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Incidence and predictors of excess disability among nursing home residents with middle-stage dementia: A prospective cohort study of functional transitions

by

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## Abstract

Disability adversely affects the well-being of a growing number of Canadians with dementia. This study aimed to inform prevention and treatment efforts by estimating the incidence and identifying the predictors of disability in excess of that attributable to dementia, and by identifying how caregivers respond to varying types of disability. During a one-year, prospective cohort study of 120 residents of nursing homes with middle-stage dementia, the ability to walk and to eat was monitored biweekly. When a functional loss was observed, staff and family members were interviewed to explore their attributions and actions in response to the functional loss. Individual and facility-specific predictors of disability were assessed using Cox proportional hazards regression models. The incidence of walking and of eating disability were both estimated to be 41% (95% confidence interval (CI): 0.33 - 0.50) while the combined incidence of walking or eating disability was estimated to be 53% (95% CI: 0.45 - 0.62). More than half of the observed disability (61% walking and 51% eating) was due to excess disability. Adjusting for individual and environmental predictors of disability, residents with more advanced dementia were estimated to experience 2.12 (95% CI: 1.18 – 3.83) and 2.27 (95% CI: 1.25 – 4.14) times the hazard of disability in walking and in eating respectively. Predictors of the composite of walking or eating excess disability included a more advanced stage of dementia (hazard ratio (HR): 1.90,  $p=0.06$ ), more comorbidities (HR: 2.28;  $p=0.02$ ), a less supportive environment (HR: 2.13;  $p=0.02$ ), use of antidepressant drugs (HR: 2.02;  $p=0.03$ ), and lack of use of cognitive enhancer drugs (HR: 2.27;  $p=0.03$ ). Family and staff members more often attributed the loss of the ability to walk to excess disability and the loss of the ability to eat to dementia. Reported actions taken

when disability was attributed to something other than dementia differed from reported actions taken when disability was attributed to dementia. Heightening the awareness of the incidence and predictors of excess disability may inform efforts to reduce it. Implications for practice, education, and policy are suggested to reduce the incidence of excess disability in nursing home residents with middle-stage dementia.

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This project would not have been possible without the contribution of 120 older adults and their family members who participated in the study. I am indebted to each of them. My gratitude is also extended to the nursing home staff, managers, and administrators who gave of their precious time to facilitate my work.

## **Dedication**

I am especially grateful to God who inspires me and gives me strength to fulfill my calling. My work is dedicated to Him.

“My help comes from the Lord,  
the Maker of heaven and earth.”

Psalm 121:1-2 (New International Version)

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## **Epigraph**

Even to your old age and gray hairs

I am he, I am he who will sustain you.

Isaiah 46:4 (New International Version)

## CHAPTER ONE - INTRODUCTION

An estimated quarter of a million Canadians were living with dementia in 1994 and this number is projected to rise to over three quarters of a million in 2031 (Canadian Study of Health and Aging Working Group, 1994; Statistics Canada, 2000). Alzheimer disease, the most common type of dementia (Canadian Study of Health and Aging Working Group, 1994), often presents with coincident vascular pathology (Kalaria et al., 1999; Snowden et al., 1997) thereby blurring the distinctions between Alzheimer disease and vascular dementia, and leading to the commonly used term mixed dementia (Román et al., 2002; Zekry et al., 2002). In this study the term dementia is used to include Alzheimer disease, vascular dementia, and mixed dementia.

One of the defining characteristics of dementia is the progressive and irreversible loss of activities of daily living function in a broad range of cognitive and physical domains (American Psychiatric Association, 2000; World Health Organization, 1997). The trajectory of decline in function through predictable stages is extensively documented in Alzheimer disease (Berg, 1988; Green et al., 1993; Njegovan et al., 2001; Reisberg et al., 1982, 1984, 1988a). While there is heterogeneity in the experience of functional loss (Teri et al., 1995), the norm is for a slow loss of instrumental activities of daily living in the mild or early stage, a rapid loss of basic activities of daily living in the moderate or middle stage, followed by a slow loss of even more basic activities of daily living in the severe or late stage (Brooks et al., 1993; Stern et al., 1994). These physical losses have far-reaching effects emotionally, socially, spiritually and economically. The personal

tragedy of dementia is compounded by caregiver burden (Schulz et al., 2004; Torti et al., 2004) and cost of care implications (Andersen et al., 2003; Taylor et al., 2001). Although dementia is not the inevitable outcome of aging (Morris, 1999), the likelihood of experiencing dementia does increase with age (Canadian Study on Health and Aging, 1994; Ebly et al., 1994; Evans et al., 1989). Alzheimer disease and related dementias are conditions which strike fear into the hearts of many older adults (Corner et al., 2004).

As grim as these losses associated with dementia may be, declining function can be aggravated by coincident factors including: symptoms of other diseases, adverse effects of medications, pain, depression, or features of the social and physical environment.

There is an opportunity, however, to respond to factors such as these which are potentially reversible. Such reversible functional loss has been termed excess disability (Brody et al., 1971; Connell et al., 2000; Dawson et al., 1986; 1993; Thomas, 2001).

Failure to recognize and treat excess disability has personal consequences for the individuals with dementia and the people who care about them, and has economic consequences for the health care system. For example, in Sweden the time to care for people with dementia living in institutions increased by 0.6 hours for each loss of a functional activity of daily living (Nordberg et al., 2007).

Although some research has focused on identifying reversible causes of cognitive impairment during the initial diagnostic process (Larson, 1997; Neumann et al., 2001; Reifler et al., 1987), most longitudinal studies of functional loss in dementia have attributed functional loss solely to dementia. The possibility that excess disability can

account for these losses is not usually acknowledged in these studies. Little research has been devoted to the complex issue of identifying the reversible factors which compromise cognitive and physical function throughout the irreversible trajectory of functional decline. This dissertation study begins to fill that gap.

The purpose of this study is to identify the temporal course and predictors of physical functional loss associated with Alzheimer disease and functional loss associated with excess disability in people with middle-stage Alzheimer disease living in nursing homes. Furthermore, the functional transitions are studied in some depth by exploring family and staff perceptions, attributions, and reported actions in relation to observed functional losses.

Unfortunately there is ambiguity around the determination of what constitutes excess disability and what constitutes functional loss related to the progression of dementia. In my clinical nursing practice I have encountered discordant perspectives from staff and families regarding what actions should or should not be taken in response to a functional loss. Usually the conflict was based on differing understandings of the cause of the loss and differing expectations of reversing the loss. Even if it is acknowledged that excess disability may be operating, there are challenges in identifying what might be the underlying cause. In part this is because people with dementia who are communicatively challenged cannot necessarily identify or describe their symptoms. In nursing home settings where 50% of Canadians with dementia live (Canadian Study of Health and Aging Working Group, 1994), this situation is further aggravated by a shortage of staff

with professional education to identify and respond to this complexity (Bowers et al., 2001; Harrington et al., 2000; Schnelle et al., 2004).

In dementia research much of the study of transitions related to functional ability has been in relation to quantifying the rate of functional loss (Dodge et al., 2003) or building mathematical models to predict the trajectory of functional decline (Ashford et al., 2001; Brooks et al., 1993; Liu et al., 2000). The transition experiences of individuals with dementia have received little research attention. Involved family members may advocate on behalf of the person with dementia and thereby may influence the ways in which staff respond to the functional losses. This study explores functional transitions in some depth from the perspectives of nursing staff and involved family members authorized to make health care decisions on behalf of the person with dementia.

The activities of daily living functions that are the focus of investigation are the changes in the ability to walk and to eat in people with middle stage dementia. The ability to walk and the ability to eat are basic human activities that most of us take for granted, yet the loss of these functions is the norm for people with dementia who are progressing from the middle to the late stage (Bullock et al., 2003). The ability to walk has been characterized as a quality of life domain for this population (Bourret et al., 2002; Trudeau et al., 2003). Walking is fundamental for many other more basic activities of daily living including bathing, dressing and toileting. Retaining the ability to walk is important because without it the individual is exposed the clinical hazards of immobility (pressure ulcers, incontinence, constipation, delirium, falls, muscle loss, contractures, pneumonia, and

bone loss), has no opportunity to maintain strength for other basic activities such as transferring from bed to chair, and is further handicapped in engaging with the environment (Bainbridge et al., 2006; Jirovec et al., 1990; Olson et al., 1967; Souren et al., 1995).

Eating is also an important aspect of quality of life. Eating offers a sensory experience and provides an opportunity of socialization (Zgola, 2004). Yet feeding oneself is a complex process requiring organizational, conceptual and physical skills which the person with dementia may no longer possess. The loss of ability to eat associated with dementia can lead to weight loss, malnutrition, and reduced energy as the efforts of nursing staff to compensate for this loss may meet with limited success (Amella et al., 2002). In addition, the loss of ability to eat may have adverse psychosocial consequences because the act of eating is steeped in social norms. Some may be embarrassed by self-feeding efforts which could be considered poor table manners if there is any messiness (Osborne et al., 1993). Others may consider the need for assistance with eating to be demeaning and therefore resist being fed (Amella et al., 2002; Henderson, 1998). Caregivers may have difficulty distinguishing between a lack of desire to eat and a lack of ability to eat (Norberg et al., 1988).

Losses in the ability to walk and the ability to eat are particularly relevant to nursing practice. First of all, the increased dependency necessitates a clear response from caregivers to adapt to these losses, if not to seek out the underlying cause. Secondly, losses of the ability to walk and to eat are clinical milestones. People are considered to be

in the severe stage of Alzheimer disease when they lose the ability to ambulate independently and to eat without assistance (Bullock et al., 2003). In some instances reaching this clinical milestone involves relocating the person to a different nursing home wing or dining area, while in other instances it may involve relocating the person to a different nursing home (Kovach, 1998). Thirdly, walking and eating are basic activities of daily living that are often lost by older adults with dementia who live in nursing homes. In these environments, working through transitions usually involves staff and family collaboration which is another level of complexity.

Apart from these clinical perspectives, there is another pragmatic reason for choosing to focus this research on the transitions specific to walking and eating. Walking and eating are basic activities of daily living that may be directly and unobtrusively observed in a public space. Previous studies of function in people with dementia have compared functional assessments via self-report, the proxy report of others, and observation of performance during testing situations (Lowenstein et al., 2001; Østbye et al., 1997; Wadley et al., 2003; Zanetti et al., 1999). It is generally recognized that assessments of function based on physical performance are more valid than, and to be preferred to, self- or proxy-reports (Guralnik et al., 1989; Mohs et al., 2000). Proxy reports of function by significant others have underestimated the functional abilities of older adults when compared to observations of performance by health professionals (Dorevitch et al., 1992; Rubenstein et al., 1984). This dissertation study is based on performance data collected by a health professional; however in contrast to previous studies in which function was assessed in “laboratory” clinic settings, this study attends to the *in vivo* experiences of

people with dementia by gathering data about functional transitions in the environments where people with dementia live, while they carry out their daily activities. This enhances the relevance and usefulness of the findings to nursing practice.

Typically, longitudinal studies of dementia are conducted with repeated measurements ranging from every three months to every five years (Aguero-Torres et al., 2002; Green et al., 1993; Hogan et al., 1999; McConnell et al., 2003; Reimer et al., 2004). This frequency of data collection does not afford the possibility of capturing the functional transitions as they happen, nor does it satisfy the assumption of continuous-time data necessary for the survival analysis techniques often applied to these data (Singer et al., 2008). In contrast to past research, in this dissertation study data are gathered at biweekly intervals.

The knowledge generated from this study is useful for several reasons. First of all, from a practice perspective, with appropriate knowledge translation, this research has the potential to contribute meaningfully to improving the quality of life of people with dementia. Heightening the awareness of the extent of excess disability in this vulnerable group of older adults with dementia living in nursing homes may lead to more concerted efforts to reduce excess disability. This research also provides guidance regarding the most likely targets for these efforts. Secondly, from a research perspective, this study contributes to the understanding of the nature of the functional transitions of walking and eating by estimating the hazard of functional loss attributable to dementia and to excess disability respectively, by investigating factors which may influence these hazards, and

by exploring the qualitative nature of the functional transitions through staff and family interviews. Given the impact of dementia on functional ability, and the implications this has for the quality of life of an aging Canadian population, the study of functional transitions with the intent of finding ways to minimize excess disability is warranted.

The next chapter of this report reviews the existing literature on functional loss associated with dementia, excess disability, functional transitions, and related attribution research.

The review of the literature is followed by a presentation of the results from this prospective one year cohort study. The dissertation concludes with a discussion of the research findings and the implications for research, practice, and policy.

## CHAPTER TWO – LITERATURE REVIEW

In this chapter the literature is reviewed on disability, disability related to dementia, excess disability in people with dementia, transitions related to dementia, and attribution theory as it is applied to people with dementia. The chapter opens with a review of the disability literature and the research on disability related to dementia. Then the research on excess disability in people with dementia and the risk factors for excess disability is reviewed. Next a brief summary of attribution theory will be followed by an overview of dementia research related to attribution theory. The chapter will conclude with the conceptual framework and the research questions guiding this study. All relevant tables are presented at the end of the chapter.

The importance of functional loss related to dementia cannot be overstated. In 1994 it was estimated that over 250 000 Canadians were diagnosed with dementia, a figure projected to rise to over 750 000 by 2031 (Canadian Study of Health and Aging Working Group, 1994; Statistics Canada, 2000). Functional ability is an important aspect of quality of life for many people with dementia (Ballard et al., 2001a; Brod et al., 1999; Kane, 2003; Lawton, 1991, 1997; Logsdon et al., 1999; Rosen et al., 1999; Smith et al., 2005; Trudeau et al., 2003). Costs of care per Canadian with Alzheimer disease have been estimated to increase substantially with the severity of Alzheimer disease: the escalating costs were largely due to institutional care and to functional disability (Hux et al., 1998; Østbye et al., 1994). Subsequently similar findings in Denmark, the UK, Sweden and the US have been reported (Andersen et al., 2003; McNamee et al., 2001; Nordberg, G.,

Taylor et al., 2001; Zhu et al., 2006). The additional cost to family caregivers, in terms of the mental and physical health consequences, as well as the financial burden, (Schulz et al., 2004; Torti, et al., 2004) is not captured in these analyses.

## **Disability**

It has been argued that disability is the fit of a physical or mental impairment “with the social, attitudinal, architectural, medical, economic, and political environment” (Zola, 2005, p. 1). There are many definitions of disability which vary from one context to another (Altman, 2001). For example clinical definitions for the purpose of therapeutic intervention will differ from epidemiological definitions for the purpose of public health intervention. Administrative definitions for the purpose of disability benefits will differ from scholarly definitions for the purpose of research. The definition of disability will also vary according to the conceptual model that is used.

Several conceptual models have been developed over the years to explain and integrate the multidimensional factors contributing to disability. Several of the more well known models are discussed here (Fougeyrollas et al., 2001; Nagi, 1965; Verbrugge et al., 1994; World Health Organization, 1980, 2001). There is controversy in the literature surrounding the role of environmental factors in the conceptualization of disability. The early biomedical models identify disability as a characteristic of the pathology and disease of the person without an explicit consideration of environmental factors. The International Classification of Disease (ICD-10) is an example of the biomedical approach that is focused on a cure and does not integrate the functional consequences of

chronic disease (World Health Organization, 1992). Nagi (1965) was the first to integrate the functional sequelae of disease into a conceptual model of disability. His model which incorporates the concepts of pathology, impairment, functional limitation, and disability was the basis for subsequent model development. In the Nagi model disability is defined as “an inability or limitation in performing socially defined roles and tasks expected of an individual within a sociocultural and physical environment” (Nagi, 1991, p. 315).

While more recently there is consensus on the significance of the environment in the experience of disability, there are differing opinions on the role of the environment in that experience. A conceptual framework entitled the “disablement process” was developed to account for environmental factors that influence the ability of people with a health problem to perform activities of daily living (Verbrugge et al., 1994). Like Nagy’s conceptual model (1965), the disablement process model includes the concepts of pathology, impairment, functional limitation, and disability, however it also integrates risk factors and individual and environmental factors as contributors to the process. These can either exacerbate or relieve disability. Disability in the disablement process model is defined as the “experienced difficulty doing activities in any domain of life due to a health or physical problem” (Verbrugge et al., 1994, p. 4).

In 1980 the World Health Organization integrated the notion of environment into to its ICD-10 model to arrive at the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). In this model disability is defined as “any restriction or lack

(resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (World Health Organization, 1980, p. 143). The ICIDH model has been criticized because of the linearity in the conceptualization of disease leading to impairment, which leads to disability, and finally to handicap. Further criticism has targeted the absence of clear distinctions between the concepts (Nagy, 1991) and the persistent focus on the individual rather than embracing an ecological perspective (Fougeyrollas et al., 2001).

The second revision of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH-2), also known as the International Classification of Functioning, Disability and Health (ICF), has attempted to clarify the role and interrelationships of environmental factors with impairments, disabilities, and handicaps (Ustun et al., 2003; World Health Organization, 2001). This model includes the following components: health context, body function/ body structures/ impairment, activity/ activity limitation, participation/ participation limitation, and environmental and personal context. While disability is not explicitly included in this version of the model, the definitions of activity limitation and participation restriction reflect the elements typically included in a disability definition. “Activity limitations are difficulties an individual may have in executing activities” while “participation restrictions are problems an individual may experience in involvement in life situations” (WHO, 2001, p. 121).

The Quebec Classification, also known as the Disability Creation Process (Fougeyrollas et al., 2001; Fougeyrollas et al., 1998) was developed to emphasize the role of the

environment in the disablement process. This is a socio-political model of disability which situates the source of the disability within the social and physical environment rather than within the corporal, behavioural, or functional characteristics of the individual (Fougeyrollas et al., 2001). It is a universal model of human development that applies to every human being with or without impairments and as such does not originate within the context of disease. The disability creation process model offers an ecological, systemic, and destigmatizing perspective that can be applied to anyone including people experiencing the consequences of disease and trauma.

Both the disablement process model (Barberger-Gateau et al., 2002, 2004) and the ICF model (Muo et al., 2005) have been applied to the experience of people with dementia. These applications could be considered to be model validation exercises. Barberger-Gateau et al. (2004) followed a random sample of 3,403 community dwellers aged 65 years or more for 10 years to examine the contribution of dementia to the disablement process and to take into account the modifying effect of risk factors and “extra-individual” factors. They estimated instantaneous risk of transition between four disability states and the transition to death using a five-state Markov model. This mathematical model also allowed for the possibility of recovery to a less severe disability state although it was not possible to estimate the recovery of people with dementia since very few people with dementia experienced a decrease in their disability level.

Muo et al. (2005) applied the International Classification of Functioning, Disability and Health (World Health Organization, 2001) to describe dementia-associated disability in

people with Alzheimer disease. The ICF categories were applied to information collected on 26 patients attending an Alzheimer's disease rehabilitation unit. Data on the activity and participation categories of the ICF showed that in addition to the limitations in activities of daily living which are commonly measured, other important aspects of daily living such as communication, social relationships, and recreation and leisure were limited in people with Alzheimer disease. Communication and eating activities were generally more compromised than the functions of language and swallowing which suggests that other factors were interfering with these activities and participations.

### **Disability Related to Dementia**

The loss of ability to carry out instrumental and basic activities of daily living (Katz, 1963; Lawton et al., 1969) is a defining characteristic of dementia. Dementia is defined as the development of multiple cognitive deficits including impaired memory, language disturbance, impaired ability to carry out motor activities despite intact motor function, failure to recognize or identify objects despite intact sensory function, and disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting) (American Psychiatric Association, 2000). These cognitive deficits cause impairment in social or occupational functioning and represent a significant decline from a previous level of function. The decline in function begins gradually and worsens steadily.

Those diagnosed with Alzheimer disease experience progressive functional decline through predictable stages. Katz et al. first posited a hierarchy of functional decline in older adults with chronic illnesses in 1963. Since then others have documented a

hierarchical order of functional decline associated with Alzheimer disease (Albert et al., 1992; Berg, 1988; Eisdorfer et al., 1992; Hughes et al., 1982; Morris et al., 1999; Njegovan et al., 2001; Reisberg, 1982, 1986, 1988a, 1988b; Saxton et al., 1990; Volicer et al., 1994). In contrast, vascular dementia, Lewy body dementia, and frontotemporal dementia initially present quite differently from Alzheimer disease and do not follow a predictable course of functional decline (McKeith et al., 1996; Neary et al., 1998; Román et al., 1993).

In the early stage of Alzheimer disease progressive functional decline is expected to affect instrumental activities of daily living such as driving, banking, shopping, home maintenance and cooking; while in the middle to late stages progressive functional decline will be observed in basic activities of daily living such as communication, bathing, dressing, toileting, walking, continence, and eating (Barberger-Gateau et al., 2004; Galasko et al., 1997; Green et al., 1993; Pérès et al., 2008; Reisberg, 1988a). Reisberg described the physical and cognitive functional losses associated with Alzheimer disease as occurring in seven stages (1982, 1986, 1988a, 1988b). Although cognitive decline and losses in instrumental activities of daily living occur in stages two to four (mild to moderate dementia), losses in basic activities of daily living begin in stage five (moderately severe cognitive decline) and losses in basic activities of daily living are most pronounced in stages six to seven. Stage six (severe cognitive decline) involves decline in functional activities pertaining to dressing, bathing and elimination while the seventh stage (very severe cognitive decline) involves losses in speech, locomotion and consciousness.

The progression of Alzheimer disease has been studied extensively in longitudinal research designs by measuring the decline in cognitive function using the Mini-Mental State Examination. This research is summarized in two reviews of the literature (Bracco et al., 1998; Han et al., 2000). A meta-analysis of 37 studies found the pooled estimate of annual rate of change scores on the Mini-Mental State Examination to be 3.3 (95% confidence interval: 2.9 to 3.7) (Han et al., 2000). Simple rates of cognitive change, estimated by taking the difference between functional assessment scores and dividing by the number of years between assessments, are misleading for several reasons. While such estimates are common in the literature, they fail to account for the increasing rate of cognitive decline as the stage of dementia progresses (Adak et al., 2004, Jacobs et al., 1994), the selective sample attrition which may result in disproportionate representation of higher functioning individuals, and the non-linear patterns of progression (Morris et al., 1993).

The rate of cognitive decline in Alzheimer disease as measured by the Mini-Mental State Examination is not linear. It has been suggested that there is a quadratic effect between baseline and annual rate of cognitive change with slow change in the early stage, more rapid change in the middle stage, and slow change again in the late stage (Liu et al., 2000). Essentially this is a documentation of the ceiling and floor effect of the Mini-Mental State Examination. Brooks et al. (1993; 1995) proposed a tri-linear model to describe this trajectory of decline. Others have employed log-normal (Mitnitski et al., 1999) and inverse (Mendiondo et al., 2000) functions to model Mini-Mental State

Examination scores as a function of time for people with Alzheimer disease. Such models account for the evidence of the variable rates of change in the Mini-Mental State Examination with the progression of Alzheimer disease (Adak et al., 2004; Ashford et al., 2001; Galasko et al., 2000; Liu et al., 2000; Stern et al., 1999). Rates of cognitive decline depend on the measures used to assess disease progression as was evident in the variation of annual progression amongst various tests in a set of standard psychometric tests that were administered to 289 people with Alzheimer disease (Storandt et al., 2002). Rates of decline also depend on when in the course of the disease trajectory the specific ability to be measured is affected.

Compared to the large number of studies measuring the rate of *cognitive* decline in people with Alzheimer disease, fewer studies have measured the rate of decline in *activities of daily living*. One of the reasons for this is that there are few measures of physical function that are sensitive over a broad range of dementia severity.

In studies which included measures of both basic and instrumental activities of daily living, the rate of functional decline was non-linear across the complete trajectory of decline (Schmeidler et al., 1998). Just as with the pattern of cognitive decline in Alzheimer disease, the rate of decline in physical function was greater for those with moderate to severe Alzheimer disease compared with those with mild or very severe Alzheimer disease. In an attempt to avoid the floor and ceiling effect, some instruments have been developed to span the broad range of basic and instrumental activities (Galasko et al., 1997; Reisberg et al., 1988a; Stern et al., 1994b).

Unlike studies of cognitive decline (in which the Mini-Mental State Examination is the widely used measure of cognition), there is less uniformity in the measures used in studies of decline in physical function. Instruments which have been used to study the trajectory of functional decline include the Blessed Dementia Scale (Blessed et al., 1968), the Dependence Scale (Brickman et al., 2002; Holtzeer et al. 2003b; Stern et al., 1994b), the Disability Assessment for Dementia (Gélinas et al., 1999), the Functional Assessment Staging Instrument (Reisberg et al., 1988a), the Instrumental Activities of Daily Living Scale (Lawton et al., 1969), the Katz Index of ADL (Katz et al., 1963), the Maryland Assessment of Patient Progress (Rovner et al., 1990), the Minimum Data Set-Activities of Daily Living (Chen et al., 2007; Morris et al., 1999), the Older American Resources and Services questionnaire (Fillenbaum, 1988), the Performance Test of Activities of Daily Living (Kuriansky et al., 1976), and the Physical Self-Maintenance Scale (Lawton et al., 1969).

