Figure 2.9. General Classifications of Dyspnea	Sorenson, H. M. (2000). Dyspnea assessment. Respiratory care, 45(11), 1331.	Copyright Permission received Sept. 5th, 2013 from Ray Masferrer, Managing Editor of Respiratory Care
9.2 Figure 2.10. Causes of Dyspnea	Thomas, L. A. (2003). Clinical management of stressors perceived by patients on mechanical ventilation. AACN Advanced Critical Care, 14(1), page 225.	Copyright Permission Granted Thursday, January 16, 2014 from Copyright Clearance Center's RightsLink service for Wolters Kluwer Health (License Number 3310901275452).
Figure 3.1. Steps During a Therapeutic Encounter	Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A., & West, P. (2002). In: A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, Ottawa, Canada, pp. 26.	Copyright Permission Granted Monday January 27th, 2014 from Sharon Baxter, Executive Director of the Canadian Hospice Palliative Care Association (CHPCA).
Figure 5.1. Map of Community Care Access Center (CCAC) Districts that Piloted the interRAI PC, Ontario, Canada	OACCAC website. Retrieved from: http://www.ccac-ont.ca/Locator.aspx?EnterpriseID=15&LanguageID=1&MenuID=46	Copyright permission received from Digital Strategy Lead, OACCAC, Jan. 17, 2014.

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Table 2.1. Potentially Treatable Underlying Causes of Dyspnea	Cancer Care Ontario. (2010). Cancer Care Ontario's Symptom Management Guide-to-Practice: Dyspnea. Retrieved from: https://www.cancercare.on.ca/toolbox/symptools/	Permission received from Cancer Care Ontario, Communications division, Sept. 4th, 2013. "Table and information borrowed with permission from Cancer Care Ontario's Symptom Management Guide-to-Practice: Dyspnea".
Table 2.2. Causes of Dyspnea in Advanced Cancer	Reprinted by permission from Macmillan Publishers Ltd: Nature Clinical Practice Oncology, Booth, S., Moosavi, S. H., & Higginson, I. J. (2008). The etiology and management of intractable breathlessness in patients with advanced cancer: a systematic review of pharmacological therapy. Nature Clinical Practice Oncology, 5(2), 90-100.	Copyright Permission Granted Thursday, January 16, 2014 from Copyright Clearance Center's RightsLink service for Nature Publishing Group (License Number 3222000329465).

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Appendix A Variables Considered for Inclusion in Multivariate Regression Analyses

	Variable	Excluded	Significant at the Bivariate Level
1	Acid Reflux	No	No
2	Activities of Daily Living Hierarchy (ADL-H)	No	<. 0001
3	Age (in increments of 10)	No	<0.0001
4	Anxious, restless or uneasy	No	No
5	Bladder Incontinence	No	0.01
6	Bloating	No	No
7	Bowel Incontinence	No	No
8	Cachexia/wasting	No	No
9	CHESS Scale	Yes: Dyspnea included in scale measure	-
10	Cognitive Performance Scale (CPS)	No	0.0006
11	Depression Rating Scale (DRS)	No	No
12	Diagnosis of cancer vs. no cancer	No	<0.0001
13	Expresses wish to die at home	Yes: Missing > 20%	-
14	Expresses wish to die now	Yes: Missing > 20%	-
15	Difficulty clearing airway secretions	No	<0.0001
16	Difficulty falling asleep	No	<0.0001
17	Fatigue	No	<0.0001
18	Gender	No	0.002
19	Have had a Hospital Stay in past 90 days	No	0.0006
20	Have visited ER in past 90 days	No	0.009
21	Home Nurse	No	<0.0001
22	Nausea	No	No
23	Obese	Yes: Missing > 20%	-
24	Occupational Therapy or Physiotherapy	No	No
25	Oxygen therapy	No	<0.0001
26	Pain	No	0.009
27	Peripheral Edema	No	<0.0001
28	Prognosis	No	<0.0001
29	Personal Support Worker	No	No
30	Receiving more or less than 6 hours of care per day	No	No
31	Geographic CCAC Site	No	<0.0001
32	Smoking	No	No
33	Too much sleep	No	<0.0001
34	Vomiting	No	No
35	Weight loss	No	<0.0001