Table 2.1 summarizes the studies which have estimated rates of decline in the physical function of people with dementia (Aguero-Torres et al., 2002b; Berg et al., 1988; Brickman et al., 2002; Chen et al., 2007; Feldman et al., 2001; Green et al., 1993; Hogan et al., 1994; Holmes et al., 2003; Holtzer et al., 2003b; Huff et al., 1990; Jacobs et al., 1994; Lucca et al., 1993; McCann et al., 2000; Morris et al., 1993; Nyenhuis et al., 2002; Perrault et al., 2002; Reimer et al., 2004; Schmeidler et al., 1998; Sloane et al., 2005; Suh et al., 2004). Because of the range in the types and stages of dementia, the measures used, and the data analysis techniques employed, it is difficult to make comparisons across the studies.

Table 2.2 summarizes the studies with a longitudinal design which treated the functional data as events or milestones in the trajectory of functional loss in people with dementia (Albert et al., 2001; Berg et al., 1988; Bracco et al., 1994; Brickman et al., 2002; Dodge et al., 2003; Galasko et al., 1995; Hogan et al., 1994; Holtzer et al., 2003b; Loewenstein et al., 1995; Reisberg et al., 1996; Rovner et al., 1990; Sloane et al., 2005; Storandt et al., 2002). The majority of these investigators use Kaplan-Meier models with the log-rank test statistic to assess the risk of reaching the functional endpoint, and Cox proportional hazards models to identify factors that are prognostic of reaching the functional endpoint. Functional endpoints included confinement to home, null activity, and null positive affect (Albert et al., 2001), nursing home admission and death (Berg et al., 1998; Bracco et al., 1994; Hogan et al., 1994; Sloane et al., 2005; Storandt et al., 2002), scoring  $\geq 17$  on the Blessed Dementia Scale (Bracco et al., 1994), needing help to find misplaced objects, needing to be watched when awake, and needing to be fed (Brickman et al., 2002), three levels of disability on the Older Americans Resources and Services questionnaire (Dodge et al., 2003), loss of one to three basic activities of daily living, and loss of five or more instrumental activities of daily living (Galasko et al., 1995), the need to be dressed, groomed, and washed, and the need for care at a level equivalent to living in a health-related facility (Holtzer et al., 2003b).

In these studies it was assumed that the functional losses observed and measured were attributable to Alzheimer disease or a related dementia. Occasionally investigators acknowledged the inappropriateness of this assumption commenting that other factors

such as comorbid illness, delirium, or depression may also contribute to functional loss (Aguero-Torres et al., 1998; Bracco et al., 1994; Dodge et al., 2003; Galasko et al., 1995; Neumann et al., 2001).

### **Excess Disability Related to Dementia**

Functional decline that may be attributed to factors other than Alzheimer disease adds complexity to the trajectory of functional loss experienced by people with Alzheimer disease. Excess disability is defined as the discrepancy between existing and potential functional capacity which is greater than that warranted by any irreversible cognitive, physical, or affective impairment (Brody, 1971; Kahn, 1965; Rogers et al., 2000).

In an attempt to differentiate between disability and excess disability in people with dementia, researchers have developed operational definitions. Dawson (1993) suggested a process of eliminating various possible causes of excess disability before assuming that the disability is due to the irreversible progression of dementia. Rogers et al. (2000) defined excess disability as the change in activities of daily living demonstrated between performance during usual care and performance during functional rehabilitation, with the assumption that lack of performance of activities of daily living does not necessarily mean a lack of ability. Reisberg (1986) developed a systematic approach to differentiate between reversible causes of disability and disability characteristic of people with Alzheimer disease. He asserts that when functional decline in people with Alzheimer disease departs from the order of functional loss which is detailed in The Functional Assessment Staging system, then other 'illnesses' or 'extraneous treatable complications' are at play.

Some researchers have found the order of functional decline in some people with Alzheimer disease to deviate from the order described by Reisberg (Cohen-Mansfield et al., 1995; Eisdorfer et al., 1992). These investigators suggested that the high prevalence of comorbidities in their sample of nursing home residents could explain the discrepancy (Cohen-Mansfield et al., 1995). Others have suggested that the assumptions regarding the hierarchical nature of activities of daily living may not always be valid (Kempen et al., 1995; Lazaridis et al., 1994; Thomas et al., 1998).

Larson (1997) recommends that efforts to minimize excess disability be the basis for the ongoing management of people with dementia, and not just part of the initial diagnostic process to identify 'reversible dementia'. Disability attributable to something other than dementia often goes unrecognized in people with dementia (Larson, 1997; Neumann et al., 2001; Reifler et al., 1987; Reisberg, 1986; Walstra et al., 1997). The identification of comorbid conditions may be more difficult in people with dementia since cognitive impairment can compromise the person's symptom interpretation and reporting (McConnell et al., 2003).

Reifler et al. define excess disability as "a treatable problem superimposed on dementia of the Alzheimer type" (1987, p. 207). Referrals to dementia speciality clinics attest to the frequent diagnosis of other conditions which can account for functional loss (Walstra et al., 1997). New diagnoses were identified in 38 (32%) patients referred to a memory

clinic by general practitioners although functional improvement was evident in only five of these patients.

It is clinically relevant to know when people with Alzheimer disease deviate from the expected pattern of disease progression, since excess disability has the potential to be reduced if it is recognized and treated appropriately (Gelb, 2000). However cognitive impairment can complicate standard treatment approaches to chronic disease management and thus can result in less aggressive treatment of comorbid conditions (McConnell et al., 2003). In this way the problem of excess disability can be aggravated in people with dementia.

There is evidence that functional disability in people with dementia can be improved if not reversed. Twenty-six (18%) community-dwelling people with Alzheimer disease improved in their functional ability over the course of a year, as measured by the Disability Assessment for Dementia scale (Feldman et al., 2001). In another longitudinal study in which 104 people with mild to moderate Alzheimer disease were followed at six-month intervals for an average of 31 months, the investigators remarked that some patients showed 'apparent improvement' (Green et al., 1993). They attributed this improvement, as measured by the Physical Self-Maintenance Scale and the Instrumental Activities of Daily Living Scale, to disease heterogeneity and unreliable proxy reports. Similarly, investigators attributed the one-year improvement detected in 37% of 374 people with Alzheimer disease to concurrent illness, scoring inconsistencies and non-linearity of the rating scales (Holmes et al., 2003). Two reports from the Consortium to

Establish a Registry for Alzheimer Disease (CERAD) have identified instances of a 'backward transition' (Neumann et al., 2001) or 'reversal of clinical milestones' (Galasko et al., 1995) in people with mild to moderate Alzheimer disease. Galasko et al. commented that intercurrent illness, delirium, depression or psychosis may lead patients to reach milestones that are later reversed as these conditions improve.

### **Risk Factors for Excess Disability**

A broad range of individual and environmental factors may contribute to excess disability in people with dementia. A summary of the research for some of the more common sources of excess disability follows.

#### *Individual Factors*

Excess disability in people with dementia has been attributed to individual factors such as comorbidities; the adverse effects of psychotropic drugs including neuroleptics, benzodiazepines, and antidepressants; depression; delirium; pain; and sensory impairment.

#### Comorbid Conditions

Comorbidities are one of the more commonly understood potential sources of excess disability for people with dementia (Aguero-Torres et al., 2002a; Barberger-Gateau et al., 2004; Larson, 1997; Neumann et al., 2001; Reifler et al., 1987; Reisberg et al., 1986; Shaw et al., 2004; Taylor et al., 2001, Thomas, 2001; Volicer et al., 1997; Walstra et al., 1997). It has been estimated that about half of the people diagnosed with Alzheimer

disease have coexisting, treatable medical or psychiatric illness and that approximately half of these people improve in function following treatment of these illnesses (Reifler et al., 1981, 1987).

### Neuroleptic Drugs

Neuroleptic drugs, also known as antipsychotic drugs, comprise a drug category which includes both conventional and atypical neuroleptics. These drugs are indicated for the treatment of psychotic symptoms and arguably for the treatment of the behavioural and psychological symptoms of dementia (Ames et al., 2005; Lanctôt et al., 1998; Rocca et al., 2007). The prevalence of neuroleptic use in nursing homes ranges from 15% to 46% (Hagen et al., 2005; Hosia-Randell et al., 2005; Lövheim et al., 2006; Snowden et al., 2006). Adverse effects of neuroleptics, especially the conventional neuroleptics, include extrapyramidal symptoms or parkinsonism, tremor, dystonia, sedation, postural hypotension, and anticholinergic effects (Ames et al., 2005; Lanctôt et al., 1998; Lee et al., 2004). All of these adverse effects have the potential to contribute to functional loss, and therefore excess disability, in people with dementia (Elby et al., 1997).

### Benzodiazepine Drugs

Benzodiazepines are indicated primarily for insomnia and anxiety disorders in older adults (Nelson et al., 1999). The Canadian Study of Health and Aging found that the use of benzodiazepines is more common among older adults who live in nursing homes compared with those who live in the community (32% and 22% respectively) (Hogan et al., 2003). The proportion of nursing home residents receiving regular doses of

benzodiazepines is reported to be 15% in Australia (Snowdon et al., 2006), 32% in Sweden (Lövheim et al., 2006), 15% to 32% in Canada (Hagen et al., 2005; Hogan et al., 2003), and 54% in Finland (Hosia-Randell et al., 2005). These drugs have been associated with an increased risk of falls, hip fractures, cognitive impairment, and functional loss (Elby et al., 1997; Hogan et al., 2003; Leipzig et al., 1999; Wagner et al., 2004) and are therefore likely candidates for excess disability in people with dementia.

#### Depression and Antidepressant Drugs

Functional disability is associated with depression in people with dementia in cross-sectional studies (Espiritu et al., 2001; Hargrave et al., 2000; Kaup et al., 2007; Pearson et al., 1989), while in prospective longitudinal studies people with both dementia and depression have significantly higher rates of functional loss than people with dementia alone (Garre-Olmo et al., 2003; Holtzer et al., 2005; Kales et al., 2005; Ritchie et al., 1998). The potential contribution of depression to excess disability in the population of people with dementia is substantial given that the prevalence of depressive symptoms in people with Alzheimer disease and related dementias has been estimated to be as high as 51% (Garre-Olmo et al., 2003; Potter et al., 2007).

Unfortunately commonly used pharmacological treatment for depression are also implicated in excess disability through their adverse effects. People who have both dementia and depression and are treated pharmacologically are at even higher risk for excess disability. Both classes of commonly used antidepressant drugs, the selective serotonin reuptake inhibitors and tricyclic antidepressants, can contribute to falls and

related disability. The selective serotonin reuptake inhibitors can cause sedation and dizziness, while the tricyclic antidepressants can lead to orthostatic hypotension, cardiac arrhythmias, and anticholinergic symptoms (Bhatia et al., 1997).

### Delirium

A systematic review of delirium superimposed on dementia revealed several studies that found delirium to accelerate the long-term functional decline in people with dementia (Fick et al., 2002). In a prospective longitudinal study of hospitalized older adults (56 people with delirium, 56 with dementia, 164 with both conditions, and 42 with neither condition) functional ability was assessed at two, six, and 12 months after hospitalization using the Barthel Index (Mahoney et al., 1965; McCusker et al., 2001). The investigators found delirium to predict significantly worse scores on the Barthel Index that were sustained during the follow-up period in all of the four patient strata. In another prospective study 325 older adults admitted to an acute hospital were followed at three and six months after discharge (Murray et al., 1993). Delirium was the sole predictor of functional decline after three months which was sustained at six months. Dementia was not a predictor of the functional loss. These two studies highlight the potential for delirium to independently contribute to excess disability in people with dementia.

### Pain and Discomfort

Pain has been identified as a source of excess disability for people with dementia (Miller et al., 2000). In particular the pain in people with dementia is often undertreated in part

because they may be unable to report their pain (Cooke et al., 1999; Malloy et al., 2004). Instead their pain may be manifested as agitated behaviour (Feldt et al., 1998).

### Sensory Impairment

Hearing and vision has been discussed as an important resource of everyday competence in activities of daily living (Brennan et al., 2005). Research suggests that vision and hearing impairment can contribute to functional loss in older adults with (Allen et al., 2003) and without dementia (Brennan et al., 2005; Keller et al., 1999).

### *Environmental Factors*

Environmental factors of nursing homes that have been implicated in excess disability of residents with dementia include the social and physical environment, profit status, staffing levels, size, and dementia education of staff. Each of these factors is reviewed below.

### Quality of the Nursing Home Environment

The physical and social environment has been identified as a source of excess disability for people with dementia (Annerstedt, 1997; Calkins et al., 2001; Kane et al., 2007; Kihlgren et al., 1992; Presbyterian Association on Aging, 2005; Reimer et al., 2004; Rovner et al., 1990). The interaction between the environment and behaviour has been conceptualized in the Competence Press Model which postulates that an individual's level of competence and the demands or press of the physical and social environment meet to determine the well-being of the individual (Lawton, 1980). If the competence of

the individual, such as the person with dementia, is reduced, then the environment assumes an increasing importance in determining well-being (Calkins, 2004). One of the goals of designing environments for people with dementia has been to reduce the environmental stress and thereby to promote functional ability and well-being (Day et al., 2000; Gitlin et al., 2003; Warren et al., 2002; Zeisel et al., 2003).

Environmental design features that are considered to be supportive of people with dementia include physical environments, programs, and administrative policies to provide privacy, to balance activity and rest, to encourage residents to do as much as they can for themselves, to preserve choices such as when to go to bed and when to rise in the morning, to personalize residents' rooms with familiar furniture and décor, to provide opportunities to socialize with staff members and others, to maintain a safe environment, and to create identifiable social spaces that facilitate meaningful activity (Brawley et al., 2001; Calkins, 2001; Day et al., 2000; Lawton et al., 2000).

There is evidence from prospective longitudinal studies that specialized environments for people with dementia may reduce the rate of functional loss (Annerstedt, 1997; Kane et al., 2007; Kihlgren et al., 1992; Presbyterian Association on Aging, 1995; Reimer et al., 2004; Rovner et al., 1990); although other evidence suggests that residents with dementia exhibit a similar decline in function over time regardless of the care setting (McCann et al., 2000; Phillips et al., 1997; Sloane et al., 2005; Swanson et al., 1994; Warren et al., 2001).

One reason for the inconsistent findings may be differing definitions of what constitutes a supportive environment for people with dementia. For example a special care unit for people with dementia is composed of multiple design features. The presence or absence of specific therapeutic features in the environment might account for the differing outcomes. However it is unclear which of these features make the difference. Day et al. (2000) call for research to examine which particular elements of an environment lead to improved resident outcomes. In contrast, Calkins (2001a, 2001b) argues that a shift away from single environmental features and discrete resident outcomes to a more holistic approach will help to understand the larger complex relationships that are found in dementia care settings.

The inconsistent findings regarding the impact of the environment on resident outcomes may also reflect a measurement issue. Instruments used to measure the physical environment may lack the necessary sensitivity and specificity to be able to discriminate between environments (Cutler et al., 2006). Measures have been developed to assess the nursing home environments including the Professional Environmental Assessment Protocol (Lawton et al., 2000), the Nursing Unit Rating Scale (Grant, 1994), various versions of the Therapeutic Environment Screening Scale (Sloane et al., 1990, 1998, 2002), and the Models of Care Instrument (Briller et al., 2000; Slaughter et al., 2005). Studies typically measure the features of specialized dementia units however few have compared specialized dementia environments with traditional nursing home environments to assess the discriminant validity of the instruments (Slaughter et al., 2006).

The discrepancy in the findings amongst studies assessing the impact of the physical and social environment on resident outcomes may also be explained by the modification or confounding of functional outcomes by other environmental factors such as nursing home staff dementia education, care routines, profit status, staffing levels, and size. Research in relation to these other environmental factors is reviewed next.

### Staff Dementia Education

Evidence from controlled trials suggests that education targeting nursing home staff who care for people with dementia may improve resident outcomes (McCabe, et al., 2007) in the particular areas of depression (Eisses et al., 2005; McCallion et al., 1999; Proctor et al., 1999), reduced disruptive behaviour (Burgio et al., 2002; Edberg et al., 2001; McCallion et al., 1999), increased nutritional intake and weight gain (Mamhidir et al., 2007), and enhanced relationships between care providers and residents (McGilton et al., 2003). However at least one study that targeted the functional ability of residents as an outcome did not find any differences between the staff education intervention group and the control groups (Proctor et al., 1999). It is generally accepted that education alone does not change provider behaviour (Aylward et al., 2003; Grimshaw et al., 2001). Kitson et al. (1998) proposed that a consideration of several factors including the evidence (Rycroft-Malone et al., 2004), the context (McCormack et al., 2002), and facilitation (Harvey et al. 2002) will optimize the uptake of evidence into practice.

### Nursing Home Care Routines

In many care settings dependency is systematically reinforced by caregivers who focus on the efficiency of completing tasks rather than maintaining the abilities of the person with dementia (Barton et al., 1980; Woods, 1998). Research has been conducted to investigate the possibility supporting the abilities of people with dementia in dressing (Beck et al., 1997; Engelman et al., 2002), in urinary continence (Schnelle et al., 1989), in mobility (Cott et al., 2002; Morris et al., 1999; Schnelle et al., 2002; Tappen et al., 2000), in bathing (Rinke et al., 1978), in a set of morning care activities including bathing, grooming, dressing, and toileting (Dawson et al., 1986; 1993; Rogers et al., 1999; Wells et al., 2000), and in eating (Amella et al., 2008; Coyne et al., 1997; Eaton et al., 1986; Van Ort et al., 1995). There are several barriers to promoting the functional ability of people with dementia in nursing homes. Actions required to improve or maintain functional ability are more time consuming to implement than usual care (Schnelle et al., 1999; 2004), stable staffing levels are generally less than what is required to provide ability supportive care (Bostick et al., 2006), and there is a widespread belief that people with dementia cannot learn new things and that the residents are just going to get worse anyway (Bayles et al., 2003; Hopper, 2003).

### Nursing Home Profit Status

There is a body of literature suggesting that the quality of care that residents of nursing homes receive varies with the nursing home profit status (Harrington et al., 2001; Hillmer et al., 2005). A Canadian review article of North American nursing homes found systematic differences between for-profit and not-for-profit nursing homes with the for-

profit nursing homes providing lower quality of care in several process and outcome quality indicators (Hillmer et al., 2005). Quebec for-profit nursing homes have a lower composite quality of care score compared with not-for-profit nursing homes (Bravo et al., 1999).

Resident outcomes also have been demonstrated to vary with the profit status of the nursing home (Aaronson et al., 1994; Castle et al., 1998a; McGregor et al., 2006). In studies in the United States not-for-profit nursing homes scored better than for-profit nursing homes in a lower use of restraints (Castle et al., 1998a) and a lower rate of pressure sores (Aaronson et al., 1994). In British Columbia for-profit long-term care facilities demonstrated higher hospitalization rates for pneumonia, anemia, and dehydration compared to not-for-profit nursing homes, when the comparison not-for-profit nursing homes were part of a larger organization (McGregor et al., 2006).

It may be that staffing levels are a mediating variable in the association between the profit status of nursing homes and resident outcomes. Not-for-profit nursing homes have been associated with higher staffing levels than for-profit nursing homes in both the United States (Harrington et al., 2001; Hillmer et al., 2005) and in Canada (McGregor et al., 2005). For example in a study of nursing homes in British Columbia, not-for-profit status was associated with an estimated 0.34 hours per resident-day of more direct care than for-profit status (McGregor et al., 2005).

### Nursing Home Staffing Levels

Nursing home staffing levels have been associated with a variety of resident outcomes and quality of care measures (Bostick et al., 2006; Schnelle et al., 2004; Zimmerman et al., 2002). In a review of staffing and quality in nursing homes functional decline was one of the three outcomes most sensitive to staffing levels (Bostick et al., 2006). Increased numbers of staff are required to maintain good outcomes. With lower staff-to-resident ratios efficiency in accomplishing tasks takes precedence over supporting the functional abilities of the residents. Several studies have found associations specifically between registered nurse staffing levels and improved resident outcomes (Anderson et al., 1998; Zimmerman et al., 2002), while others have found associations between nurse aide staffing and improved quality of care indicators (Schnelle et al., 2004).

The quality of care in nursing homes as measured by resident outcomes, including the support of resident functioning, has been associated with the quality and quantity of nursing home staff, often measured as staff-to-resident ratios. Increased functional ability is related to increased nurse staffing ratios (Castle et al., 2007; Harrington et al., 2003). This relationship has been demonstrated in prospective longitudinal studies (Bliesmer et al., 1998; Castle et al., 1998; Cohen et al., 1996; Reid et al., 2003; Schnelle et al., 2004; Spector et al, 1991). For example, in an analysis of administrative datasets, changes over a six month interval in a range of quality indicators from the Resident Assessment Instrument-Minimum Data Set were computed for 4,217 residents, with a mean age of 83 years, living in 268 US nursing homes (Castle et al., 1998). Improvement

in activities of daily living scores from the Minimum Data Set was significantly associated with higher nurse aide-to-resident ratios ( $p \leq 0.001$ ).

### Nursing Home Size

The nursing home literature suggests that size matters. Larger nursing homes (Bravo et al., 1999; Castle et al., 1998; Leon et al., 1999; McGregor et al., 2006) and smaller nursing units (Calkins, 2001a; Morgan et al., 1998; Sloane et al., 1998) are associated with improved resident outcomes. The benefit of larger nursing homes has been explained by the economies of scale afforded by their connection to larger administrative structures (McGrail et al., 2007) and by improved staff retention in larger facilities (Bostick et al., 2006). For example residents may have greater access to specialized health professionals when specialists are shared across facilities. This point is illustrated in a recent Canadian study of British Columbian nursing homes (McGregor et al., 2006). Residents experienced better outcomes in not-for-profit facilities compared to for-profit facilities when the not-for-profit facilities were attached to a hospital, were amalgamated to a regional health authority, or were multisite. The beneficial outcomes were not present when the not-for-profit nursing homes were single-site facilities. The benefit of smaller nursing units may explained by the staff getting to know the residents better because there are fewer residents, and by the reduced environmental press on the residents because of fewer people and noise in the environment (Calkins, 2001a).

### **Transitions Related to Dementia**

Transition is defined as a passage from one state, stage or place to another (Webster's New Collegiate Dictionary, 1973). It has been conceptualized as a three phase adjustment process in response to change (Bridges, 1980). Schumacher et al. (1999) suggests that a transition is precipitated by a significant marker event or turning point involving a passage from one life phase, situation, or status to another. Transitions relevant to nursing practice include developmental, situational, organizational, and health-illness transitions (Schumacher et al. 1994). For the older adult multiple transitions may take place simultaneously within a relatively short timeframe (Schumacher et al., 1999).

During a transition period, disequilibrium and upheaval can lead to redefining meanings, modifying expectations, restructuring life routines, developing new knowledge and skills, maintaining continuity, and making new choices (Schumacher et al., 1999). A series of qualitative studies was designed to understand the strategies employed by people with early to middle stage dementia in response to problems with activities of daily living. The people with dementia described a variety of 'common sense behaviours' that they used to retain a sense of control over everyday matters (Nygard, 2004).

Transition in the context of dementia has often been synonymous with relocation to a long-term care facility (Liken, 2001; Mead et al., 2005), however this conceptualization of "transition" is too restrictive. More recently research has expanded the understanding of transition in people with dementia to include functional transitions (Chen et al., 2007; Covinsky et al., 2003; Dodge et al., 2003; Neumann et al., 2001). With Alzheimer

disease the construct of transition is particularly relevant because change is ongoing throughout the course of the disease in multiple domains, including the domain defined as activities of daily living.

In a ten year prospective cohort study of 1201 community-dwelling older adults, functional transitions among three levels of disability in instrumental activities of daily living were assessed every two years (Dodge et al., 2003). Multinomial logistic regression was used to estimate the active life expectancies of men and women in relation to different degrees of disability. This analytic approach captured all of the possible transitions in disability levels, including improvements. The study found that people with Alzheimer disease spent more years of life with disability than those without Alzheimer disease.

To characterize the functional trajectories of people with and without cognitive impairment during the last two years of life, the ability to bathe, eat, walk and be continent was assessed every three months in a cohort of 917 frail older adults who met the criteria for nursing home placement but who lived and died at home (Covinsky et al., 2003). The incidence of decline was estimated for each functional activity for those with and without cognitive impairment. During the last two years of life ability to walk declined in 56% with cognitive impairment compared with 36% without cognitive impairment, and ability to eat declined in 49% with cognitive impairment compared with 26% without cognitive impairment. Logistic regression models were used to assess the relationship between functional decline and cognitive impairment. After adjusting for

age, sex, and comorbid conditions, it was estimated that for patients with cognitive impairment the odds of losing the ability to eat were 2.6 times the odds of those without cognitive impairment ( $p < 0.001$ ). In relation to mobility, it was estimated that for patients with cognitive impairment the odds of losing the ability to walk were 2.4 times the odds of those without cognitive impairment ( $p = 0.05$ ).

In a cohort of 1145 dementia patients annual transition probabilities were estimated for changes in the stage (mild, moderate, severe) of Alzheimer disease and in the living situation (community, nursing home) (Neumann et al., 2001). In addition, Cox regression models were used to estimate the hazard ratios for each stage-to-stage and stage-to-nursing home transition. The majority of the patients with mild-stage dementia progressed to the severe/nursing home stage (25.3%) or died (25.5%) in five years. The transition probabilities did not vary with the duration of time spent in a particular stage suggesting that some people may progress through the stages more rapidly than others. It is noteworthy that 4.3% of the cohort underwent a 'backward transition' from moderate to mild Alzheimer disease. The authors speculated that this apparent improvement might reflect either a variation in clinical assessments, the presence of depression, or medication adjustment. The latter two explanations suggest the presence of excess disability.

### **Attributions and Dementia**

The ways in which people think about dementia and the behaviour of the person with dementia are likely to influence their behaviour towards the person (Kitwood, 1997; Weiner, 1985a). Various explanatory models may guide the understanding of dementia

including the explanation of dementia as a neurological condition, as a neuro-psychiatric condition, as a normal part of aging, or as a result of a malignant social psychology (Downs et al., 2006; Sabat, 1994). Dementia understood as a neurological condition has led to rehabilitative efforts to optimize the function of people who live with significant impairment. Dementia understood as a neuro-psychiatric condition has led to the use of drugs to manage symptoms. Dementia understood as a malignant social psychology has led to the development of supportive relationships and environments aimed at affirming the personhood of the individual. Dementia understood as a normal part of aging has led to the acceptance that there is nothing to be done except to carry on as usual (Downs et al., 2006).

### *Attribution Theory*

Attribution is a social psychological construct referring to how individuals explain the behaviour of others. Behaviour has been linked to the structure of thought through a theory of attribution. The origin of attribution theory is credited to Fritz Heider. In his book *The Psychology of Interpersonal Relations* (1958), Heider argues that people act as intuitive psychologists employing naive theories about people. He describes the processes by which individuals come to understand their own and other's behaviour and by which future behaviour may be predicted and controlled. Starting from the position that all people make attributions, he proposed a "common-sense psychology" that action depends on factors within the person and factors within the environment. Attribution of outcomes links an event to its underlying conditions in the individual or in the environment, while attribution of intentional actions links an event to the actor's motives. Heider's ideas are

foundational for social psychological theorizing about causal attribution and explanation (Ickes, 1976; Malle, 2006).

Four streams of research which have evolved from Heider's work, highlight different yet complementary aspects of the attribution and explanation processes: knowledge structure, covariational analysis, correspondent inference, and conversational explanation.

Attribution theory development in relation to these research streams is summarized in several recent reviews (Hilton, 2007; Malle, 2006), however a brief overview of each research stream is offered here.

The knowledge structure perspective of attribution theory draws from research in neuropsychology and developmental psychology suggesting that there are innate brain structures for perceiving action and emotion. For example people's general knowledge about usual patterns of behaviour spontaneously leads them to make attributions about people who behave inappropriately (Brown et al., 1989). Another example of an innate knowledge structure is the way in which people automatically and unconsciously analyze action as goal oriented (Schank et al., 1977).

The covariational analysis perspective of attribution theory suggests that individuals function as "naive scientists" to arrive at the best explanation for an event by looking for covariation in the person-environment circumstances surrounding the event. The three relevant circumstances proposed by Kelley et al. (1967, 1973) include consistency of the person, the consensus of the action, and distinctiveness of the occasion. Empirical

research suggests that people do take this covariation information into account if it is available, and may seek out this information for an *unintentional event*. However explanation for *intentional action* will more likely focus on the actor's goals, beliefs, and motives.

The correspondent inference perspective of attribution theory was developed to explain intentional action by means of inferences about the actor (Jones et al., 1965). The focus of this research has been an explanation of action based on the stable dispositions, traits, motives or attitudes of the intentional actor. Less attention has been focused on inferring the reasons for an unintentional action.

The conversational explanation perspective of attribution theory attends to the interpersonal and functional aspects of causal attribution (Hilton, 1990). In the context of a conversation the explainer is not necessarily attempting to find meaning but instead may be attempting to manage the inquirer's understanding and subsequent behaviour. Furthermore the explainer being sensitive to the perspective of the inquirer is likely to select from a range of possible explanations that are true, informative, relevant, and clear to the inquirer (Slugoski et al., 1993). Thus the explanation(s) may vary according to who is engaged in the conversation.

#### Attribution Theory Applied to Dementia

Several studies have examined the attributions that either family or professional caregivers make in response to the diagnosis of dementia or the symptoms of dementia

(Athlin et al., 1987; Bond et al., 2005; Cullen et al., 2005; Fopma-Loy et al., 1997; Levy et al., 2000; Paton et al., 2004; Polk, 2005; TARRIER et al., 2002; Todd et al., 2005; Wadley et al., 2001; Whitehouse et al., 2000). Three of these studies used vignette research designs to link attributions to the behavioural intentions of nursing home staff or family members (Fopma-Loy et al., 1997; Wadley et al., 2001; Whitehouse et al., 2000).

Dementia and its symptoms have been attributed to a wide range of attributions. The caregivers of 22 people with Alzheimer disease attending geriatric outpatient clinics identified numerous causal attributions for repetitive behaviours (Cullen et al., 2005). Attributions of the behaviour offered during interviews included memory failure, comfort-seeking, conversation-making, low mood, anger, conversational rehearsal, agitation, anxiety and purposeful activity gone awry. In one of the largest research surveys on dementia involving family caregivers, physicians and the general population from six countries (n=2423), over 80% of the respondents attributed the symptoms of early stage Alzheimer disease to normal aging (Bond et al., 2005).

Age was also a frequently identified attribution by family caregivers of people with dementia in two other studies (Levy et al., 2000; Patton et al., 2000). Paton et al. (2004) conducted semi-structured interviews with 205 family caregivers of people with Alzheimer disease. When caregivers identified a behaviour or symptom that they found troubling, they were asked, "What do you believe is the cause of this behaviour?" Contrary to the investigators' assumption that the behaviours were due to the onset of Alzheimer disease, the majority of family caregivers spontaneously attributed the

behaviours to causes other than dementia despite being aware of the dementia diagnosis. Their attributions included normal aging, an unknown cause, poor diet, loneliness, attention seeking, boredom, premorbid personality, physical illness, and medication.

In interviews with 40 family caregivers of people with dementia from four different cultural groups, 17 different attribution categories emerged from the data (Levy et al., 2000). On average the caregivers reported four causes of their relative's dementia. The most frequent attribution categories were related to aging, body, brain, disease, genetics, immigration, and lack of social support. White Americans mentioned the biomedical attributions (body, brain, disease and genetics) more often as a cause of dementia while minority groups (Chinese, African American and Latino) mentioned age and a lack of social support more often. The authors suggested that the multiple attributions could lead to uncertainty about which attributions and corresponding actions should be given priority by the caregivers.

One of the main findings in a study to understand the attributions of seven family caregivers regarding Alzheimer disease was the uncertainty about the extent to which Alzheimer disease was the cause of challenging behaviour (Polk, 2005). For example caregivers explained how they tried to reduce their uncertainty by monitoring the person with dementia and consulting with a doctor prior to attributing a behaviour change to a medication. The behaviours of the person with Alzheimer disease were attributed to medications and personality but none of the caregivers mentioned normal aging as a reason for the behaviour.

The attribution theory of achievement motivation and emotion has been used to explain the connection between a caregiver's attribution, emotional response, and the provision of assistance to a person with dementia (Weiner, 1985a). According to this theory attributions which are organized according to the constructs of "locus," (internal-external) "stability," (stable-unstable) and "controllability" (controllable-uncontrollable), influence caregiving behaviour through the mediating influence of emotional reactions. For example the theory suggests that when the cause of behaviour, such as a functional decline, is perceived to be beyond the control of the individual, then pity is experienced and people are likely to provide assistance (Weiner, 1985a). Furthermore, if the cause of the functional decline is perceived to be stable and uncontrollable, so that the person will not be able to function in the future, then greater pity is elicited and people are even more likely to provide assistance. The attribution theory of achievement motivation and emotion has been applied in six studies to understand the consequences of the attributions of both formal and informal caregivers of people with dementia (Athlin et al., 1987; Fopma-Loy et al., 1997; TARRIER et al., 2002; Todd et al., 2005; Wadley et al., 2001; Whitehouse et al., 2000). The findings of each of these studies are reviewed briefly below.

Fopma-Loy et al. (1997) studied the attributions and behavioural intentions of 54 nursing home staff members caring for residents with Alzheimer disease. Staff members responded to vignettes of agitated residents who were not feeding themselves using a standard set of attribution and caregiver behaviour statements derived from pilot work.

Those who attributed difficulty with self-feeding to unstable (reversible) causes, rather than to dementia, were more likely to identify caregiving behaviours to encourage self-feeding. Affective reactions were not found to be related to caregiving behaviour.

Fifty-one nurses and psychologists caring for people with dementia were interviewed to study the association between their attributions of challenging behaviour, and their willingness to help to change the behaviour (Todd et al., 2005). During the interviews accounts of witnessed physical aggression, wandering, and excessive verbal behaviour were elicited. The attributions tended to be stable, internal, and uncontrollable although this varied with the type of behaviour. Emotions rather than attributions were associated with the willingness to help. Optimism and sympathy were associated with a willingness to help while burnout was not. The health professionals reported a mean of 9.7 attributions for the behaviours discussed during each interview. The most common attributions for the challenging behaviours included dementia, the client's negative emotion, personality, feeling threatened, lacking stimulation, and seeking attention.

During interviews with 100 informal caregivers of people with Alzheimer disease 1861 attributions were made in relation to reported adverse behaviours, situations or events (Tarrier et al., 2002). Following Weiner's theory, the attributions were coded as internal-external, controllable-uncontrollable, and stable-unstable. Like Todd et al., (2005) these investigators found that attributions made by this sample of caregivers were predominantly internal and uncontrollable but were evenly distributed between stable and unstable causes. The attributions were categorized as illness (n=128), cognitive features

(n=331), psychiatric symptoms (n=563), behavioural disturbance (n=209), and activities of daily living (n=293). The belief that the behaviour was under the volitional control of the person with dementia was associated with critical and hostile emotional responses from the caregiver and attempts to coerce the person to exert more control. In contrast, the belief that the behaviour was not under the control of the person was associated with warm emotional responses and attempts to protect the person.

In a university undergraduate experiment 221 female social psychology students responded to selected vignettes describing the inappropriate behaviour of one of their parents (Wadley et al., 2001). They were asked to identify whether they felt angry or sympathetic, whether they attributed the behaviour to personality or to something that cannot be controlled, and whether or not they would help their parent. When daughters attributed the inappropriate behaviour of their parent to Alzheimer disease they felt more sympathy toward the parent, ascribed less responsibility for the behaviour, and expressed a willingness to help.

Twenty-one staff members working with older adults with a learning disability responded to a series of vignettes describing behavioural changes in older and younger people with learning disabilities (Whitehouse et al., 2000). The study found that if a change in behaviour was attributed to dementia then it was likely to be viewed as stable and uncontrollable. Staff members were pessimistic about being able to change the behaviour attributed to dementia but expressed a willingness to help as much as possible. The

investigators concluded that when the behaviour is perceived as uncontrollable helping behaviour increases.

A set of six case studies examined the attitudes and interpretations of caregivers assisting residents to eat when a change from a task assignment to a patient assignment care system was introduced (Athlin et al., 1987). The summaries of case studies connected the staff members' interpretations or attributions of eating difficulty to their actions. As the Nurse Aides worked more consistently with specific residents they began to establish relationships with these residents and they interpreted and responded to the eating behaviours of the residents in new ways. They were able to recognize subtle cues from the residents and began to attribute individual residents' specific challenges to such things as decreased ability to concentrate, decreased ability to swallow fluids and solid foods given at the same time, fatigue, or oral dyskinesia. According to their attributions the nurse caregivers began to adjust their feeding techniques by reducing distractions in the environment, reminding the resident to eat, or adjusting when to put the spoon into the resident's mouth without interfering with involuntary tongue movements.

Furthermore in all six case studies the staff caregivers reported feeling a closer connection to the residents and reported observing the residents as more active participants in the eating process. It appears that the change from a task assignment to a patient assignment enhances the social environment of the residents.

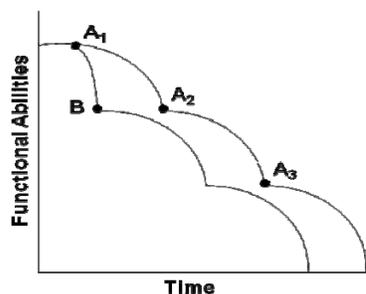
These six studies provide broad support for Weiner's attribution theory of achievement motivation and emotion, however one study using vignettes failed to find a role for

emotion as a mediator between attribution and helping behaviour (Fopma-Loy et al., 1997) and another study using vignettes did not specifically study the emotional response of the caregivers (Whitehouse et al., 2000). While the attributions of staff and family caregivers may influence their behavioural response to people with dementia, none of the research summarized above, with one exception (Athlin et al., 1987), has studied the actual behaviour of either the caregivers or the person with dementia. Instead behavioural intentions and the willingness to act are reported in relation to the past behaviour of residents or hypothetical situations.

### Conceptual Framework

The ‘functional transitions model’ serves as the conceptual framework for this study (Slaughter et al., 2007). It integrates the theoretical notions of progressive functional decline associated with Alzheimer disease (e.g.  $A_1$ ,  $A_2$ ,  $A_3$ ), excess disability (e.g. B), and intermittent transitions along the trajectory of functional decline. The model emerged from clinical practice and is oriented towards maximizing ability in the context of progressive disability associated with Alzheimer disease.

**Figure 2.1 Functional transitions model**



The transition experience from ability to disability for people with dementia is characterized by uncertainty. The functional transitions model proposes that a change in the ability to function which is experienced by the person with Alzheimer disease is ambiguous and may lead to differing interpretations of what is taking place in the person. Such functional losses may be due to the progression of Alzheimer disease, excess disability, or both. Depending on how the loss of function is understood, actions may (or may not) be taken to mobilize resources to assess and treat. For example nursing home staff members who have repeatedly witnessed functional decline in people with dementia may not expect any functional improvement. However family members who may not understand that the losses in cognitive function are also accompanied by losses in physical function may expect an active assessment and treatment response. It is paradoxical to attempt to minimize excess disability while anticipating the progressive decline associated with Alzheimer disease. If an attempt is made to identify the underlying factors that may have led to the functional loss then there is either the possibility of restoring functional ability or forestalling the further loss of function.

Occasionally functional ability may be improved if it is accepted that excess disability may be present and if efforts are made to identify and to treat it. While it may not be possible to restore the person to the previous level of function some improvement may be possible. If attempts to identify excess disability are unsuccessful, then it is likely that the functional loss will be irreversible and that this signifies another step in the trajectory of functional decline related to dementia. In any case it should be possible to compensate for a loss of functional ability.

### **Research Questions**

This study will generate new knowledge about the functional transitions that people with dementia typically experience in the middle stage of the trajectory of decline. Changes in the ability to walk and to eat will be investigated prospectively by estimating the incidence of excess disability, by identifying predictors of excess disability, and by exploring family and staff member attributions of a functional loss and the actions reportedly taken in response to the functional loss. The research questions guiding this study are:

1. What proportion of functional decline in walking and eating is attributable to Alzheimer disease in people with middle-stage Alzheimer disease living in a nursing home?
2. What proportion of functional decline in walking and eating is attributable to excess disability in people with middle-stage Alzheimer disease living in a nursing home?
3. To what extent do resident-specific and facility-specific factors predict excess disability?
4. What are the staff and family member attributions and reported actions taken in response to a functional loss in walking or eating?

**Table 2.1 Characteristics of longitudinal studies reporting the rate of functional change**

Author Year	Population / Sample				Follow-up years / # assessments	Analysis	Measures	Rate of Change
	N	Mean age	Type of subjects	Stages of dementia				
Aguero-Torres et al. 2002b	223	86	133 AD	mild mod - sev	7/2		Katz ADL	3.3 - 5.4 pts /7 yrs
Berg et al. 1988	101	52 VaD 43 other AD 58 normal	AD normal	CDR=1 Methods	5/5	changes in 50 <sup>th</sup>	BDS	5 at baseline 7.3 at 15 mth 13.5 at 34 mth at 50 mth 19 at 66 mth
Brickman et al. 2002	230	73	AD	mild	3/6	GEE analysis	Dep. Scale	1 pt / yr
Carpenter et al. 2006	7001	86 85	dementia	moderate	0.5/3	difference	MDS-ADL	1.8 pts/6 mth 1.7 pts/6 mth
Chen et al. 2007	314	91	dementia	advanced	1/4	ANCOVA	MDS-ADL	2.4 pts/yr
Feldman et al. 2001	140	71	AD	mild-mod	1/3	difference	DAD	12 ±19 pts/yr
Green et al. 1993	104	68	severe AD	mild-mod	2.5/5	multiple	PSMS IADLS	2.44 ± 4 pts/yr 2.06 ± 3 pts/yr

**Table 2.1 Characteristics of longitudinal studies reporting the rate of functional change (continued)**

Author	Year	Population / Sample				Methods			
		N	Mean age	Type of subjects	Stage of dementia	Follow-up years / # assessments	Analysis	Measure	Rate of Change
Hogan et al.	1994	462	72	AD		5/5	difference	BDS	(slow) 2.6 ± 0.4 pts/yr (typical) 4.0 ± 0.3 pts/yr (rapid) 4.4 ± 0.4 pts/yr
Holmes et al.	2003	374	83	AD	all	3/4	difference	BDS	
Holtzer et al.	2003b	236	73	AD	mild-mod	5/10	difference	Dep. Scale	1.9 ± 2.2 pts/yr 1.6 pts in 1 <sup>st</sup> yr 1.0 pts in 2 <sup>nd</sup> yr pts in 3 <sup>rd</sup> yr 0.9 pts in 4 <sup>th</sup> yr 0.2 pts in 5 <sup>th</sup> yr 1.2
Jacobs et al.	1994	127	64 78	AD	early onset late onset	2/4	regression	BDS	1.3pts ± 0.9/6 mth 1.0 pt ± 1.0/6 mth
Lucca et al.	1993		75	AD	mild-mod	1/4	difference	BDS	
McCann et al.	2000	56	85	AD		2/3		PADL	3.5 ± 3.7 pts/yr
Morris et al.	1993	177	71	AD			difference	BDS	
		430		all		4/4			2.1 ± 1.8 pts/yr

**Table 2.1 Characteristics of longitudinal studies reporting the rate of functional change (continued)**

Author	Year	Population / Sample				Methods			
		N	Mean age	Type of subjects	Stage of dementia	Follow-up years / # assessments	Analysis	Measure	Rate of Change
Nyenhuis et al.	2002	113	77	AD VaD	mild-mod	7/7	random	Barthel	4.5 pts/yr (VaD)
								IADL items	9.0 pts/yr (AD) 0.2 pts/yr (VaD)
Perrault et al.	2002	90	80	dementia	mild	5/2	regression	OARS	47 lost 1-4 activities 26 lost ≥ 5 activities
Reimer et al.	2004		82	dementia	mid-late	1/4		FAST	0.2 - .5 pts/yr
Schmeidler et al.	1998	185	66	AD	mild	1/1	difference ANOVA	IADLS	2.4 pts/yr (mild)
		71			moderate				4.5 pts/yr (mod)
79		69							
73		66			severe effects very severe				0.3 pts/yr(mild) 1.5 pts/yr(mod) 3.5 pts/yr(sev) 4.3 pts/yr(sev) 3.3 pts/yr(vsev)

regression

**Table 2.1 Characteristics of longitudinal studies reporting the rate of functional change (continued)**

Author Year	Population / Sample				Methods			
	N	Mean	Type of subjects	Stage of dementia	Follow-up years / # assessments	Analysis	Measure	Rate of Change
Sloane et al. 2005	age	85	dementia	mild AL mild NH mod-sev AL mod-sev NH	1/2	GEE to estimate	MDS-ADL	4.29 pts/yr 5.8 pts/yr 0.87 pts/yr 1.13 pts/yr
	1252							
Suh et al. 2004	107	80	AD			difference	DAD (mild)	16.6±11.6 pts/yr
			all	1/3	differences		(typical)	19 ± 12 pts/yr

AD (Alzheimer disease), AL (assisted living), ANOVA (analysis of variance), NH (nursing home), GEE (generalized estimating equation), BDS (Blessed Dementia Scale), ANCOVA (Analysis of Covariance), DAD (Disability Assessment for Dementia), Dep. Scale (Dependence Scale), FAST (Functional Assessment Staging Instrument), IADLS (Index of Activities of Daily Living Scale), Katz (Index of Activities of Daily Living), MDS-ADL (Minimum Data Set – Activities of Daily Living), OARS (Older American Resources and Services), PADL (Performance Test of Activities of Daily Living), PSMS (Physical Self-Maintenance Scale)

**Table 2.2 Characteristics of longitudinal studies reporting functional milestones**

Author	Year	Population / Sample			Methods			Milestone
		N	Mean age	Type of subjects	Stage of dementia	Follow-up years / # assessments	Analysis	
Albert et al. 2001		150	75	AD			milestones & survival	home confinement null activity null positive affect
				all	4/8			
Berg et al. 1988		101	43 58	AD normal	CDR=1	5/5	milestones & survival	BDS nursing home admit death
Bracco et al. 1994		145	65	AD	all	5/10	survival	BDS score > 17 on BDS
Brickman et al. 2002		230	73	AD	mild	3/6	survival	Dep. Scale help to find things need to be watched need to be fed
Dodge et al., 2003		87	75	AD	mild	10/6	multinomial logistic Regression	OARS loss of 0-1 IADLs loss of 2-5 IADLs loss of 6-7 IADLs death
Galasko et al. 1995		343	71	AD	all		milestones in 3 years	BDS lost feeding 7% lost dressing 17% lost toileting 10% lost $\geq 5$ IADL 47%
					3/3			

**Table 2.2 Characteristics of longitudinal studies reporting functional milestones (continued)**

Author	Year	Population / Sample				Follow-up	Analysis	Measures		
	N	Mean age	Type of subjects	Stage of dementia	years / # assessments					
Hogan et al.	1994	462	72	AD				milestones	nursing home admission death	
Holtzer et al.	2003b	236	73	AD	all	mild to moderate	Methods/10	survival	Milestone Dep. Scale need to be dressed, groomed, & washed. need care of health facility.	
Loewenstein et al.	1995	52	77	AD		mild to moderate	1/1	percent deterioration in 1 year	DAFS reading a clock time orientation using a telephone identifying currency counting currency writing a check balancing checkbook shopping with a list eating dressing & grooming	15% 30% 35% 33% 10% 24% 32% 11% 24% 29%
Reisberg et al.	1996	103	70	AD		all	5/2	survival	FAST stg 4 (mild) stg 5 (mod.) stg 6 (severe)	1.6 yrs 1.4 yrs 2.4 yrs
								stage duration	stg 7 (v. severe)	1.6 yrs

**Table 2.2 Characteristics of longitudinal studies reporting functional milestones (continued)**

Author	Year	Population / Sample				Follow-up	Analysis	Measures	
		N	Mean age	Type of subjects	Stage of dementia	years / # assessments			
Rovner et al.	1990	14 <sub>14</sub>	77 <sub>87</sub>	AD SCU non-SCU		1/2	counts	MAPP	2 (14%) declined 9 (64%) declined
						Methods		Milestone	
Sloane et al.	2005		85	dementia		1/2	survival	milestone	death
					all				
Storandt et al.	2002	1252	289	74	AD	early		milestones	nursing home admit death
						20/20	survival		

AD (Alzheimer disease), BDS (Blessed Dementia Scale), DAFS (Direct Assessment of Functional Status Scale), Dep. Scale (Dependence Scale), FAST (Functional Assessment Staging Instrument), IADL (Instrumental Activities of Daily Living) IADLS (Index of Activities of Daily Living Scale), MAPP (Maryland Assessment of Patient Progress), OARS Older Americans Resources and Services questionnaire), PSMS (Physical Self-Maintenance Scale), SCU (special care unit)

## **CHAPTER THREE – METHODS**

The chapter begins with an overview of the design and epistemological stance of the study. This will be followed by a description of the study population, data collection procedures, and methods used to analyze the data. The chapter will conclude with a discussion of ethical considerations.

### **Design and Epistemology**

A mixed methods approach was used to understand and explain the functional loss that occurs in people with middle stage dementia who live in nursing homes. In this study the mixed methods design included two aspects: a one-year, prospective cohort investigation and a related exploratory descriptive investigation using interviews. Each type of data supplemented the other. The data triangulation and methodological triangulation that was possible through observations, interviews, and health record reviews strengthened the research (Denzin, 1978; Glaser et al., 1967). Observations and health record reviews contributed primarily to the cohort aspect of the study, while data collected during the interviews primarily contributed to the descriptive aspect of the study, although there was some cross-over between study aspects in the use of the data. This research design allowed for mutual verification of the findings. The observations of functional loss were intended to provide a focus for the interviews; while the interviews which were conducted contemporaneously with the functional loss were intended to validate and to help explain the observations (Sandelowski, 2000). It was expected that new insights

could be introduced during the interviews when the respondents reflected upon theirs and the researcher's observations.

### *Prospective Cohort Design*

The cohort design is an epidemiological, analytic design which is ideally suited to studying aging, "the process of growing old" (McKean, 2005, p. 30), because it provides a framework for investigating change over time (Campbell et al., 1987; Ingram et al., 1998; Singer et al., 2003). Although cross-sectional studies can provide useful information, it is only by monitoring change in people with dementia that a more complete understanding of the transitions throughout the course of the syndrome is possible (Yesavage et al., 1991). In a cohort study a group of individuals without the health problem of interest is classified with respect to an exposure status at the start of the study, and is monitored for subsequent development of the health problem of interest over time (Hennekens, et al., 1987). The most common limitations of cohort studies include the possible loss to follow-up (Kristman et al., 2004; Sackett, 1979) and the potential for practice effects and carry over effects which would influence the values of repeated measures (Cantor, 1989; Portney et al., 2000; Wall et al., 1970).

### *Exploratory, Descriptive Design*

In the descriptive aspect of the study the views of family members and involved nursing staff about the meanings, practices, and experiences associated with functional loss of residents in nursing homes were examined during interviews (Bond et al., 2001).

Interviews were scheduled when functional loss in specific domains was observed by the researcher. In this way an exploratory, descriptive design complemented the prospective, cohort design.

### *Epistemology*

The epistemological stance of this study is objectivism: things exist as meaningful entities independent of consciousness and experience. As such, careful research may uncover objective truth and meaning (Crotty, 1998a). The philosophical stance of this study is post-positivism, which has been described as an “attenuated form of positivism” (Crotty, 1998b, p. 29). Although positivism and post-positivism require precision, logical reasoning and attention to evidence, post-positivism has been defined as the search for approximated truth as opposed to the search for absolute truth (Clark, 1998; Crotty, 1998b; Denzin et al., 2000; Lincoln et al., 2000). From a post-positivist perspective, scientific knowledge is generated by positing a hypothesis or conjecture and then gathering data to find evidence against that hypothesis (Crotty, 1998b; Lincoln et al., 2000; Popper, 1988). If no evidence is found to refute the null hypothesis then truth is held tentatively. The findings are accepted until the next study succeeds in finding evidence against the null hypothesis (Kuhn, 1970). In contrast, positivism espouses a confidence, certainty, and conviction that scientific knowledge is accurate. Hypotheses are to be verified rather than attempted to be falsified (Crotty, 1998b; Lincoln et al., 2000). Post-positivist knowledge claims are modest and represent probabilities about phenomena in specific contexts. Data can include the accurate representation of

interpreters' views of reality, meanings and experiences (Bronowski, 1956). This contrasts with positivist claims about generalizable universal laws that are verified with phenomena that are perceived through the senses (Comte, 1830-1842).

## **Sampling and Recruitment**

### *Inclusion and Exclusion Criteria*

Residents of nursing homes in the Calgary Health Region were eligible to participate in the study if they had been diagnosed with Alzheimer disease, vascular dementia, or mixed dementia; were able to walk with or without a walking aid; were able to put food into their mouths and swallow; were in the middle stage of dementia as measured by a score of 5 or 6 on the Global Deterioration Scale (Reisberg et al., 1982); lived in the nursing home for at least one month to allow time for settling into the facility; and received regular visits from their authorized representatives who made health care decisions on their behalf.

Residents were ineligible to participate in the study if they had a diagnosis of Lewy body dementia (which progresses unpredictably with episodes of functional decline and functional improvement); had a diagnosis of frontotemporal dementia (which does not have a well described pattern of functional decline); lacked an authorized representative to provide informed consent on their behalf; or expressed dissent in relation to participating in an interview.

### *Sample size*

The sample was drawn from a circumscribed population of residents living in nursing homes within the Calgary Health Region. This clearly defined population allows for a comparison of some characteristics of the sample with the population. The sample size was calculated to estimate a proportion with a specified margin of error and 95% confidence. The formula for the confidence interval of an estimated proportion, using a large-sample Gaussian approximation, is:

$$CI = p \pm 1.96 \sqrt{[p (1 - p) / n]}$$

Based on the clinical experience of the researcher and on the findings of Perrault et al. (2002), it was assumed that 50% of the sample would experience functional decline over the course of the year of data collection. The value 50% also yields a confidence interval with the largest width (i.e., a conservative interval). The margin of error was specified to be  $\pm 10\%$ . Given these assumptions the sample size is calculated as:

$$0.1 = 1.96 \sqrt{[0.5 (1 - 0.5) / n]}$$

By solving for n the required sample size was calculated to be 96 residents.

### *Recruitment*

Appointments were made with senior administrators of nursing homes in the Calgary Health Region to discuss their organizations' participation in this study. Copies of the

research protocol were provided to assist them in assessing the organizational impact of the work. Administrators indicated their agreement for the research to proceed in their nursing homes by signing a “Departmental Approvals Form”, which is part of the application for scientific, administrative, and ethical review of health research at the University of Calgary.

Due to the vulnerability of prospective research participants, several ethical considerations were integrated into the recruitment process. Research involving people with Alzheimer disease raises the ethical issue of competence to provide informed consent (Slaughter et al., 2007). For those who lack capacity to provide informed consent on their own behalf, informed consent was obtained from “authorized representatives who are acting in the interests of the potential subjects and are not influenced by conflict of interest” (Tri-council, 2003, p. 2.9). According to the hierarchy of substitute decision-makers listed in the Tri-council policy statement, first priority was given to court-appointed substitute decision-makers, which in Alberta include agents named in personal directives (2003) and legal guardians appointed under the Dependent Adults Act (2003). If a person was unable to give consent and had no named agent or legal guardian then decision-making authority fell to a spouse or to other family members (Scott et al., 2003).

Residents in this study were not able to provide informed consent to their participation due to the stage of their dementia; therefore informed consent was sought from the legal guardian, the agent named in a personal directive, or the next-of-kin who normally made

health care decisions on their behalf. Once informed consent was obtained from these authorized representatives, assent (cooperation) of residents to participate in the study was assessed during a semi-structured interview at the time of recruitment.

Assent has been variously defined as: ‘the agreement to participate in research based upon less than full understanding’ (Keyserlingk et al., 1995, p. 340); the initial and ongoing willingness of the participants themselves to participate (Brodaty et al., 1999); and a subject’s affirmative agreement to participate in research (Cahill et al., 2000). Dissent has been equated with refusal to participate even when the proxy provides consent (Cohen-Mansfield, 2003). Assent (or dissent) may be expressed clearly and verbally, or it may be inferred when an individual co-operates (or not) with the research process (Dresser, 2001). Objections of people with impaired capacity related to dementia will typically be expressed indirectly by indications of frustration, discomfort, unhappiness or passivity (Slaughter et al., 2007, p. 32).

In this study residents’ participation in the interview served as the indicator of their assent to participate in the study. Dissent to participate in an interview resulted in the researcher discontinuing the assessment that day and attempting to engage the resident in conversation later that same week. If the person dissented a second time, then the resident was excluded from the study.

With the approval of senior nursing home administrators, nursing unit managers were approached to identify residents who met the study inclusion criteria. To protect their privacy, all initial contacts with residents and their authorized representatives were made through the nursing home staff. Authorized representatives were introduced to the study by a nursing home staff member using a standard script: “A research project sponsored by the University of Calgary is taking place here. The research is about how people are able to do basic self care activities. Anyone with memory problems who can still walk and eat independently is invited to participate. Would you be willing to have a nurse researcher give you a call to tell you about the study and to see if you would be willing to have your family member included in the study? (*If yes*) May I give your name and phone number to this researcher? (*Whether yes or no*) Thank you.”

Those authorized representatives agreeing to speak to the researcher were contacted by telephone to receive details of the study and to have their questions answered. If the authorized representative agreed to the resident’s participation, then the researcher obtained written informed consent (Appendix 1) by fax, by e-mail, by visiting the authorized representative at home, or by meeting the authorized representative at the nursing home where the resident lived. Both the authorized representative and the researcher received a copy of the signed consent form and a copy was filed on the resident’s health record. Once written informed consent was obtained, an interview with the authorized representative ensued immediately to obtain background information that would inform the initial interview with the resident.

Eligibility of residents for the study was assessed during the researcher's first contact with the authorized representative and the resident. This was accomplished by: 1) speaking with authorized representatives to obtain informed consent, 2) reviewing health records to confirm a diagnosis of Alzheimer disease, vascular dementia or mixed dementia, 3) interviewing residents to assess their assent, 4) administering a dementia staging instrument to ensure that the residents were in the middle stage of dementia, and 5) verifying that residents were able to walk and feed themselves.

### **Data Collection**

Both resident-specific and facility-specific data were collected using a range of data collection methods. Resident-specific data included baseline data gathered through interviews, observations, and health record reviews; and longitudinal data gathered repeatedly through observations and health record reviews. Facility-specific data were collected at the end of the study through observations and interviews.

#### *Resident-Specific Data*

Resident-specific baseline data were collected during initial interviews with authorized representatives (Appendix 2), initial interviews with residents, reviews of residents' health records (Appendix 3), and observations of residents walking and eating a meal. Data included date of birth, sex, education, list of comorbidities, score on the Charlson Comorbidity Index (Charlson et al., 1987), score on the revised Charlson Comorbidity

Index (Bravo et al., 2002), specific dementia diagnosis, date and score of the most recent Mini-Mental State Examination (Folstein et al., 1975), total score on the Global Deterioration Scale (Reisberg et al., 1982), date of admission to the nursing home, list of all drugs administered at the time of recruitment, use of a cognitive enhancer drug (Donepezil, Galantamine, Rivastigmine, or Memantine), use of a neuroleptic drug, use of a benzodiazepine drug, use of an antidepressant drug, and whether or not the resident was independent in walking and eating.

Resident-specific time-varying covariates were gathered every two weeks at the time of resident observations. These included the introduction or discontinuation of any drugs and relocation (between rooms, between nursing units, between nursing homes, or to hospital).

#### Global Deterioration Scale (GDS)

The Global Deterioration Scale was used to identify the stage of dementia for resident participants and to assess their assent to participate in the study (Reisberg et al., 1982; Reisberg et al., 1997) (Appendix 4). This instrument consists of five seven-point axes: concentration, recent memory, past memory, orientation and functioning/self-care. The five axes are averaged for a total individual GDS score out of seven. The GDS has been demonstrated to reliably identify the stage of Alzheimer disease in several studies conducted in various settings with inter-rater reliability coefficients ranging from 0.82 to 0.97 (Foster, et al., 1988; Gottlieb et al., 1988). Concurrent validity of the seven GDS

stages has been supported by studies which have shown robust relationships with a variety of other measures (Johansson et al., 1991; Reisberg et al., 1988c). Specific content validity of the GDS has been supported in a study employing principal components analysis (Overall et al., 1990), and the optimal weighting of the GDS clinical descriptions has been supported (Reisberg et al., 1989). However, evidence that functional impairment occurred earlier than the GDS predicted it would has led some researchers to question the hierarchical nature of the items in the instrument (Eisdorfer et al., 1992).

Initial face-to-face contact with residents involved semi-structured interviews which integrated items from the GDS. Typically the interview began with a discussion about the distant past such as the resident's birthplace, parents, and past employment (axis 3). Then the interview centred on orientation to people (name of spouse and children) and orientation to time (axis 4). The interview then moved to more recent memories with a discussion of the merits of their current living environment, their most recent meal, and the current Prime Minister (axis 2). After rapport had been established, the interview ended with the "game" or "puzzle" of either counting backwards from ten to zero for the most cognitively impaired residents, to completing serial 7 subtractions for the most cognitively intact residents (axis 1). Data pertaining to personal care (ability to be continent and to dress) were collected either from the health record or from the nurse aide working with the resident that day. Residents who dissented to participate in the interview with the researcher were re-approached later the same week. If they declined a

second time then they were assessed as dissenting to participate in the research and were not reapproached.

#### Charlson Comorbidity Index

Residents often had coexisting medical problems listed in their health records which had the potential to contribute to excess disability. The number and severity of diagnoses in addition to the primary dementia diagnosis were classified using the Charlson Comorbidity Index (Charlson et al., 1987). This standardized index was developed to predict mortality on acute medical units and is among the most widely used of methods to characterize the comorbidity of an individual. The Charlson Comorbidity Index is derived by summing the scores assigned to 19 weighted medical conditions. Its predictive validity was originally evaluated with respect to short-term and long-term mortality for medical patients and breast cancer patients (Charlson et al., 1987) and later with respect to functional decline in nursing home residents (Bravo et al., 2002). Comorbidities listed on each resident's health record at baseline were coded using the Charlson Comorbidity Index (Appendix 5).

#### Revised Charlson Comorbidity Index

A revised version of the Charlson Comorbidity Index was recently developed to predict the functional decline of people living in long-term care settings (Bravo et al., 2002). The revised index adds three comorbidities (valvular disease, hearing disability, and urinary problems) to the original list of 19, deletes 13 comorbidities, and adjusts the weighting of

the remaining nine. This revision to the index is reported to improve upon its prognostic accuracy in predicting functional decline (Bravo et al., 2002).

The revised index appears to be particularly relevant in this study which focuses on a decline in function over time in a long-term care population, because, as mentioned previously, the revised index was developed precisely for the purpose of predicting the functional decline of people living in long-term care settings. Comorbidities listed on each resident's health record at baseline were coded using this revised version of the Charlson Comorbidity Index (Appendix 6).

#### Mini-Mental State Examination (MMSE)

Mini-Mental State Examination scores were present on all of the residents' health records (Folstein et al., 1975). This, the most familiar and widely used cognitive assessment instrument world-wide, was originally developed as a brief cognitive assessment to measure changes in the mental functioning of older adults with psychiatric diagnoses: it was not intended to be used for the diagnosis of dementia (Folstein et al., 1975; Tombaugh et al., 1996; Wind et al., 1997). The MMSE is a 17-item rating scale with scores ranging from 0 (severe cognitive impairment) to 30 (no cognitive impairment). Cognitive domains included in the instrument are orientation, registration, short-term memory, attention, calculation, language and visual construction. In view of the extensive use of the MMSE in the discourse of health care professionals MMSE scores were abstracted from participating residents' health records to characterize the sample.

However the MMSE scores were not included in the analysis as a potential predictor variable because these data were out of date and the MMSE was not administered again at baseline to bring them up-to-date.

The psychometric properties of the MMSE have been documented extensively (Lopez et al., 2005; Tombaugh et al., 1992, 1996). Reliability testing has included both internal consistency and test-retest reliability. Internal consistency of the MMSE has been variously assessed to range from 0.54 to 0.96 using Cronbach alpha coefficients (Foreman, 1987; Holzer et al., 1984; Jorm et al., 1988; Tombaugh et al., 1996). In summarizing the test-retest reliability coefficients for the MMSE from 14 studies, Tombaugh et al. (1992) reported that the coefficients ranged from 0.80 to 0.95.

Evaluation of the validity of the MMSE includes estimates of sensitivity and specificity in addition to correlations with other measures of cognitive function. The sensitivity and specificity of an instrument varies with the cut-off score used to discriminate between different levels of impairment. In a broad range of populations using the cut-off score of 23 as recommended by Folstein et al. (1975), sensitivity or the ability to correctly identify individuals as cognitively impaired, ranged from 100% to 21% (Tombaugh et al., 1992). Sensitivity in the neurology and psychiatry populations was particularly low (21% to 76%) and this was thought to be due to the insensitivity of the MMSE to right hemisphere damage and to language impairment. The probability of obtaining higher levels of sensitivity increased as the level of impairment in the sample increased. The specificity

of the MMSE, or the ability of the MMSE to correctly identify individuals as cognitively intact, ranged from 62%, for those without a clinical diagnosis, to 46% for those with some psychiatric condition (Tombaugh et al, 1992).

The correct classification of an individual as cognitively impaired or cognitively intact is highly dependent on the age and education level of the individual, regardless of the cut-off score. This was demonstrated in a study in which the sensitivity of the MMSE to detect Alzheimer's disease was plotted against the probability of a false positive (1-sensitivity) (Tombaugh et al., 1996). Then the sample was stratified according to age (65 to 79 and 80 to 89) and according to education level (0 to 8 years and 9+ years). Using an Alzheimer's disease diagnosis by a consensus of physicians and neuropsychologists as the gold standard, it was found that approximately 90% of those in either age group, with nine or more years of education, were correctly classified as cognitively intact with the MMSE using 23 as the cut-off score; while only 74% in the younger group and 51 % in the older group, with less than nine years of education, were correctly classified as cognitively intact (Tombaugh et al., 1996).

In Tombaugh et al.'s (1992) comprehensive review of the psychometric properties of the MMSE, numerous studies were reported supporting the construct validity of the instrument. The MMSE correlated with the other cognitive screening tests (0.66 to 0.93); with intelligence and memory tests (0.66 to 0.78); with neuropsychological tests; with activity of daily living measures (0.40 to 0.75); and with plaque counts on post-mortem

histopathological findings (-0.70). Furthermore, evidence from numerous longitudinal studies, which demonstrate declining MMSE scores for people with Alzheimer's disease over time, contributes to the construct validity of the MMSE (Clark et al., 1999; Frisoni et al., 1995; Mendiondo et al., 2000; Pernecky et al., 2006).

#### *Resident-Specific Longitudinal Data*

The ability of nursing home residents to walk and to eat was observed biweekly by the researcher for 12 months. To make the assessment of walking and eating ability as acceptable as possible for the residents, observations were integrated into the context of their daily living situation rather than framing the assessment as a testing situation. Therefore residents were observed as they entered or exited the dining room and as they ate their meals. After each observation of walking, which took approximately 15 seconds, residents' walking abilities (either maintained or lost) were recorded on an observational flowsheet (Appendix 7). After each observation of eating, which took between 30 seconds to five minutes, residents' eating abilities were recorded on the observational flowsheet as maintained, requiring some physical or verbal prompting, or requiring physical assistance. Most of the time associated with the observations involved travelling to the nursing home and locating the resident. Any observed functional loss that was sustained over three consecutive observations was validated during a subsequent interview with the authorized representative and a staff member.

If residents were absent when an observation was scheduled (e.g., if the resident went out with family for a meal), then they were observed on another occasion within one or two days of the attempted observation. If residents were hospitalized at the time an observation was scheduled, then their hospital health records were reviewed to determine their walking and eating status on that day. The acute care nursing flowsheets provided a shift-to-shift record of these activities of daily living.

After three consecutive observations of functional loss, authorized representatives and nursing staff were interviewed using a semi-structured interview guide (Appendix 8). While informed consent had been obtained from authorized representatives during the recruitment process, informed consent was obtained from nursing staff just prior to interviews with them (Appendix 9). An audio-recorded telephone interview was conducted with the authorized representative, while a face-to-face interview was conducted in a private staff space with a professional nursing staff member who knew the resident well. To maximize the likelihood of staff participation in the interviews, fieldnotes were taken during staff interviews rather than audio-recording them. Interview questions centred on the functional changes that they may have noticed in the resident, reasons that they attributed to the functional changes, and any actions that they had taken, or were aware of being taken, in response to the functional changes.

When a change in functional ability was observed, the health record was reviewed using a case report form (Appendix 10) with special attention given to new events that occurred

the week before, concurrently with, or three weeks after the observed change in function. The abstracted data included new symptoms, investigations, referrals and associated consultation reports, diagnoses, changes in drugs, environmental changes and other interventions.

#### *Facility-Specific Environmental Data*

One year after the study commenced data were collected on the physical and social environments of the participating nursing homes by observation and during semi-structured interviews with the nursing home managers. Written informed consent was obtained prior to any interviews with the managers (Appendix 11). Data collected during these interviews included day shift staffing patterns, the type and availability of dementia education provided to staff, profit status of the nursing home, and the characteristics of the policies and practices regarding the use of the environment.

To generate facility staff-to-resident ratios, data were gathered on the number of residents who were served and the number of full-time equivalents of the staff members of various categories who provided service during the day shift including: registered nurses, licensed practical nurses, nurse aides, recreation therapists and assistants, occupational therapists and assistants, physical therapists and assistants, and volunteer coordinators.

### Professional Environmental Assessment Protocol (PEAP)

To further characterize the features of the environments where residents in the sample lived, the Professional Environmental Assessment Protocol was used to measure the quality of the care centre environments. The PEAP was developed to provide a standardized method for the expert evaluation of special care units in nursing homes for people with dementia (Norris-Baker et al., 1999) (Appendix 12). It originated through an inductive process defining how aspects of environmental design can support a relatively small number of human needs (Lawton et al., 2000). The PEAP provides a global assessment of the quality of dementia care environments for use by person-environment researchers and designers on nine dimensions deemed to be therapeutic for people with dementia: awareness and orientation, safety and security, provision of privacy, regulation of stimulation, quality of stimulation, support of functional abilities, opportunities for personal control, facilitation of social contact, and continuity of the self with the past through personal and familiar objects. It involves a subjective evaluation of the physical and social environment, on a 13-point scale for each dimension (Weisman et al., 1996). To assist with scoring the instrument, detailed descriptions are provided for each of five anchors (unusually limited support, low support, moderate support, high support, and exceptionally high support) along the continuum from 1 to 13.

Inter-rater reliability for the PEAP was assessed in 20 special care units using three methods (Norris-Baker et al., 1999). Percentage agreement ranged from 91.7% for safety and security to 58.3% for facilitation of social contact. Spearman's rho ranged from 0.88

for continuity of self to 0.69 for provision of privacy. Kappas ranged from 0.85 for continuity of self to 0.69 for facilitation of social contact. Thus all PEAP dimensions have demonstrated good or very good potential for inter-rater reliability (Norris-Baker et al., 1999).

Validity of the PEAP was demonstrated in two studies (Lawton et al., 2000; Morgan et al., 2004). A correlation (0.89) of PEAP total scores with the more established Therapeutic Environment Screening Scale (Sloane et al., 1997) provided evidence for criterion-related validity (Lawton et al., 2000). Correlations among the PEAP dimensions ranged from 0.45 to 0.85 (median, 0.64) suggesting that quality seems to have been defined by the raters as a general feature of the environment rather than a collection of distinct features (Lawton et al., 2000). This conclusion was also supported with a principal components analysis which generated a single factor structure for the nine PEAP dimension ratings accounting for 67% of the total variance (Lawton et al., 2000).

In a comparison of rural Canadian nursing homes the PEAP discriminated between special care units and integrated facilities (Morgan et al., 2004). Using the 13 point scale, eight special care units had a significantly higher mean summary score on the PEAP ( $M=76.6$ ,  $SD=17.2$ ) compared with eight integrated facility units ( $M=55.3$ ,  $SD=12.3$ ),  $F(1,14)=8.2$ ,  $p<.05$ , suggesting that the special care units were more supportive environments.

A standardized PEAP questionnaire guided the semi-structured interviews with the managers (Appendix 12). Drawing on data collected from observations of the social and physical environment over the course of the year, and on the data elicited during the manager interviews about the policies and practices on the use of the environment, total PEAP scores were calculated immediately following each manager interview.

## **Data Analysis**

### *Data Entry and Data Accuracy*

Baseline and longitudinal data were entered into a STATA 10 (StataCorp, 2007, College Station, TX: Stata Corporation) database directly from the collection forms. All statistical analyses were completed using STATA 10. To assess the accuracy of the data entry, at the end of the data collection period the raw data corresponding to 24 residents (20 percent of the data) were visually compared with data entered into the STATA spreadsheet. Distributions of all variables were plotted to check that the ranges fell within expected values and to assess for outlier data.

All recorded interviews with authorized representatives were transcribed verbatim. The interview transcripts were checked against audio files to assess the accuracy of the transcripts and any inaccuracies were corrected. Fieldnotes written by hand during the staff interviews were typewritten within 24 hours of the interviews being conducted.

*Outcome variables*

The target outcomes or disability events were loss of ability to walk, loss of ability to eat, or either. Loss of ability to walk was defined as using a wheelchair to mobilize or staying in bed and not mobilizing at all. Walking independently could include the use of a walking aide such as a cane or walker, and could include the need for assistance to stand from a sitting position. The second target event, loss of ability to eat, was defined as being fed by another person or failing to put food into one's mouth and to swallow. Eating independently could include assistance with setting up the meal (e.g. cutting food or opening packages), and could include verbal prompts to eat. A composite functional outcome was constructed by considering the first occurrence of either of the two outcomes: a loss of the ability to walk and a loss of the ability to eat.

Excess disability, or disability other than that attributable to dementia, was operationally defined as either functional loss which is subsequently regained; or functional loss which is not regained but for which both staff and family members attribute the loss to something other than dementia. There could be other ways to operationalize the construct of excess disability. For example, the nurse researcher could have made a clinical judgement regarding the presence or absence of excess disability following a thorough clinical assessment. This option was discarded because of the significant potential for measurement and observer bias. Alternatively a panel of clinicians could have evaluated

the residents to reach a consensus regarding the presence or absence of excess disability. This option was discarded because of the limited resources available to conduct the study.

Separate analyses were completed for six different definitions of a disability event: at least one observation of 1) a loss of ability to walk for any reason, 2) a loss of ability to eat for any reason, 3) a loss of either the ability to walk or the ability to eat for any reason, 4) a loss of the ability to walk due to excess disability, 5) a loss of the ability to eat due to excess disability, and 6) a loss of the ability to walk or the ability to eat due to excess disability. The definitions for each of these events or outcomes are summarized in Table 3.1. This study focused only on the first instance of functional loss. It did not account for repeated events which could have happened if residents recovered their ability to walk or to eat.

**Table 3.1 Definitions of Disability Outcomes**

Outcome	All-Cause Disability	Excess Disability
Walking	- Loss of ability to walk for any reason (i.e., using a wheelchair to mobilize to the dining room or staying in bed)	- loss of the ability to walk which is later regained or a loss which is attributed to something other than dementia by both staff and family members
Eating	- Loss of ability to eat for any reason (i.e., being fed by another person or not eating at mealtime)	- loss of the ability to eat which is later regained or a loss which is attributed to something other than dementia by both staff and family members

Composite (walking & eating)	- Loss of ability to walk or to eat for any reason (as defined above), whichever occurs first. These losses may occur simultaneously.	- Loss of ability to walk or to eat as defined above, whichever occurs first (i.e., a loss which is later regained or a loss which is attributed to something other than dementia by both staff and family members) These losses may occur simultaneously.
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### *Predictor Variables*

Resident-specific predictor variables included resident characteristics which were gathered at baseline, and time varying covariates which were gathered every two weeks. Facility-specific predictor variables included total PEAP scores, care centre profit status, any staff dementia education offered during the previous year (yes or no), care centre bed number (nursing home beds only), and staff-to-resident ratios. These ratios were calculated based on the number of full time equivalent staff members on the day shift for a particular category of staff, divided by the number of residents served by that category of staff. Staff categories included professional nurses (registered nurses and licensed practical nurses), nurse aides, and rehabilitation staff (physiotherapists, occupational therapists, recreation therapists, their assistants, and volunteer coordination staff members).

In this study each of the measured variables were converted into binary variables by grouping the residents into low-risk and high-risk groups. Univariate analyses were

performed on all predictor variables to assess ranges, means, and standard deviations.

Preliminary analysis of the measured predictor variables involved an exploration of the four quartile groups using Kaplan-Meier (product-limit) plots to identify any separation in the subgroups in relation to the cumulative proportion of events over time.

Age was dichotomized using the pre-specified standard definition of “oldest old”,  $\geq 85$ , as the cut point (Rosenwaik, 1985). Dichotomization by sex was based on biological reasoning. Education was simply dichotomized according to those who did or did not complete high school (grade 12). Scores on the Charlson Comorbidity Index and the revised Charlson Comorbidity Index were compared using quartile plots to determine the best separation of the four sub-groups for each variable. The median cut point for the Charlson Comorbidity Index provided the best separation between sub-groups. Dementia diagnoses were dichotomized by grouping those with Alzheimer disease and mixed dementia together since mixed dementia, by definition, includes Alzheimer disease. Vascular dementia and unspecified dementia were grouped together. Scores on the Global Deterioration Scale were explored with quartile plots and subsequently dichotomized using the median score, 5.4, as the cut point. Following an assessment of quartile plots, duration of admission in the nursing home prior to the first observation in the study was dichotomized to separate the upper quartile from the lower three quartiles. This cut point was 582 days.

Cognitive enhancer drugs including the three cholinesterase inhibitors and the N-methyl-D-aspartate inhibitor were included in the analysis because of reports that they can have a modest benefit of maintaining the functional ability of people with moderate to severe Alzheimer disease (Burns et al., 2004; Feldman et al., 2001; 2003; Kurz et al., 2004; Reisberg et al., 2003; Tariot et al., 2004; Winblad et al., 2006). Three categories of psychotropic drugs (neuroleptics, benzodiazepines and antidepressants) were included as potential predictor variables in the analysis because they are widely used to treat behavioural challenges in older adults with dementia despite their known contribution to adverse events (Ebly et al., 1997). The combined use of neuroleptic, benzodiazepine, and antidepressant drugs at baseline was assessed by generating a 'psychotropic' variable to include these three drug categories. Residents were coded 1 according to whether they were taking a cognitive enhancer or psychotropic drug at baseline, and zero otherwise. The same coding scheme was used for any neuroleptic, benzodiazepine, and antidepressant drugs taken at baseline.

Scores on the Professional Environmental Assessment Protocol underwent a preliminary assessment of quartile plots and were then dichotomized according to the median score, 79. Profit status was dichotomized by grouping the public and voluntary, non-profit nursing homes together to compare them with the private, for-profit nursing homes. Staff dementia education data were dichotomized according to whether or not dementia education of any kind had been offered to staff during the past year of data collection. Based on exploratory Kaplan-Meier plots of bed number quartiles, care centre bed

numbers were dichotomized to separate the lower quartile with the upper three quartiles. This cut point was 60. Likewise, Kaplan-Meier plots of quartiles for all three categories of staff-to-resident ratio data were the basis for the decision to dichotomize the staff-to-resident ratio variables as close to the median values as possible.

#### *Event-Free Survival Analysis*

Event-free survival analysis is a collection of methods which aim to describe whether and when events occur and to explain why certain events do or do not occur (Allison, 2004; Singer et al., 2003). Two types of survival analyses were performed using the Kaplan-Meier and Cox proportional hazards regression methods. The Kaplan-Meier method was used to describe the continuous-time event data (i.e. the proportion of residents with a loss of ability as a function of time) by estimating failure functions. The Cox regression method was used to test whether the risk of functional loss varied systematically with potential predictor variables.

Event-free survival analysis incorporates three methodological features which must be clearly defined: a target event, the time of origin for the analysis, and a metric for recording elapsed time (Allison, 2004; Singer et al., 2003). The target events or outcomes have been defined above. The time of origin for the analysis began when data collection began: that is on the day of the first baseline observation when the resident was walking and eating independently. Baseline was defined as three consecutive observations of the resident walking and eating independently. Time was specified in days rather than in

weeks. This smaller time interval enabled the exploitation of a more powerful set of continuous-time survival methods than would be possible with wider time intervals requiring the use of simpler discrete-time survival methods (Singer et al., 2003).

Censoring was determined in advance, by design, to be at the end of one year of observation when data collection ended. It was expected that some residents would die before an event occurred and before the end of the study. Residents who died under these circumstances were likely to have experienced an event had they lived, and were more like residents who had experienced a functional loss than residents who survived to the end of the study and were censored. For this reason residents who died were coded as having had an irreversible event rather than being censored. A sensitivity analysis was conducted to assess the effect of coding deaths as events compared with coding deaths as censored. The results of log rank tests for equality of survivor functions were compared for both coding strategies.

#### Kaplan-Meier Method

The Kaplan-Meier estimate of the failure function was computed. The failure function is  $1 -$  the survivor function. The survivor function,  $S(t_{ij})$ , is defined as the probability for resident  $i$  at time  $t_j$  that his or her event time,  $T_i$ , will exceed  $t_j$ .

$$S(t_{ij}) = \Pr[T_i > t_j]$$

The cumulative hazard function,  $H(t_{ij})$ , assesses, at each point in time, the total amount of accumulated risk that resident  $i$  has faced from the beginning of the study until  $t_j$ .

The cumulative hazard function is related to the survivor function,  $S(t_{ij})$ , by the equation:

$$H(t_{ij}) = -\ln[S(t_{ij})].$$

The cumulative hazard is an integral of the instantaneous hazard function,  $h(t_{ij})$ . The instantaneous hazard is the probability or risk of a loss of function occurring for resident  $i$  in a small time interval at time  $t_j$ , given that the resident did not have the functional loss before that time. A steep rise in the hazard curve indicates a high risk of functional loss, while a slight rise indicates a low risk.

Log-rank tests were used to compare the survival distributions of different groups defined by the predictor variables.

#### Cox Proportional Hazards Regression Method

The Cox regression method calculates regression coefficients for the predictor variables, the exponents of which are hazard ratios. Cox regression is sensitive to ties: events for two or more people occurring at the same time. Truly continuous data should contain no ties however because of rounding, most datasets, including the dataset for this study, do contain ties. In this study the Breslow method of approximation for handling ties was used which assumes that the observed ties happened sequentially.

Cox regression analysis assumes proportional hazards meaning that the ratio between two hazards is the same (constant) at all follow-up time points. When the proportional hazards assumption is not met, this implies that the hazard ratio varies over time. Computing a single hazard ratio in this case essentially yields an ‘average’ hazard ratio. The proportional hazards assumption was evaluated in two ways. First the proportional hazard assumption was assessed by examining the set of Schoenfeld residuals for each independent variable. Schoenfeld residuals compare the observed and expected values of predictor variables. If there is no evidence against the null hypothesis of proportional hazards, then these residuals will be unrelated to time (Singer et al., 2003). Secondly, the complementary log-log plots were visually inspected to see if the curves for each of the subgroups of the dichotomized predictor variables were parallel (no evidence against the proportional hazards assumption) or if there was a funneling effect over time (evidence against the proportional hazards assumption).

Resident-specific and facility-specific variables were included in a series of bivariate Cox regression models to assess the influence of each of the 19 potential predictor variables on each of the six outcomes. The 12 resident-specific predictor variables were age, sex, education, Charlson Comorbidity Index, type of dementia, and stage of dementia, duration of stay in the nursing home, cognitive enhancers, neuroleptics, benzodiazepines, antidepressants, and a combined variable, psychotropic drugs. The seven facility-specific variables were the Professional Environmental Assessment Protocol scores, nursing home

profit status, staff dementia education, size of nursing home, professional nurse-to-resident ratio, nurse aide-to-resident ratio, and rehabilitation staff-to-resident ratio.

A priori there was a hypothesized relationship between stage of dementia and disability. Cox proportional hazards regression models were constructed to assess for the potential effect modification or confounding of this relationship by including all of the variables that had p-values of  $< 0.20$  in the bivariate regression analyses (Hosmer et al., 2000). A strategy of backwards elimination of variables was used to reduce the model to its most parsimonious form. The Type 1 error rate was set at 0.05 for all tests of significance.

To minimize the number of statistical tests, effect modification was assessed using the likelihood ratio test to compare the saturated model with all of the interaction terms, to the nested model without any interaction terms (Ramsey et al., 2002). The likelihood ratio test is an omnibus test which is useful in minimizing the number of statistical tests performed. Confounding is typically accomplished by comparing the crude and the adjusted estimates of the measure of association to see if the difference between the estimates exceeds 10% to 20% (Aschengrau et al., 2003). For the purpose of this study confounding covariates were identified when the inclusion of the variable changed the magnitude of the association of the stage of dementia variable with the disability outcome by 15% or more (Maldonado et al., 1993; Mickey et al., 1989).

### Time-varying Covariate Analysis

It is possible that the value of some predictors varied over the year of follow-up. With event-free survival analysis it is possible to assess the influence of predictor variables for only the duration of the time that they influence the outcome. For example drugs that were administered to a resident at the beginning of the study are assumed to be administered to the resident for the duration of the study with fixed time analysis. Misclassification error results if the drugs are only administered for a portion of the study however time-varying covariate analysis is able to correct this misclassification. Time-varying covariate analysis was carried out for all four of the drug variables.

### *Attributions and Actions*

Quantitative content analysis of the transcripts from authorized representative interviews, and fieldnotes from staff interviews, was completed to apply meaning to the information collected and to help identify patterns in the text (Morgan, 1993; Wilkinson, 2003). Each interview was the unit of analysis, however in a few cases more than one functional loss was discussed within a single interview. In these instances discussion pertaining to each functional loss was the unit of analysis. Text from the transcripts and fieldnotes was categorized a priori into two categories based on the interview questions (Stemler, 2001; Wilkinson et al., 2003) (Appendix 8). Only those portions of the transcripts and fieldnotes were analyzed which specified attributions for the functional transitions (either to Alzheimer disease or to something else), and identified actions taken (if any) in response to the functional transitions. Counts and lists of the attributions and actions were

summarized for each type of outcome (loss of ability to walk, loss of ability to eat, or both) and for each type of informant (Morgan, 1993). Congruence between the views of the authorized representatives and the nursing staff was assessed.

### **Ethical Considerations**

The original proposal and two subsequent modifications to the proposal received ethical approval from the Conjoint Health Research Ethics Board in Calgary, Alberta (Appendix 13). A number of ethical considerations guided the conduct of the research. This was a minimal risk research study. Residents, families, staff and managers were assured that participation in the study was voluntary and that any decision to participate, or to not participate, would not affect the care that the residents received in any way. Names or other identifying information were not attached to any data. All data were rendered anonymous through the assignment of numerical codes for both the participating nursing home and the participating resident. The key for linking participant codes to resident and facility identities was available only to the researcher and her supervisor. No data were reported in any way which could identify individuals. Everyone who provided informed written consent to participate in the study received a copy of the consent form which included written details of these ethical provisions. All data were initially stored in a locked cupboard situated in a locked and security-alarm protected research office. During the latter half of the study, the data were relocated to a locked filing cabinet in the researcher's home. According to the policy of the Conjoint Health Research Ethics Board (CHREB) all study material will be archived for 12 years commencing from the time the

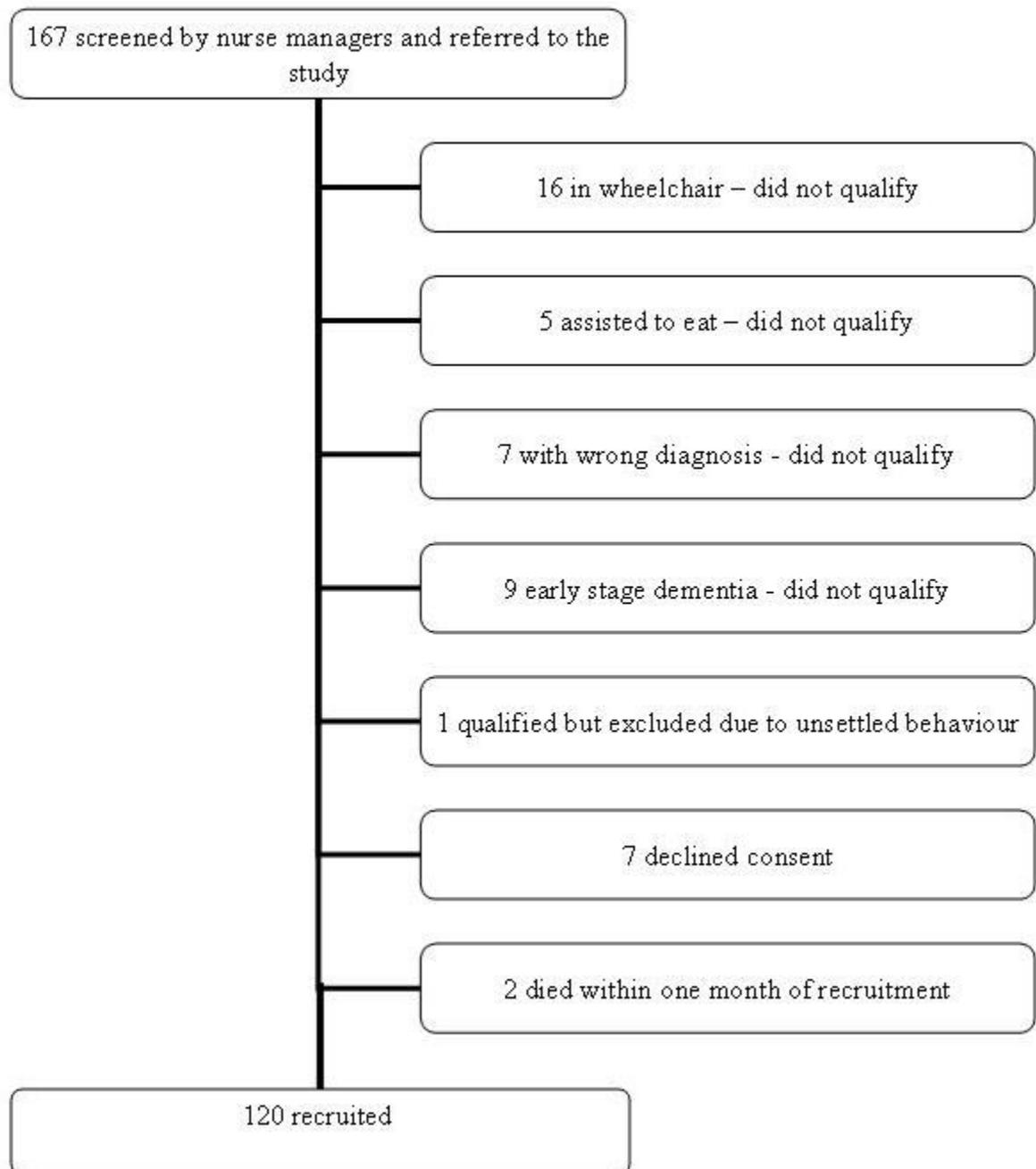
'Completion Report' is submitted to the CHREB, and then destroyed (G. Godlovitch, personal communication, July 11, 2006).

## CHAPTER 4 – RESULTS

This chapter describes the results from the two aspects of the study. First, descriptions of the recruitment process and characteristics of the sample are provided. Then, the results from content analysis of the structured interviews are presented. Both the attributions and actions in response to a loss of ability are presented in some detail. This is followed by a presentation of the findings from the observational data. Using event-free survival methods, the estimates of the incidence of disability and excess disability, and the assessments of potential predictor variables in bivariate and multivariate analyses for each of the six disability outcomes are summarized. The chapter concludes with an adjustment of the final Cox regression models using time-varying covariates.

### **Characteristics of the Sample**

From the population of residents living in nursing homes within the Calgary Health Region, a sample of 120 residents with middle stage dementia and their authorized representatives were enrolled in the study from August 2006 to March 2007. Data were gathered between August 2006 and March 2008. The residents lived in 15 nursing homes which represented a range of public, voluntary non-profit, and private for-profit facilities. The flow diagram in Figure 4.1 summarizes the results of the recruitment process. Ten residents met the inclusion and exclusion criteria but were not included in the sample because they: (a) declined to consent (n=7), (b) died within a month of admission to the study (n=2), or (c) were relocated to a more intensive behavioural care setting (n=1).

**Figure 4.1 Recruitment process flowchart**

The final sample size exceeded the calculated sample size of 96 deemed necessary for sufficient statistical power. Because of comorbidities, general frailty, and advanced age of the participants, it was decided that a larger sample size would help to compensate for sample attrition due to death. In fact, during the course of the year of observation, there were only six occurrences of death prior to a loss of function. There was no loss to follow-up.

The demographic characteristics of the sample are summarized in Table 4.1 below. The 94 women and 26 men in the study had a mean age of 86 years (SD = 6.5 years; range 71 to 98). Forty-four (37%) had completed high school. Fifty-seven (47%) were diagnosed with Alzheimer disease, 10 (8%) with vascular dementia, 38 (32%) with mixed dementia, and 15 (13%) with an unspecified dementia. Their median Charlson Comorbidity Index score was 1.5 (range 0 to 9), and their mean Mini-Mental State Examination score was 15.9 (SD = 4.5; range 4 to 25) indicating that the majority of the sample had significant cognitive impairment. All residents were able to walk, were able to feed themselves independently, and had mean Global Deterioration Scale scores ranging from 4.8 to 6.4 (median = 5.6), suggesting middle stage dementia. At the time of recruitment residents had lived in their current nursing home for a median of 7 months (range 0.2 to 149.9). At the beginning of the study 47 (39%) residents were taking a cognitive enhancer: either a cholinesterase inhibitor or an N-methyl-D-aspartate (NMDA) antagonist. Other psychotropic drugs taken at baseline included neuroleptics 50 (42%), benzodiazepines 21 (18%), and antidepressants 36 (30%). Combining the neuroleptic, benzodiazepine, and

antidepressant drug categories into one variable, psychotropic drugs, 78 (65%) of the residents were taking at least one psychotropic.

**Table 4.1 Characteristics of residents in the sample**

Characteristic	mean (SD)	median	range
Age (years)	86 (6.5)		71 - 98
Charlson Comorbidity Index	-	1.5	0 - 9
Mini-Mental State Examination score	15.9 (4.5)		4 – 25
Global Deterioration Scale score	-	5.6	4.8 – 6.4
Duration of admission (days)	-	211	7 – 4497
	n (%)		
Female	94 (78)		
Grade 12 education	44 (37)		
Dementia Diagnosis			
Alzheimer disease	57 (47)		
Vascular dementia	10 (8)		
Mixed dementia	38 (32)		
Dementia unspecified	15 (13)		
Cognitive enhancer use	47 (39)		
Neuroleptic use	50 (42)		
Benzodiazepine use	21 (18)		
Antidepressant use	36 (30)		
Psychotropic use <sup>1</sup>	78 (65)		

<sup>1</sup> neuroleptics, benzodiazepines or antidepressants

Comparisons between the 120 residents in the study and the 10 residents who qualified to participate in the study but did not participate were limited by the dearth of data available for the latter. Likewise, detailed information was unavailable for the 4677 residents (range 52 – 442) living in care centres within the Calgary Health Region who comprised the population. The only information available from a regional manager was that 2919 (62%) residents in the Calgary Health Region live in for-profit nursing homes. A summary of the characteristics of the 15 care centres included in the study appears in Table 4.2.

**Table 4.2 Characteristics of care centres in the sample**

Characteristic	Sample n = 15	
	mean (SD)	range
PEAP scores	81 (20)	47 - 109
Number of beds	164 (109)	60 – 442
RN / LPN ratio	0.04 (0.02)	0.02 – 0.07
Nurse aide ratio	0.14 (0.01)	0.11 – 0.16
Rehabilitation staff ratio	0.04 (0.02)	0.01 – 0.07
	Number of beds (%)	
For-profit status	874 (37)	
Some staff dementia education	76 (63)	

**Interview Data: Attributions and Actions**

A total of 72 interviews were conducted when 30 residents were observed on three consecutive occasions to experience a loss in either the ability to walk or the ability to eat. The 36 audio-recorded interviews were conducted with legally authorized representatives who were all family members including 15 daughters, nine sons, three wives, one husband, one daughter-in-law, and one niece. The mean duration of these audio-recorded interviews was 12.6 minutes ( $SD = 7.8$ ; range: 3.1 to 37.9). The 35 face-to-face interviews with professional nursing staff members, which were not audio-recorded, were usually completed within approximately five minutes.

Interviews focused on 39 functional losses in the 30 residents: some residents experienced a loss of both the ability to walk and the ability to eat. When both abilities were lost the timing of these two losses determined whether the discussion regarding each loss was combined into one interview or separated into two. With a few exceptions, the interviews validated the researcher's observations of a loss in the ability to eat and/or walk, however two sons had not observed a loss of ability to eat when they visited between meals and brought their mothers cookies, chocolate, and potato chips. These sons had created a supportive context for eating. The snacks were appealing, the food was being offered in a social context, and the finger food was easy to manage.

### *Attributions*

Some family members found it difficult to identify an attribution when they were asked the open question: “What do you think may be causing this change in ability?” They commented, “I don’t know”, “It really baffles me”, or “I have no idea. I actually have no idea.” This occurred during 17 of the 36 interviews. Nevertheless the respondents often continued by saying, “I wonder if ...”, “I’m not sure but ...”, or “ I thought maybe it was ...” Most family members went on to identify more than one possible reason for the observed loss of ability. Staff members were somewhat more confident in their attributions. They expressed uncertainty only during seven interviews in which one resident was discussed in each interview.

At times the outcomes of actions taken in response to functional loss helped to identify an attribution. For example a son attributed his mother’s loss of ability to walk to his reduced frequency of visiting. He explained that she “seemed to perk up” after he resumed his usual visiting routine of every other day. Another son explained:

I noticed when I had lunch with her the other day that if I directed her to keep eating then she could manage it. I kinda think she forgets what she’s doing. That her attention span is reduced that much or that she’s distracted that easily, hard to say. But I don’t think it’s physical. (Family 154)

### Walking Disability

During the interviews the loss of ability to walk was discussed for 23 residents. The mean number of attributions by family members for the loss of the ability to walk was 2.6 (SD

= 1.5, range: 1 to 6) and by staff members was 1.8 (SD = 0.8, range: 1 to 4). At the 95% confidence level, there was evidence against the null hypothesis of no difference in the number of attributions between the two categories of respondents for the loss of walking ability (paired t-test:  $t = 2.17$ ,  $p\text{-value} = 0.02$ ). Family members identified significantly more reasons for the loss of ability to walk than did staff members. Attributions for the loss of ability to walk included dementia, advanced age, weakness, falls or unsteadiness, a fracture, a possible neurological event (e.g. seizure or small stroke), depression, an infection, acute illness (cancer, gangrenous foot, myelodysplasia), a non-specific decline in health, pain, use of a neuroleptic drug, wheelchair convenience, and reduced frequency of family visits. Further details regarding the number and type of attributions made by each category of respondent are summarized in Table 4.3 below.

**Table 4.3 Attributions for functional loss in walking and eating by family and staff members**

Attribution	Family members		Staff members	
	Walking n = 23	Eating n = 16	Walking n = 23	Eating n = 16
Dementia	6	9	6	10
Age	4	0	1	1
Weakness / fatigue	10	0	6	4
Falls / unsteadiness	8	0	8	0
Fracture	2	0	2	0
Possible neurological event	5	1	0	0
Depression	2	1	2	2

Infection	4	0	1	0
Declining health	4	0	4	2
Pain	4	2	8	2
Medication	2	1	1	1
Wheelchair convenience	2	0	1	0
Environment	1	2	1	2
Poor appetite	0	2	0	4
Difficulty chewing/swallowing	0	5	0	0
GI problems	0	2	0	1
Lifelong eating issues	0	0	0	3
Reduced coordination	0	2	0	0
Reduced vision	0	2	0	0

Both family and staff members attributed the loss of the ability to walk to dementia for six (26%) of the 23 residents.

### Eating Disability

Loss of the ability to eat was discussed during the interviews for 16 residents. The mean number of attributions by family members for the loss of the ability to eat was 2.0 (SD = 1.4, range: 0 to 5) and by staff members was 2.1 (SD = 1.2, range: 1 to 5). At the 95% confidence level, there was no evidence against the null hypothesis of no difference in the number of attributions between the two categories of respondents for the loss of eating ability (paired t-test:  $t = -0.25$ ,  $p\text{-value} = 0.60$ ). Attributions for the loss of the ability to

eat included dementia, age, weakness or fatigue, a possible neurological event (e.g. stroke), depression, a non-specific decline in health, pain, medications (sedative, appetite suppressant), environment (dishes cleared from table too quickly, disturbing table partner, boredom, reduced frequency of family visiting), poor appetite, difficulty chewing or swallowing, gastrointestinal problems, lifelong eating issues, reduced coordination, and reduced vision. Further details regarding the number and type of attributions made by each category of respondent are summarized in Table 4.3 above.

#### Comparison of Family and Staff Member Responses

During interviews regarding the walking disability of 23 residents, six (26%) family members and six (26%) staff members attributed the loss of the ability to walk to dementia. In contrast, during interviews regarding the eating disability of 16 residents, nine (56%) family members and ten (62%) staff members attributed the loss of eating ability to dementia. Thus both family and staff members were more likely to attribute the loss of the ability to eat to dementia (56% and 63% of attributions respectively) compared with only 26% of attributions to dementia for the loss of the ability to walk.

There was no consistent concordance in the attributions to dementia made by the family and staff members. For two residents with a loss of ability to walk both the family and the staff member attributed the disability to dementia, while for eight residents the attribution to dementia was made by one respondent but not by the other. There was somewhat more concordance in the attributions to dementia for the loss of eating ability. For six residents

both the family and the staff member agreed that the reason for the loss of ability to eat independently was dementia, while for seven residents the attribution to dementia was made by one respondent but not by the other. To assist in defining excess disability for the purpose of the regression analyses, if both the family member and the staff member agreed that the reason for a functional loss was due to something other than dementia then this event was defined as excess disability.

#### Attribution to Dementia

Fifteen family members identified dementia as a reason for a loss of either eating or walking ability. Eleven of these spontaneously offered the dementia attribution in response to an open question, while four offered the dementia attribution only after the researcher asked the closed question, “Is this because of dementia or because of something else?” Family members struggled to understand how dementia might be influencing their relatives’ *physical* functioning: “Who knows? I mean it could be the disease telling her, ah, you know, she’s forgotten how to walk” (Family 151).

“It’s a strange thing. I think they’re hungry but they don’t understand about eating. It’s like he’s day dreaming. He puts the spoon down between every bite. It’s strange. His eating habits are really weird. It’s a perception. It must be some part of the brain that’s being affected. ‘Cause he doesn’t perceive that you’re handing him something. And then he’ll say, “Oh there it is!” But even to put a sandwich, a quarter of a sandwich in his hand is quite an episode because he can see the sandwich but he doesn’t know. It’s like sitting down in the chair. He doesn’t know which way to sit” (Family 92).

I guess to a degree it’s maybe cognitive – to a degree. But I think it’s - well I know! Part of it is too that she doesn’t see very well. So I’m not sure that she knows really

what she's eating all the time. Actually I'm positive she doesn't know what she's eating all the time. She probably just decides she either likes it or doesn't like it. And then she doesn't tend to handle her utensils very well either. So I wouldn't say it was. I think it could be a portion dementia, but I think it might be physical (Family 158).

I sometimes wonder with the dementia if it's not somehow a case of forgetting how to do things. It sounds so bizarre because it's such a simple thing. Something we do so naturally. But some of the other things that she's forgotten are things that we, you know, like body function wise. You'd think you'd always remember how to do but she doesn't. So I think it could well be the dementia... Like you get her to sit on the toilet and like now what do I do kind of thing (Family 165).

There were instances in which dementia was discounted or minimized as a cause of functional decline because the family members saw no evidence of further *cognitive* decline in their relative coinciding with the *physical* decline: "Oh I would say something else at this point. I mean I don't think her mind is gone any worse" (Family 45). "So yes, that's the attribution. Not because she forgot how to walk but I think she's weak" (Family 103).

I'm not sure how to answer that. You know it could be dementia. It ah, you know, but but there's, how can I put it? She's you know, there's days when I notice that she's worse. And other days she's like she used to be ... in terms of her ability to talk and remember things (Family 142).

One daughter explained how it was difficult to say whether or not the losses she observed in her mother were due to dementia. The changes in her mother's physical abilities were not what she expected for dementia based on what she had learned from the media.

It's so different from what I imagined like Alzheimer's to be when you. I mean the only contact I had with it is movies or whatever and seeing how it was presented in the media or whatever, or reading about it in a magazine article or something. And with the dementia, like hers was so totally different from that... These people always have some kind of realization that this is happening to them. And then they have periods of normalcy. She never had that. She never had the realization that things were happening to her. So I don't know. I just sometimes wonder like is it dementia (Family 165)?

### *Actions*

Interview respondents identified a broad range of interventions that they took in response to the functional losses experienced by the residents diagnosed with dementia.

### Walking Disability

A total of 64 actions were reported by family members and 66 actions by staff members in response to the walking loss of 23 residents. The mean number of actions by family members for the loss of the ability to walk was 2.8 (SD = 2.0, range: 0 to 9) and by staff members was 2.9 (SD = 1.6, range: 0 to 5). There was no difference in the number of actions reported between the two categories of respondents for the loss of walking ability.

Actions taken in response to the loss of the ability to walk included informally communicating with involved parties such as the resident, the family, or the nurses; formally consulting a family physician, a physical therapist, an occupational therapist, or a geriatric mental health specialist; diagnostic testing; monitoring vital signs and behaviour; introducing a wheelchair (including specialized wheelchairs and seatbelts); encouraging supervised walking; limiting walking; introducing safety measures (hip

protector, fall mat, nightlight, bed sensor, moving bed closer to bathroom); providing foot care; pain interventions (analgesic, anti-inflammatory, hot pack); adjusting psychotropic and other drugs (diuretic, antibiotic, bronchodilator, erythropoetic); administering oxygen; and facilitating socialization. Further details regarding the number and type of actions identified by each category of respondent are summarized in Table 4.4.

**Table 4.4 Actions taken for functional loss in walking by family members and staff members**

Action	Family members n = 23	Staff members n = 23
Communicate	8	3
Consult MD	3	1
Consult GMHCS	1	1
Diagnostic imaging	8	5
Hospital assess & treat	3	3
Blood / urine tests	2	2
Monitor	0	5
PT/OT assess & treat	4	8
Wheelchair interventions	7	5
Encourage supervised walking	3	6
Minimize walking	1	3
Safety interventions	2	6
Foot care	4	0
Pain interventions	6	9

Psychotropic drugs	4	4
Other drugs	3	3
Oxygen	3	1
Increased socialization	2	1

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GMHCS = Geriatric Mental Health Consulting Service, OT = occupational therapist, PT = physiotherapist

Of the 46 walking events that were discussed during the interviews, 12 were attributed to dementia. Table 4.5 summarizes the number and type of actions reported for events attributed and not attributed to dementia.

**Table 4.5 Actions to respond to walking disability reported by respondents attributing and not attributing functional loss to dementia**

Action	Dementia n = 12	Not dementia n = 34
Communicate	0	11
Consult MD	1	3
Consult GMHCS	1	1
Diagnostic imaging	2	11
Hospital assess & treat	0	6
Blood / urine tests	0	4
Monitor	4	1
PT/OT assess & treat	2	10
Wheelchair interventions	3	9
Encourage supervised walking	1	8
Minimize walking	0	4

Safety interventions	4	4
Foot care	0	4
Pain interventions	1	14
Psychotropic drugs	6	2
Other drugs	1	5
Oxygen	2	2
Increased socialization	1	2

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Fewer respondents (26%) attributed a walking disability to dementia and they identified proportionately fewer actions (22%) in response to this loss compared to those who attributed the loss of the ability to walk to something other than dementia. The actions reported by those who attributed the walking disability to dementia were more often related to psychotropic drug use, safety interventions, and monitoring; while the actions reported by those who attributed the walking loss to something other than dementia were more often related to communicating, treating pain, diagnostic imaging, consulting a rehabilitation specialist, encouraging supervised walking, and arranging for a wheelchair. Thus when a loss of walking ability was attributed to excess disability the actions reported were more oriented to assessment and treatment than when the disability was attributed to dementia.

### Eating Disability

A total of 59 actions were reported by family members and 57 actions by staff members in response to the loss of eating ability of 16 residents. The mean number of actions reported by family members in relation to the loss of the ability to eat was 3.7 (SD = 2.0, range: 1 to 8) and by staff members was 3.6 (SD = 1.3, range: 2 to 6). There was no difference in the number of actions reported between the two categories of respondents for the loss of eating ability.

Actions taken in response to the loss of the ability to eat included encouraging to eat (prompting, reminding); physically assisting to eat; changing dining areas (increased supervision, reduced distraction); enhancing mealtime socialization (family visits, hired companion); modifying the environment (increasing chair height, delaying dish removal); modifying food texture (minced, pureed); adjusting dentures; supplementing meals (Resource, Ensure, Boost); offering snacks, finger food, and smaller portions; communicating with stakeholders; referring to geriatric mental health services; seeking information (surfing the internet, reading, watching other residents); adjusting psychotropic drugs, gastrointestinal drugs (appetite stimulant, peristalsis enhancer, antacid, laxative), and other drugs (analgesic, antibiotic), monitoring (weight, blood sugar, behaviour); promoting rest between meals; and increasing hydration. Further details regarding the number and type of actions identified by each category of respondent are summarized in Table 4.6.

**Table 4.6 Actions taken for functional loss in eating by family members and staff members**

Action	Family Members n = 16	Staff members n = 16
Encourage eating	12	6
Physically assist to eat	4	7
Change table to increase supervision	6	3
Enhance mealtime socialization	7	3
Change table to reduce distraction	0	2
Environmental intervention	1	1
Modify food texture & dentures	7	2
Nutritional supplement	7	8
Snacks	3	1
Finger food	1	4
Smaller portions	1	2
Stakeholder communication	3	1
GMHCS referral	1	0
Seek information	3	0
Psychotropic drugs	1	3
Gastrointestinal drugs	2	6
Other drugs	0	2
Monitor	0	3
Rest between meals	0	1
Extra fluids	0	2

Of the 32 eating events that were discussed during the interviews, 19 of the events were attributed to dementia. Table 4.7 summarizes the number and type of actions reported for events attributed and not attributed to dementia.

**Table 4.7 Actions to respond to eating disability reported by respondents attributing and not attributing functional loss to dementia**

Action	Dementia n = 19	Not dementia n = 13
Encourage eating	11	7
Physically assist to eat	7	4
Change table to increase supervision	7	2
Enhance mealtime socialization	7	3
Change table to reduce distraction	1	1
Environmental intervention	2	0
Modify food texture & dentures	5	4
Nutritional supplement	8	7
Snacks	3	1
Finger food	3	2
Smaller portions	1	2
Communication	0	4
GMHCS referral	1	0
Seek information	0	3
Psychotropic drugs	3	1
Gastrointestinal drugs	5	3
Other drugs	2	0

Monitor	0	3
Rest between meals	1	0
Extra fluids	2	0

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More respondents (59%) attributed an eating disability to dementia and they identified proportionately more actions (59%) in response to this loss of ability, compared with those who attributed the loss to excess disability. Comparing the 19 interviews in which eating disability was attributed to dementia with the 13 interviews in which disability was attributed to something other than dementia, socialization, supervision, and encouragement to eat were reported twice as often when disability was attributed to dementia. That is, these supportive interventions were reported on 25 occasions for eating disability attributed to dementia but on only 12 occasions for eating disability attributed to something other than dementia. In contrast, communication, information seeking, and monitoring were reported more often (on ten occasions) when eating disability was attributed to something other than dementia. These more vigilant types of intervention were never reported when eating disability was attributed to dementia.

#### *Functional Transitions as Processes Rather than Events*

Rather than a functional loss being clearly a defined event which occurred at a specific time, sometimes a gradual loss of ability alternating between good days and bad days was observed. The following scenarios describe the typical processes that were observed when the loss of ability eating and in walking was gradual rather than sudden.

Eating Scenario: The transition from being able to eat to an eating disability often began by taking an inordinate amount of time to eat or by eating only a small portion of a meal. This was still coded as independent eating. Residents became distracted by things such as a napkin, a package of sugar, or something taking place in the dining room such that the resident did not initiate eating until someone provided a reminder to do so. As weeks and months passed a prompt to eat was required several times during the meal. The residents used their hands to eat food such as mashed potatoes and tried to eat porridge with a spoon upside down. The residents mixed foods together and then walked away from the dining table without eating anything. Eventually reminders to eat did not help. At some point a staff or family member began to physically assist the resident to eat and this was defined as the time of the disability onset for the purpose of the survival analysis. Initially the assistance took the form of completing the meal that the resident had begun, and over time progressed to assisting with the entire meal. In these situations, attributions to dementia were more likely to be made by both staff and family members however some family members attributed the need for physical eating assistance to ill-fitting dentures, difficulty swallowing, or a poor appetite.

Walking Scenario: Some residents continued to walk despite become progressively more unsteady and more at risk for falling. Eventually a staff or family member intervened by arranging for a wheelchair. This often was precipitated by a fall or a series of falls. In these situations some family and staff members attributed the use of the wheelchair to

falling and not dementia, whereas others attributed the use of the wheelchair to a progressive motor decline and/or the loss of balance related to dementia.

### **Cohort Data**

The accuracy of data entry into the STATA database was assessed in a random selection of 24 (20%) resident data files. An error rate of 1% of the data elements was detected which was deemed to be acceptable. All identified errors were corrected in the dataset.

### *Baseline Data*

The results of dichotomizing the resident-specific variables are summarized in Table 4.8.

**Table 4.8 Resident-specific variable categories**

Predictor Variable	Dichotomous Categories	Sample Size (%)
Age	< 85	48 (40)
	≥ 85	72 (60)
Sex	Male	26 (22)
	Female	94 (78)
Education	< grade 12	76 (63)
	≥ grade 12	44 (37)
Charlson Comorbidity Index	≤ 1	60 (50)
	>1	60 (50)
Dementia Diagnosis	Vascular / Dementia	25 (21)
	Alzheimers / Mixed	95 (79)
Global Deterioration Scale	≤ 5.4	56 (47)
	>5.4	64 (53)
Duration of Admission	≤ 582	91 (76)
	>582	29 (24)
Cognitive Enhancer drugs	No	73 (61)
	Yes	47 (39)
Neuroleptic drugs	No	70 (58)
	Yes	50 (42)
Benzodiazepine drugs	No	99 (82)
	Yes	21 (18)
Anitdepressant drugs	No	84 (70)
	Yes	36 (30)
Psychotropic drugs	No	42 (35)
	Yes	78 (65)

The results of dichotomizing the facility-specific variables are summarized in Table 4.9.

**Table 4.9 Facility-specific variable categories**

Predictor Variable	Dichotomous Categories	Sample Size (%)
PEAP score	≤ 79	60 (50)
	> 79	60 (50)
Profit status	Not- for-profit	86 (72)
	For profit	34 (28)
Staff dementia education	Some	76 (63)
	None	44 (37)
Care centre bed number	≤ 60	29 (24)
	> 60	91 (76)
RN / LPN-to-resident ratio	≤ 0.04	66 (55)
	> 0.04	54 (45)
Nurse aide-to-resident ratio	≤ 0.13	45 (38)
	> 0.13	75 (62)
Rehabilitation staff-to-resident ratio	≤ 0.045	59 (49)
	> 0.045	61 (51)

PEAP = Professional Environmental Assessment Protocol

### *Outcome Data*

For each of the six disability outcomes the cumulative proportion of residents experiencing an event was calculated, bivariate Cox regression analyses for each potential predictor variable were computed, and multivariate Cox regression models to identify potential moderating, confounding, and covariate variables were developed. The key message in these analyses is that excess disability is a distinct entity in a sample of people with dementia, which is separate from all-cause disability, and which has a set of predictors which are also separate from the predictors of all-cause disability.

## Deaths

Six residents died prior to an observation of functional loss. Rather than censoring the data for these residents and thereby equating them to residents who were censored because they had successfully completed a year of observation without a loss of function, these six deaths were coded as functional loss events. A sensitivity analysis was conducted to compare the results from bivariate Cox regression analyses for the all-cause walking, eating, and composite outcomes when the six residents were coded as censored and when the six residents were coded as an event. The results of these analyses are summarized in Table 4.10 below.

**Table 4.10 Log-rank test p-values for deaths as events compared with deaths as censored**

Predictor variable	Walking disability (deaths as events)	Walking disability (deaths as censored)	Eating disability (deaths as events)	Eating disability (deaths as censored)	Composite disability (deaths as events)	Composite disability (deaths as censored)
Age	0.34	0.58	0.99	0.64	0.42	0.67
Sex	0.31	0.18	0.81	0.61	0.46	0.32
Education	0.99	0.80	0.80	0.58	0.82	0.65
Charlson Comorbidity Index	<b>0.05</b>	0.08	<b>0.005</b>	<b>0.01</b>	<b>0.007</b>	<b>0.01</b>
Dementia diagnosis	0.22	0.54	0.66	0.82	0.70	0.85
Global Deterioration Scale	<b>0.04</b>	0.11	<b>0.005</b>	<b>0.02</b>	<b>0.006</b>	<b>0.02</b>
Duration of admission	0.42	0.49	<b>0.05</b>	<b>0.05</b>	0.29	0.34
Cognitive enhancers	0.18	0.35	0.95	0.61	0.10	0.20
Neuroleptics	0.95	0.70	0.99	0.67	0.84	0.54
Benzodiazepines	0.71	0.70	0.47	0.47	0.90	0.88
Antidepressants	0.30	0.32	0.31	0.31	0.30	0.33
Psychotropics	0.36	0.12	0.62	0.26	0.29	0.11
PEAP scores	<b>0.02</b>	<b>0.02</b>	0.07	0.12	<b>0.007</b>	<b>0.01</b>
Profit status	<b>0.02</b>	<b>0.02</b>	0.38	0.42	<b>0.05</b>	<b>0.05</b>
Dementia education	0.89	0.68	0.10	0.14	0.27	0.36

Bed number	0.09	0.10	0.65	0.75	0.35	0.42
RN/LPN ratios	0.81	0.73	0.23	0.24	0.54	0.58
Nurse aide ratios	0.65	0.57	0.41	0.32	0.30	0.24
Rehabilitation ratios	0.21	0.18	0.18	0.16	0.19	0.17

For the most part the variables which were significant when the six deaths were coded as an event remained significant when the six deaths were coded as censored. Likewise the non-significant variables remained non-significant regardless of the coding scheme. Since there was a minimal difference in the log-rank test results between the two coding approaches, and conceptually it was preferable to treat the deaths as events, for all analyses in this study, the six deaths were coded as functional loss events.

#### *Bivariate Survival Analyses*

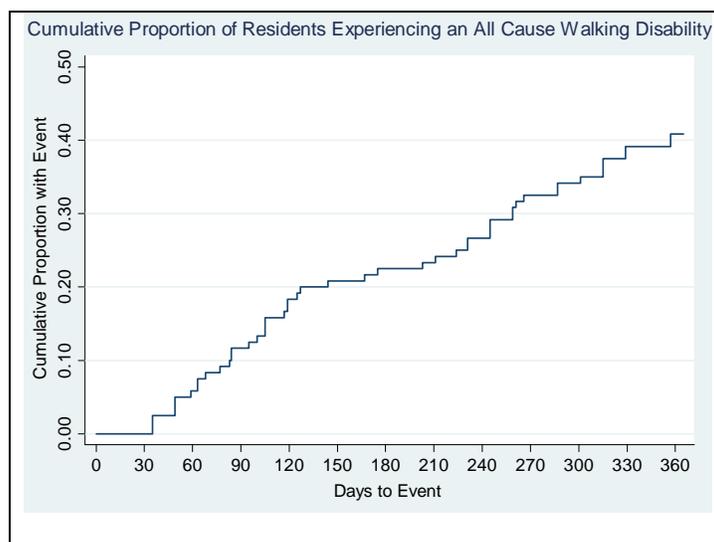
The resident outcomes were analyzed in three sections. Analyses focused first on the walking disability, then on the eating disability, and finally on the combined walking and eating, or the ‘composite’ disability. For each section separate analyses were conducted for losses in ability due to any reason, and for losses in ability attributable to excess disability.

#### Walking Disability: Losses in Ability for Any Reason

The residents were coded as having a walking event if during a mealtime observation they did not walk to the dining room but instead used a wheelchair or remained in bed. The Kaplan-Meier failure curve in Figure 4.2 illustrates the cumulative proportion of residents experiencing a loss of ability to walk for any reason during the year of

observation. Forty-nine (41%) residents in the sample experienced an inability to walk to the dining room on at least one occasion or died within a one year period. Taking into consideration the total analysis time at risk, the one year Kaplan-Meier estimate of failure was 0.41 (95% confidence interval: 0.33 – 0.50).

**Figure 4.2 Cumulative proportion of residents experiencing an all-cause walking disability**



The influence of the predictor variables on the proportion of the sample experiencing the inability to walk for any reason was assessed using Cox regression. Hazard ratios for each of the resident-specific variables are presented in Table 4.11.

**Table 4.11 All-cause walking disability hazard ratios for resident specific-predictor variables**

Predictor variable	All-cause walking hazard ratio	(95% Confidence interval)	p-value
<b>Age</b>			
<85 years	1.00		
≥85 years	1.33	(0.74 – 2.39)	0.34
<b>Sex</b>			
Male	1.00		
Female	1.48	(0.69 – 3.15)	0.31
<b>Education</b>			
< Grade 12	1.00		
≥ Grade 12	1.00	(0.56 – 1.79)	0.99
<b>Charlson Comorbidity Index</b>			
≤ 1	1.00		
> 1	1.77	(0.99 - 3.14)	0.05
<b>Dementia diagnosis</b>			
Vascular /Dementia	1.00		
Alzheimer/Mixed	0.68	(0.36 - 1.28)	0.23
<b>Global Deterioration Scale</b>			
≤ 5.4	1.00		
> 5.4	1.83	(1.02 – 3.28)	0.04
<b>Duration of admission</b>			
≤ 582 days	1.00		
> 582 days	0.75	(0.38 - 1.51)	0.42
<b>Cognitive enhancers</b>			
No	1.00		
Yes	0.67	(0.37 - 1.22)	0.19
<b>Baseline neuroleptics</b>			
No	1.00		
Yes	0.98	(0.56 – 1.74)	0.95
<b>Baseline benzodiazepines</b>			
No	1.00		
Yes	1.14	(0.55 - 2.36)	0.72
<b>Baseline antidepressants</b>			
No	1.00		
Yes	1.36	(0.76 - 2.45)	0.31
<b>Baseline psychotropics</b>			
No	1.00		
Yes	1.32	(0.72 – 2.43)	0.37

The Charlson Comorbidity Index category and the stage of dementia were the only statistically significant resident-specific predictors of walking loss for any reason. The residents with more comorbidities, as measured by a score of more than 1 on the Charlson Comorbidity Index, were estimated to experience 1.8 times the hazard of a loss of ability to walk for any reason compared with those with fewer comorbidities (95% confidence interval: 0.99 to 3.14, p-value = 0.05). Furthermore, the residents who were more advanced in their stage of dementia, as measured by a score of more than 5.4 on the Global Deterioration Scale, were estimated to experience 1.8 times the hazard of a loss of ability to walk for any reason compared with those who were less advanced in their stage of dementia (95% confidence interval: 1.02 to 3.28, p-value = 0.04).

Hazard ratios for each of the facility-specific variables are presented in Table 4.12.

**Table 4.12 All-cause walking disability hazard ratios for facility-specific predictor variables**

Predictor variable	All-cause walking hazard ratio	(95% Confidence interval)	p-value
PEAP scores			
≤ 79	1.00		
> 79	0.49	(0.28 - 0.88)	0.02
Profit status			
No profit	1.00		
For profit	1.97	(1.11 – 3.49)	0.02
Staff dementia education			
Some	1.00		
None	0.96	(0.53 -1.73)	0.89
Care centre bed number			
≤ 60	1.00		
> 60	1.91	(0.90 – 4.08)	0.09
RN / LPN-to-resident ratio			
≤ 0.04	1.00		
> 0.04	0.93	(0.53 – 1.65)	0.82
Nurse aide-to-resident ratio			
≤ 0.13	1.00		
> 0.13	0.88	(0.50 -1.55)	0.65
Rehabilitation staff-to-resident ratio			
≤ 0.045	1.00		
> 0.045	1.44	(0.82 – 2.53)	0.21

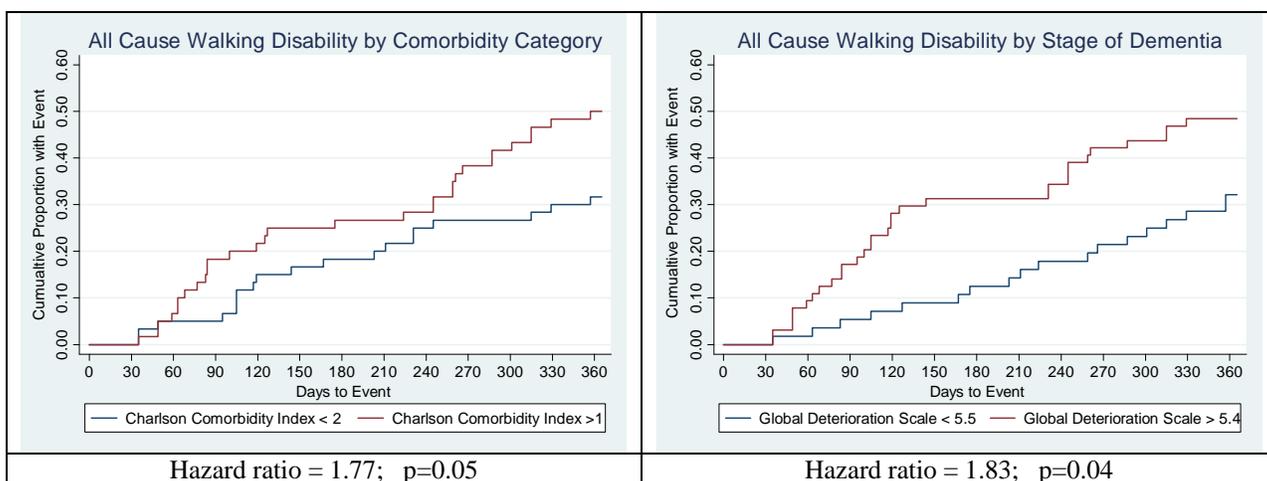
The quality of the nursing home environment and the profit status of the nursing home were the only statistically significant facility-specific predictors of walking loss.

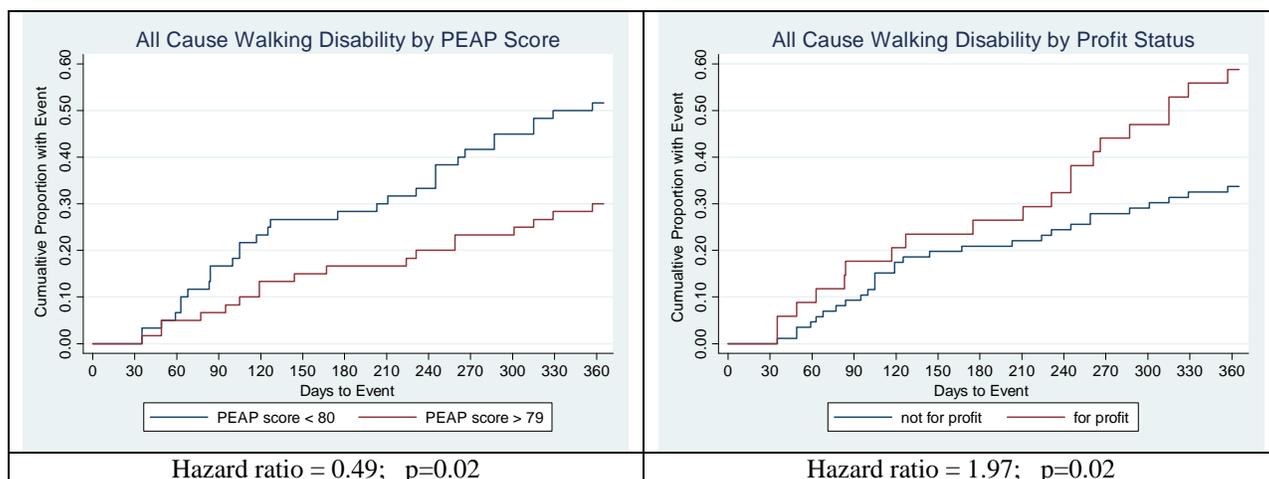
Residents living in higher quality nursing homes, as measured by a score of more than 79 on the Professional Environmental Assessment Protocol, experienced half of the hazard of a loss of ability to walk for any reason compared with those living in facilities which scored ≤ 79 (95% confidence interval: 0.28 to 0.88, p-value = 0.02). Residents who lived in for-profit nursing homes experienced twice the hazard of a loss of ability to walk for

any reason, compared with those living in not-for-profit nursing homes (95% confidence interval: 1.11 to 3.49, p-value = 0.02).

The Kaplan-Meier method was used to plot the dichotomized subgroups of the predictor variables. Figure 4.3 displays selected Kaplan-Meier failure curves and log-rank test results for the two resident-specific and two facility-specific variables which were statistically significant predictors of loss of all-cause walking ability: comorbidity, stage of dementia, environment quality as measured by the Professional Environment Assessment Protocol, and care centre profit status.

**Figure 4.3 Kaplan-Meier plots of all-cause walking outcome by selected predictor variables**

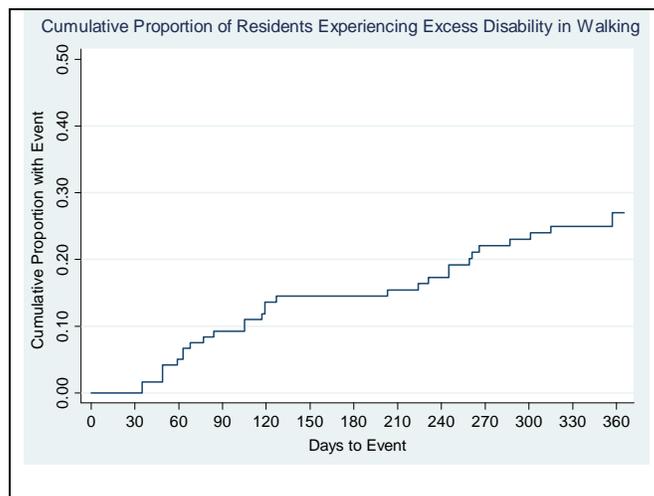




### Walking Disability: Losses in Ability Attributable to Excess Disability

The residents were coded as having a walking event due to excess disability if after being unable to walk to the dining room they subsequently were observed to successfully do so. Excess disability was also coded if both the staff member and the family member attributed the loss of walking ability to something other than dementia. The Kaplan-Meier failure curve in Figure 4.4 illustrates the cumulative proportion of residents experiencing excess disability in walking during the year of observation. Thirty (25%) residents in the sample experienced at least one episode of excess disability in walking within a one year period. Taking into consideration the total analysis time at risk, the one year Kaplan-Meier estimate of failure was 0.27 (95% confidence interval: 0.20 to 0.37).

**Figure 4.4 Cumulative proportion of residents experiencing excess disability in walking**



The influence of the predictor variables on the proportion of the sample experiencing excess disability in walking was assessed using Cox regression. Hazard ratios for each of the resident-specific variables are presented in Table 4.13.

**Table 4.13 Walking excess disability hazard ratios for resident-specific predictor variables**

Predictor variable	Walking excess disability hazard ratio	(95% Confidence interval)	p-value
<b>Age</b>			
<85 years	1.00		
≥85 years	1.40	(0.66 – 3.00)	0.38
<b>Sex</b>			
Male	1.00		
Female	1.43	(0.55 - 3.73)	0.47
<b>Education</b>			
< Grade 12	1.00		
≥ Grade 12	0.74	(0.34 – 1.61)	0.45

1

Charlson Comorbidity Index			
≤	1.00		
>1	2.20	(1.03 - 4.71)	0.04
Dementia diagnosis			
Vascular /Dementia	1.00		
Alzheimer/Mixed	0.81	(0.35 - 1.90)	0.63
Global Deterioration Scale			
≤ 5.4	1.00		
> 5.4	1.57	(0.76 - 3.26)	0.23
Duration of admission			
≤ 582 days	1.00		
> 582 days	0.90	(0.39 – 2.10)	0.81
Cognitive enhancers			
No	1.00		
Yes	0.35	(0.14 – 0.85)	0.02
Baseline neuroleptics			
No	1.00		
Yes	0.72	(0.34 – 1.54)	0.40
Baseline benzodiazepines			
No	1.00		
Yes	1.27	(0.52 – 3.11)	0.60
Baseline antidepressants			
No	1.00		
Yes	1.94	(0.94 – 3.99)	0.07
Baseline psychotropics			
No	1.00		
Yes	1.36	(0.62 – 2.97)	0.44

The Charlson Comorbidity Index category and the use of a cognitive enhancer drug at baseline were the statistically significant predictors of excess disability in walking.

Residents with more comorbidities, as measured by a score of more than 1 on the Charlson Comorbidity Index, were estimated to experience 2.2 times the hazard of a loss of ability to walk due to excess disability compared with those with fewer comorbidities

(95% confidence interval: 1.03 to 4.71, p-value = 0.04). Residents taking a cognitive enhancer drug at baseline were estimated to experience 0.35 times the hazard of a loss of ability to walk due to excess disability compared with those who were not taking a cognitive enhancer drug (95% confidence interval: 0.14 to 0.85; p-value = 0.02).

Hazard ratios for each of the facility-specific variables are presented in Table 4.14.

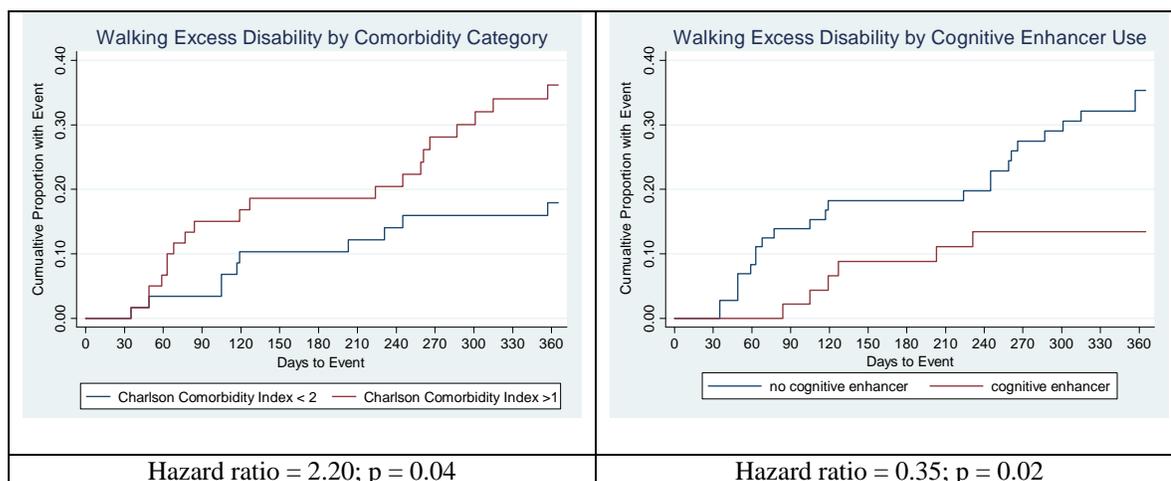
**Table 4.14 Walking excess disability hazard ratios for facility-specific predictor variables**

Predictor variable	Walking excess disability hazard ratio	(95% Confidence interval)	p-value
<b>PEAP scores</b>			
≤ 79	1.00		
> 79	0.58	(0.28 – 1.20)	0.14
<b>Profit status</b>			
No profit	1.00		
For profit	1.42	(0.66 – 3.03)	0.37
<b>Staff dementia education</b>			
Some	1.00		
None	1.04	(0.50 – 2.19)	0.91
<b>Care centre bed number</b>			
≤ 60	1.00		
> 60	2.38	(0.83 – 6.83)	0.11
<b>RN / LPN-to-resident ratio</b>			
≤ 0.04	1.00		
> 0.04	1.24	(0.61 – 2.54)	0.55
<b>Nurse aide-to-resident ratio</b>			
≤ 0.13	1.00		
> 0.13	1.20	(0.56 – 2.57)	0.64
<b>Rehabilitation staff-to-resident ratio</b>			
≤ 0.045	1.00		
> 0.045	1.60	(0.77 – 3.33)	0.21

There were no statistically significant facility-specific predictors of excess disability in walking.

Figure 4.5 displays Kaplan-Meier failure curves and log-rank test results for the two statistically significant predictors of excess disability in walking: comorbidity and the use of a cognitive enhancer drug at baseline.

**Figure 4.5 Kaplan-Meier failure curves and log-rank test results for two predictors of excess disability in walking: comorbidity and the use of a cognitive enhancer**

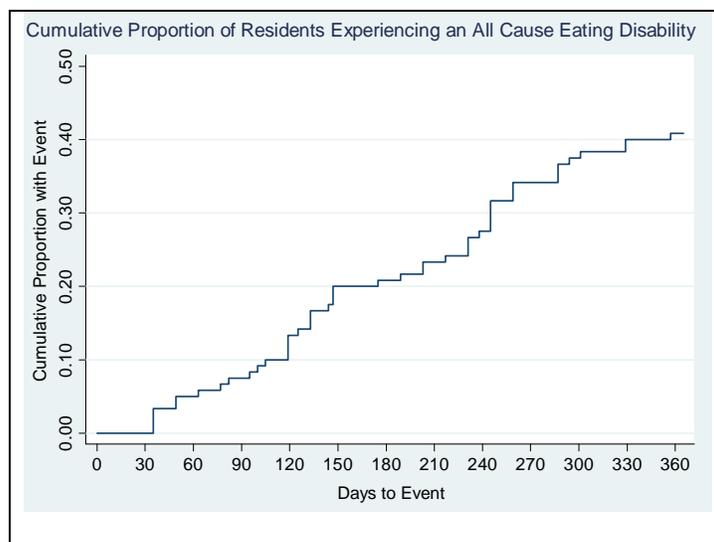


#### Eating Disability: Losses in Ability for Any Reason

The residents were coded as being unable to eat independently for any reason if they did not eat, or if they received the physical assistance of another person, usually a staff member, to do so. The Kaplan-Meier failure curve in Figure 4.6 illustrates the cumulative

proportion of residents experiencing disability in eating for any reason during the year of observation. Forty-nine (41%) residents in the sample experienced at least one episode of disability in eating or died within a one year period. Taking into consideration the total analysis time at risk, the one year Kaplan-Meier estimate of failure was 0.41 (95% confidence interval: 0.33 – 0.50).

**Figure 4.6 Cumulative proportion of residents experiencing an all-cause eating disability**



The influence of resident-specific and facility-specific variables on the proportion of the sample experiencing the inability to eat for any reason was assessed using Cox regression. Hazard ratios for each of the resident-specific variables are presented in Table 4.15.

**Table 4.15 All-cause eating disability hazard ratios for resident-specific predictor variables**

Predictor variable	All-cause eating hazard ratio	(95% Confidence interval)	p-value
<b>Age</b>			
<85 years	1.00		
≥85 years	1.00	(0.56 – 1.76)	0.99
<b>Sex</b>			
Male	1.00		
Female	1.09	(0.54 - 2.18)	0.81
<b>Education</b>			
< Grade 12	1.00		
≥ Grade 12	0.93	(0.51 – 1.67)	0.80
<b>Charlson Comorbidity Index</b>			
≤ 1	1.00		
> 1	2.27	(1.26 - 4.09)	0.01
<b>Dementia diagnosis</b>			
Vascular /Dementia	1.00		
Alzheimer/Mixed	0.86	(0.44 - 1.69)	0.67
<b>Global Deterioration Scale</b>			
≤ 5.4	1.00		
> 5.4	2.28	(1.26 - 4.15)	0.01
<b>Duration of admission</b>			
≤ 582 days	1.00		
> 582 days	0.45	(0.20 – 1.01)	0.05
<b>Cognitive enhancers</b>			
No	1.00		
Yes	1.02	(0.58 – 1.80)	0.95
<b>Baseline neuroleptics</b>			
No	1.00		
Yes	1.00	(0.56 – 1.76)	1.00
<b>Baseline benzodiazepines</b>			
No	1.00		
Yes	0.75	(0.34 – 1.66)	0.47
<b>Baseline antidepressants</b>			
No	1.00		
Yes	1.36	(0.75 – 2.44)	0.31
<b>Baseline psychotropics</b>			
No	1.00		
Yes	1.16	(0.64 – 2.11)	0.62

The Charlson Comorbidity Index category, the stage of dementia, and the duration of residence in the nursing home prior to entering the study were the statistically significant resident-specific predictors of eating loss for any reason. The residents with more comorbidities, as measured by a score of more than 1 on the Charlson Comorbidity Index, were estimated to experience 2.3 times the hazard of a loss of ability to eat for any reason compared with those with fewer comorbidities (95% confidence interval: 1.26 to 4.09, p-value = 0.01). Furthermore, the residents who were more advanced in their stage of dementia, as measured by a score of more than 5.4 on the Global Deterioration Scale, were estimated to experience 2.3 times the hazard of a loss of ability to eat for any reason compared with those who were less advanced in their stage of dementia (95% confidence interval: 1.26 to 4.15, p-value = 0.01). The residents who lived more than 582 days in the nursing home prior to entering the study were estimated to experience 0.45 times the hazard of loss in the ability to eat for any reason compared with those who lived in the nursing home for a shorter period of time (95% confidence interval: 0.20 to 1.01, p-value = 0.05). Hazard ratios for each of the facility-specific variables are presented in Table 4.16.

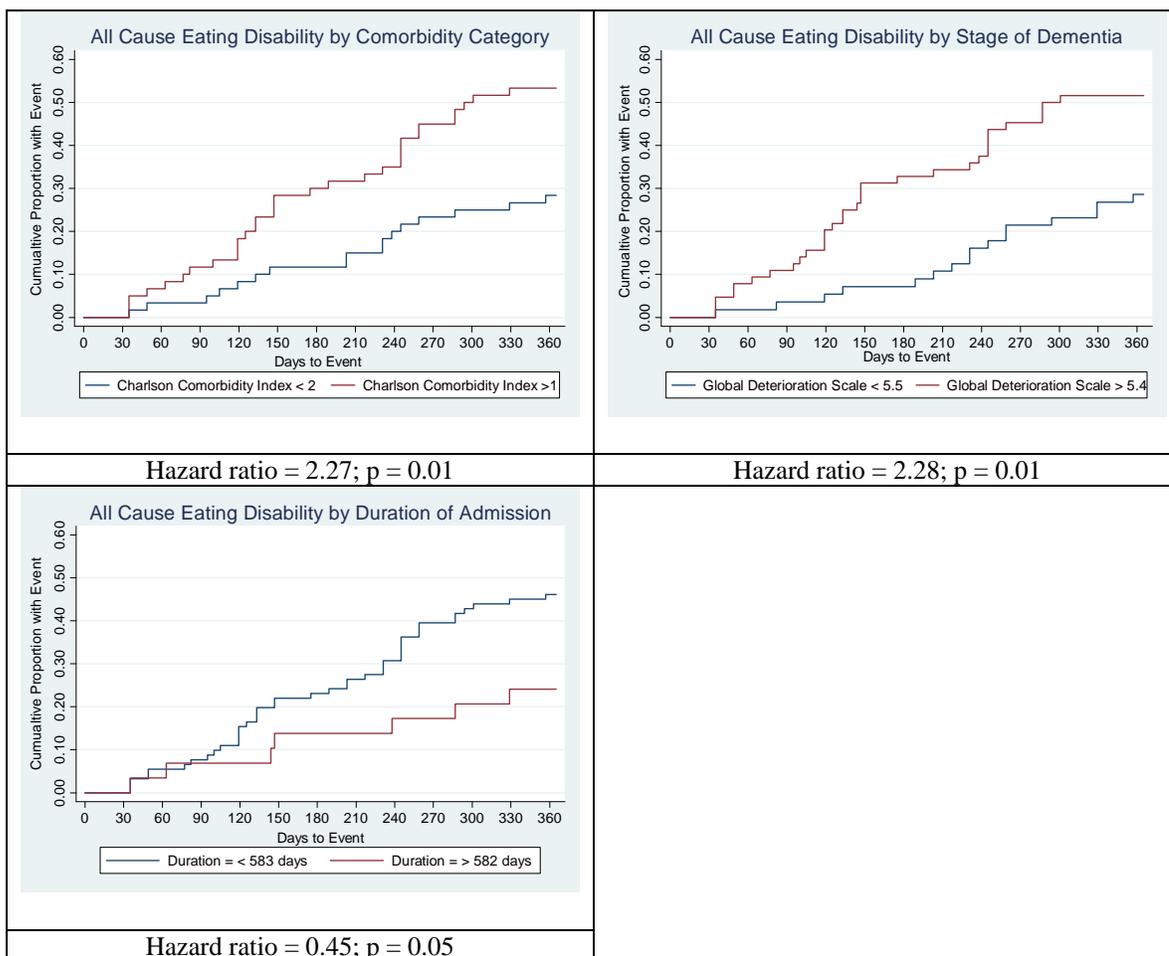
**Table 4.16 All-cause eating disability hazard ratios for facility-specific predictor variables**

Predictor variable	All-cause eating hazard ratio	(95% Confidence interval)	p-value
<b>PEAP scores</b>			
≤ 79	1.00		
> 79	0.60	(0.34 - 1.06)	0.08
<b>Profit status</b>			
No profit	1.00		
For profit	1.31	(0.71 – 2.37)	0.38
<b>Staff dementia education</b>			
Some	1.00		
None	1.59	(0.90 -2.79)	0.11
<b>Care centre bed number</b>			
≤ 60	1.00		
> 60	1.17	(0.60 – 2.28)	0.65
<b>RN / LPN-to-resident ratio</b>			
≤ 0.04	1.00		
> 0.04	1.41	(0.80 – 2.46)	0.23
<b>Nurse aide-to-resident ratio</b>			
≤ 0.13	1.00		
> 0.13	0.79	(0.45 -1.39)	0.41
<b>Rehabilitation staff-to-resident ratio</b>			
≤ 0.045	1.00		
> 0.045	1.46	(0.83 – 2.58)	0.19

There were no statistically significant facility-specific predictors of eating loss for any reason.

Figure 4.7 displays Kaplan-Meier failure curves and log-rank test results for the three statistically significant predictors of all-cause eating disability: comorbidity, stage of dementia, and duration of nursing home admission prior to entering the study.

**Figure 4.7 Kaplan-Meier failure curves and log-rank test results for three predictors of all-cause eating disability: comorbidity, stage of dementia, and duration of nursing home admission**

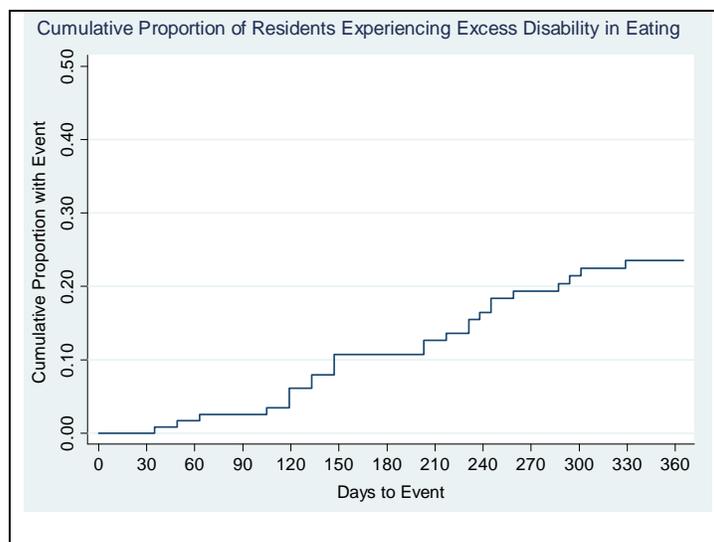


### Eating Disability: Losses in Ability Attributable to Excess Disability

The residents were coded as being unable to eat due to excess disability if after receiving assistance to eat they subsequently were observed to eat independently. Excess disability was also coded if both the staff member and the authorized representative attributed the loss of eating ability to something other than dementia. The Kaplan-Meier failure curve

in Figure 4.8 illustrates the cumulative proportion of residents experiencing excess disability in eating during the year of observation. Twenty-five (21%) residents in the sample experienced at least one episode of excess disability in eating within a one year period. Taking into consideration the total analysis time at risk, the one year Kaplan-Meier estimate of failure was 0.24 (95% confidence interval: 0.17 to 0.33).

**Figure 4.8 Cumulative proportion of residents experiencing excess disability in eating**



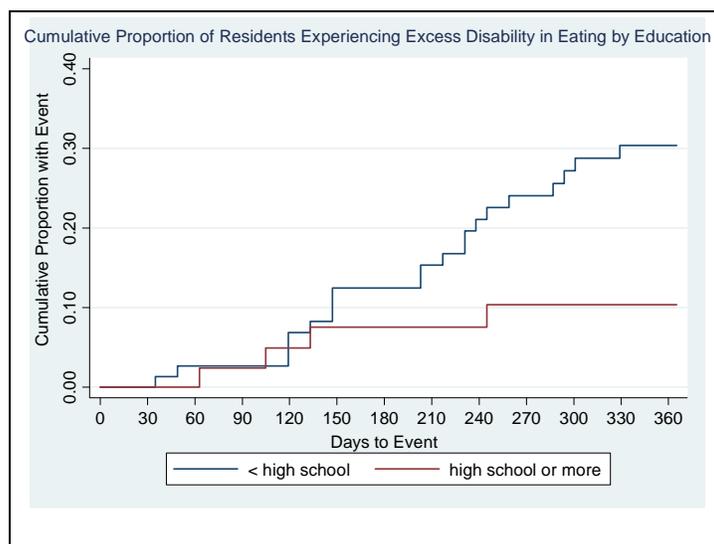
The influence of resident-specific and facility-specific variables on the proportion of the sample experiencing excess disability in eating was assessed using Cox regression. Hazard ratios for each of the resident-specific variables are presented in Table 4.17.

**Table 4.17 Excess disability in eating hazard ratios for resident-specific predictor variables**

Predictor variable	Eating excess disability hazard ratio	(95% Confidence interval)	p-value
<b>Age</b>			
<85 years	1.00		
≥85 years	0.88	(0.40 – 1.93)	0.74
<b>Sex</b>			
Male	1.00		
Female	0.72	(0.30 - 1.72)	0.46
<b>Education</b>			
< Grade 12	1.00		
≥ Grade 12	0.33	(0.11 – 0.97)	0.05
<b>Charlson Comorbidity Index</b>			
≤ 1	1.00		
> 1	2.16	(0.95 - 4.89)	0.07
<b>Dementia diagnosis</b>			
Vascular /Dementia	1.00		
Alzheimer/Mixed	1.30	(0.45 - 3.80)	0.63
<b>Global Deterioration Scale</b>			
≤ 5.4	1.00		
> 5.4	1.99	(0.88 - 4.51)	0.10
<b>Duration of admission</b>			
≤ 582 days	1.00		
> 582 days	0.52	(0.18 – 1.50)	0.22
<b>Cognitive enhancers</b>			
No	1.00		
Yes	0.69	(0.30 – 1.60)	0.39
<b>Baseline neuroleptics</b>			
No	1.00		
Yes	1.34	(0.61 – 2.93)	0.47
<b>Baseline benzodiazepines</b>			
No	1.00		
Yes	0.61	(0.18 – 2.05)	0.43
<b>Baseline antidepressants</b>			
No	1.00		
Yes	1.71	(0.77– 3.80)	0.19
<b>Baseline psychotropics</b>			
No	1.00		
Yes	1.78	(0.71 – 4.47)	0.22

Residents' education was the only statistically significant predictor of excess disability in eating. Residents who completed high school were estimated to experience one third of the hazard of excess disability in eating compared with those who did not complete high school (95% confidence interval: 0.11 to 0.97,  $p$ -value = 0.05). Figure 4.9 displays the Kaplan-Meier failure curve and log-rank test results for this predictor of excess disability in eating.

**Figure 4.9 Cumulative proportion of residents experiencing excess disability in eating by resident education**



It is apparent from Figure 4.9 that there were very few residents in the group who completed high school and experienced an excess disability in eating. In fact there were only four in this group although the expected number was nine.

Hazard ratios for each of the facility-specific variables are presented in Table 4.18.

**Table 4.18 Excess disability in eating hazard ratios for facility-specific predictor variables**

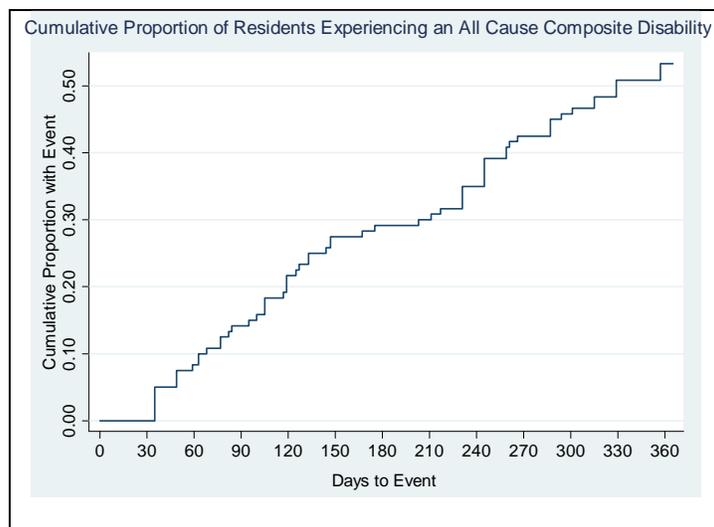
Predictor variable	Eating excess disability hazard ratio	(95% Confidence interval)	p-value
<b>PEAP scores</b>			
≤ 79	1.00		
> 79	0.80	(0.36 - 1.75)	0.57
<b>Profit status</b>			
No profit	1.00		
For profit	0.85	(0.34 – 2.13)	0.73
<b>Staff dementia education</b>			
Some	1.00		
None	1.82	(0.83 -3.98)	0.14
<b>Care centre bed number</b>			
≤ 60	1.00		
> 60	1.07	(0.43 – 2.68)	0.89
<b>RN / LPN-to-resident ratio</b>			
≤ 0.04	1.00		
> 0.04	1.73	(0.78 – 3.81)	0.18
<b>Nurse aide-to-resident ratio</b>			
≤ 0.13	1.00		
> 0.13	0.76	(0.34 -1.66)	0.49
<b>Rehabilitation staff-to-resident ratio</b>			
≤ 0.045	1.00		
> 0.045	1.65	(0.74 – 3.66)	0.22

There were no statistically significant facility-specific predictors of excess disability in eating.

### Composite Disability: Losses in Ability for Any Reason

The residents were coded as having a composite eating/walking disability for any reason if they did not walk to the dining room at mealtime or they did not eat independently at mealtime. The Kaplan-Meier failure curve in Figure 4.10 illustrates the cumulative proportion of residents experiencing disability in walking or eating for any reason during the year of observation. Sixty-four (53%) residents in the sample experienced at least one episode of disability in walking or eating or died within a one year period. Taking into consideration the total analysis time at risk, the one year Kaplan-Meier estimate of failure was 0.53 (95% confidence interval: 0.45 to 0.62).

**Figure 4.10 Cumulative proportion of residents experiencing an all-cause composite disability**



The influence of resident-specific and facility-specific variables on the proportion of the sample experiencing the inability to walk or to eat for any reason was assessed using Cox regression. Hazard ratios for each of the resident-specific variables are presented in Table 4.19.

**Table 4.19 All-cause composite disability hazard ratios for resident-specific predictor variables**

Predictor variable	All-cause composite hazard ratio	(95% Confidence interval)	p-value
<b>Age</b>			
<85 years	1.00		
≥85 years	1.23	(0.74 – 2.04)	0.43
<b>Sex</b>			
Male	1.00		
Female	1.27	(0.68 – 2.37)	0.46
<b>Education</b>			
< Grade 12	1.00		
≥ Grade 12	0.94	(0.57 – 1.57)	0.82
<b>Charlson Comorbidity Index</b>			
≤ 1	1.00		
> 1	1.97	(1.19 - 3.26)	0.01
<b>Dementia diagnosis</b>			
Vascular /Dementia	1.00		
Alzheimer/Mixed	0.89	(0.49 - 1.61)	0.70
<b>Global Deterioration Scale</b>			
≤ 5.4	1.00		
> 5.4	2.00	(1.20 – 3.32)	0.01
<b>Duration of admission</b>			
≤ 582 days	1.00		
> 582 days	0.73	(0.39 - 1.33)	0.30
<b>Cognitive enhancers</b>			
No	1.00		
Yes	0.65	(0.39 - 1.10)	0.11
<b>Baseline neuroleptics</b>			
No	1.00		
Yes	1.05	(0.64 – 1.73)	0.84

Baseline benzodiazepines			
No	1.00		
Yes	1.04	(0.55 - 2.00)	0.90
Baseline antidepressants			
No	1.00		
Yes	1.31	(0.78 - 2.21)	0.31
Baseline psychotropics			
No	1.00		
Yes	1.33	(0.78 - 2.25)	0.30

The Charlson Comorbidity Index category and the stage of dementia were the statistically significant resident-specific predictors of disability in walking or eating for any reason.

The residents with more comorbidities, as measured by a score of more than 1 on the Charlson Comorbidity Index, were estimated to experience 1.97 or twice the hazard of a loss of ability to walk or to eat compared with those with fewer comorbidities (95% confidence interval: 1.19 to 3.26, p-value = 0.01). Likewise, the residents who were more advanced in their stage of dementia, as measured by a score of more than 5.4 on the Global Deterioration Scale, were estimated to experience twice the hazard of a loss of ability to walk or to eat compared with those who were less advanced in their stage of dementia (95% confidence interval: 1.20 to 3.32, p-value = 0.01).

Hazard ratios for each of the facility-specific variables are presented in Table 4.20.

**Table 4.20 All-cause composite disability hazard ratios for facility-specific predictor variables**

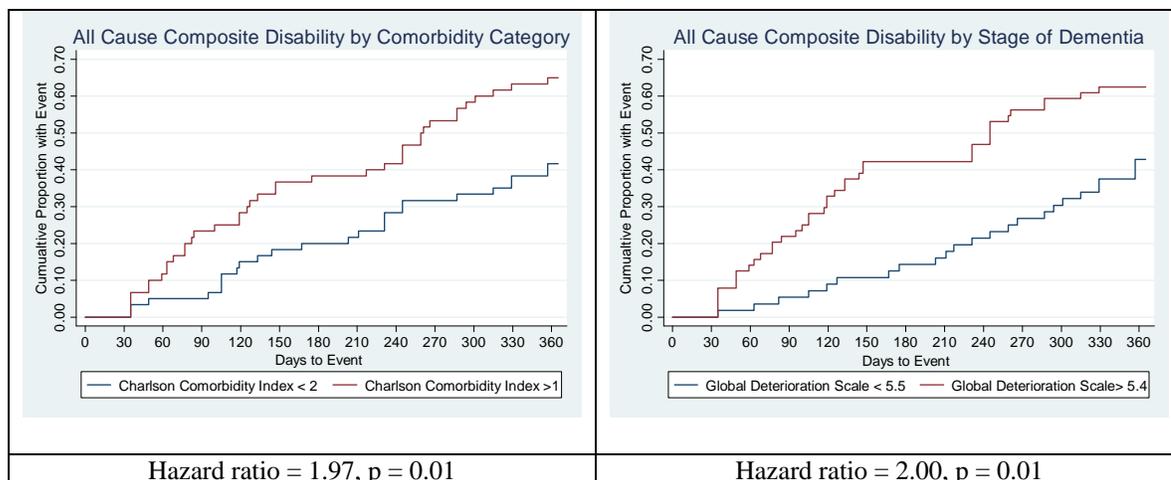
Predictor variable	All-cause composite hazard ratio	(95% Confidence interval)	p-value
PEAP scores			
≤ 79	1.00		
> 79	0.51	(0.31 - 0.84)	0.01
Profit status			
No profit	1.00		
For profit	1.65	(0.99 – 2.75)	0.05
Staff dementia education			
Some	1.00		
None	1.31	(0.80 -2.17)	0.28
Care centre bed number			
≤ 60	1.00		
> 60	1.32	(0.73 – 2.40)	0.35
RN / LPN-to-resident ratio			
≤ 0.04	1.00		
> 0.04	1.16	(0.71 – 1.90)	0.55
Nurse aide-to-resident ratio			
≤ 0.13	1.00		
> 0.13	0.77	(0.47 -1.27)	0.31
Rehabilitation staff-to-resident ratio			
≤ 0.045	1.00		
> 0.045	1.39	(0.85 – 2.27)	0.19

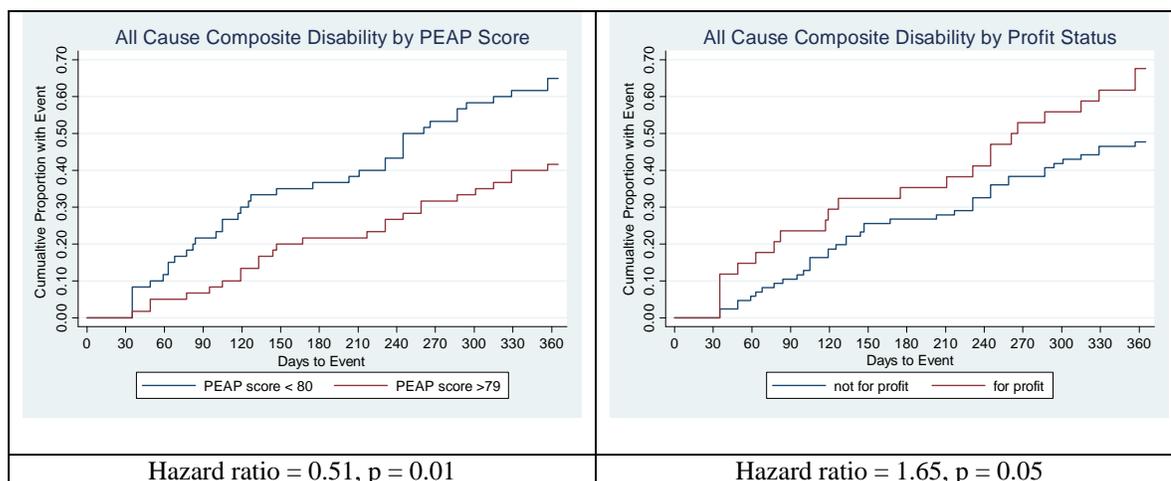
The quality of the nursing home environment and the profit status of the nursing homes were the statistically significant facility-specific predictors of walking or eating loss for any reason. Residents living in higher quality nursing homes, as measured by a score of more than 79 on the Professional Environmental Assessment Protocol, are estimated to experience half of the hazard of a loss of ability to walk or to eat for any reason compared with those living in nursing homes that scored ≤ 79 (95% confidence interval: 0.31 to

0.84,  $p$ -value = 0.01). Residents living in for-profit nursing homes are estimated to experience 1.65 times the hazard of a loss of ability to walk or to eat for any reason compared with those living in not-for-profit nursing homes (95% confidence interval: 0.99 to 2.75,  $p$ -value = 0.05).

Figure 4.11 displays Kaplan-Meier failure curves and log-rank test results for the four statistically significant predictors of all-cause disability in walking or eating: comorbidity, stage of dementia, quality of the environment as measured by the Professional Environment Assessment Protocol, and care centre profit status.

**Figure 4.11 Kaplan-Meier failure curves and log-rank test results for four predictors of all-cause disability in walking or eating: comorbidity, stage of dementia, quality of the environment, and care centre profit status**

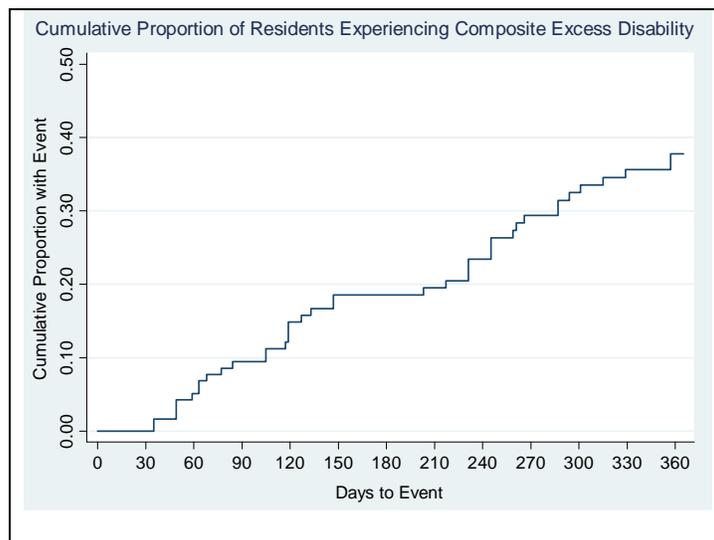




### Composite Disability: Losses in Ability Attributable to Excess Disability

The residents were coded as experiencing a composite outcome due to excess disability if after experiencing a walking or eating event they subsequently were observed to walk to the dining room and / or to eat independently. Excess disability was also coded for the composite outcome if both the staff member and the authorized representative attributed the loss of walking ability or the loss of eating ability to something other than dementia. The Kaplan-Meier failure curve in Figure 4.12 illustrates the cumulative proportion of residents experiencing excess disability in walking or eating during the year of observation. Forty (33%) residents in the sample experienced at least one episode of excess disability in walking or eating within a one year period. Taking into consideration the total analysis time at risk, the one year Kaplan-Meier estimate of failure was 0.38 (95% confidence interval: 0.29 to 0.48).

**Figure 4.12 Cumulative proportion of residents experiencing composite excess disability**



The influence of resident-specific and facility-specific variables on the proportion of the sample experiencing excess disability in walking or eating was assessed using Cox regression. Hazard ratios for each of the resident-specific variables are presented in Table 4.21.

**Table 4.21 Composite excess disability hazard ratios for resident-specific predictor variables**

Predictor variable	Composite excess disability hazard ratio	(95% Confidence interval)	p-value
<b>Age</b>			
<85 years	1.00		
≥85 years	1.23	(0.65 – 2.33)	0.53
<b>Sex</b>			
Male	1.00		
Female	1.01	(0.48 – 2.11)	0.99
<b>Education</b>			
< Grade 12	1.00		
≥ Grade 12	0.56	(0.27 – 1.15)	0.11
<b>Charlson Comorbidity Index</b>			
≤ 1	1.00		
> 1	2.34	(1.22 - 4.48)	0.01
<b>Dementia diagnosis</b>			
Vascular /Dementia	1.00		
Alzheimer/Mixed	1.00	(0.46 - 2.16)	0.99
<b>Global Deterioration Scale</b>			
≤ 5.4	1.00		
> 5.4	1.80	(0.96 – 3.40)	0.07
<b>Duration of admission</b>			
≤ 582 days	1.00		
> 582 days	0.82	(0.39 - 1.73)	0.61
<b>Cognitive enhancers</b>			
No	1.00		
Yes	0.39	(0.18 - 0.81)	0.01
<b>Baseline neuroleptics</b>			
No	1.00		
Yes	0.96	(0.51 – 1.81)	0.91
<b>Baseline benzodiazepines</b>			
No	1.00		
Yes	1.26	(0.58 - 2.74)	0.56
<b>Baseline antidepressants</b>			
No	1.00		
Yes	1.79	(0.95 - 3.37)	0.07
<b>Baseline psychotropics</b>			
No	1.00		
Yes	1.59	(0.79 – 3.18)	0.19

The Charlson Comorbidity Index category and cognitive enhancer use at baseline were the statistically significant resident-specific predictors of excess disability in walking or in eating. Residents with more comorbidities, as measured by a score of more than 1 on the Charlson Comorbidity Index, were estimated to experience 2.3 times the hazard of excess disability in walking or eating compared with those with fewer comorbidities (95% confidence interval: 1.22 to 4.48, p-value = 0.01). Residents taking a cognitive enhancer at baseline were estimated to experience 0.4 times the hazard of an excess disability in walking or eating compared with those who were not taking a cognitive enhancer drug (95% confidence interval: 0.18 to 0.81, p-value 0.01).

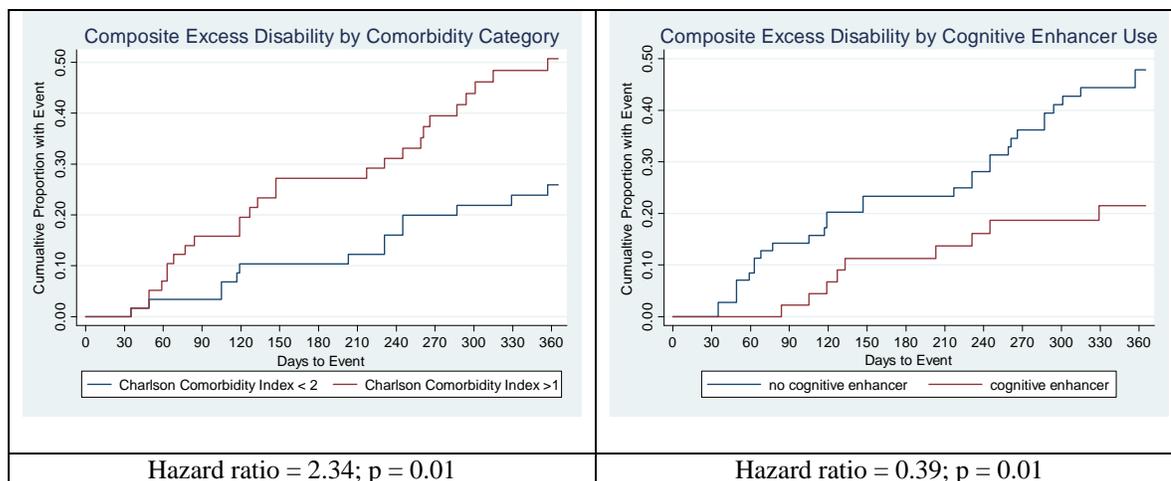
Hazard ratios for each of the facility-specific variables are presented in Table 4.22.

**Table 4.22 Composite excess disability hazard ratios for facility-specific predictor variables**

Predictor variable	Composite excess disability hazard ratio	(95% Confidence interval)	p-value
<b>PEAP scores</b>			
≤ 79	1.00		
> 79	0.65	(0.35 - 1.21)	0.17
<b>Profit status</b>			
No profit	1.00		
For profit	1.12	(0.56 – 2.25)	0.75
<b>Staff dementia education</b>			
Some	1.00		
None	1.43	(0.76 - 2.67)	0.27
<b>Care centre bed number</b>			
≤ 60	1.00		
> 60	1.48	(0.68 – 3.22)	0.32
<b>RN / LPN-to-resident ratio</b>			
≤ 0.04	1.00		
> 0.04	1.32	(0.71 – 2.45)	0.38
<b>Nurse aide-to-resident ratio</b>			
≤ 0.13	1.00		
> 0.13	0.90	(0.48 - 1.70)	0.75
<b>Rehabilitation staff-to-resident ratio</b>			
≤ 0.045	1.00		
> 0.045	1.41	(0.76 – 2.63)	0.28

There were no statistically significant facility-specific predictors of excess disability in walking or in eating. Figure 4.13 displays selected Kaplan-Meier failure curves and log-rank test results for the two resident-specific variables which were statistically significant predictors of excess disability in walking or eating: comorbidity and the use of a cognitive enhancer drug at baseline.

**Figure 4.13 Kaplan-Meier failure curves and log-rank test results for two predictors of excess disability in walking or eating: comorbidity and use of a cognitive enhancer**



### *Multivariate Cox Regression*

This section outlines the results from each step of the multivariate analysis which privileges the relationship between stage of dementia and each of the six disability outcomes. Only predictor variables which had  $p < 0.2$  in the bivariate analyses were modeled in the assessment of effect modification, confounding and covariates (Hosmer et al., 2000). Based on this guideline the variables that were included in the Cox regression models for each of the six outcomes are listed in Table 4.23.

**Table 4.23 Variables included in the multivariate Cox regression models to study the relationship between stage of dementia and the six outcomes**

Outcome	All-cause Disability	Excess Disability
Walking	Comorbidity Cognitive enhancer PEAP score Profit status	Comorbidity Cognitive enhancers Antidepressants PEAP score Size
Eating	Comorbidity Duration of admission PEAP score Dementia education Rehabilitation staff-to-resident ratio	Resident education Comorbidity Antidepressants Dementia education RN / LPN-to-resident ratio
Composite	Comorbidity Cognitive enhancers PEAP score Profit status Rehabilitation staff-to-resident ratio	Resident education Comorbidity Cognitive enhancers Antidepressants Psychotropic drugs PEAP score

Cross-tabulations of every predictor variable with every other predictor variable revealed problems with small cell sizes and colinearity. Cross tabulations yielded a zero cell for PEAP score x profit status, PEAP score x size, profit status x size, and size x rehabilitation staff-to-resident ratio. For example, there were no for-profit nursing homes with less than 60 beds. When combining two variables yielded an empty cell, then the two variables were not combined in the same multivariate model.

Cox regression models were constructed to assess for potential effect modification and confounding of the relationship between stage of dementia and disability. Using the likelihood ratio test and the standard criterion of  $\alpha = 0.05$  there was no evidence against

the null hypothesis of no effect modification in any of the models which were constructed for any of the six outcome variables. Confounding was assessed using 15% as the cutoff for comparing the crude with the adjusted hazard ratios (Maldonado, 1993). Only the score on the Professional Environmental Assessment Protocol was demonstrated to confound the relationship between stage of dementia and the composite excess disability outcome. In Table 4.24 the effects of the selected variables on the relationship between the privileged variable, stage of dementia, and the various disability outcomes are summarized.

**Table 4.24 Summary of the effect of selected variables on the outcome-stage of dementia relationship**

Outcome	All-cause Disability		Excess Disability	
	Variable	Effect of variable	Variable	Effect of variable
Walking	Comorbidity Cognitive enhancer PEAP score Profit status	covariate none covariate none	Comorbidity Cognitive enhancers Antidepressants PEAP score Size	none covariate covariate none none
Eating	Comorbidity Duration of admission PEAP score Dementia education Rehabilitation ratio	covariate covariate none covariate none	Resident education Comorbidity Antidepressants Dementia education RN / LPN ratio	none none none none none
Composite	Comorbidity Cognitive enhancers PEAP score Profit status Rehabilitation ratio	covariate none covariate none none	Resident education Comorbidity Cognitive enhancers Antidepressants Psychotropic drugs PEAP score	none covariate covariate covariate none confounder

The predictor variables remaining in the final models together with estimated hazard ratios, 95% confidence intervals, and p-values appear in Table 4.25.

**Table 4.25 Final models including confounders and covariates for each outcome**

Outcome for each model	Variables in each model	Effect of variables	Hazard ratio	95% Confidence interval	p-value
All-cause walking disability	Stage of dementia		2.12	1.18 – 3.83	0.01
	Comorbidity category	covariate	1.77	0.99 – 3.15	0.05
	Quality of environment	covariate	0.43	0.24 – 0.77	0.01
Walking excess disability	Stage of dementia		1.34	0.64 – 2.80	0.44
	Cognitive enhancer	covariate	0.34	0.14 – 0.83	0.02
	Antidepressant	covariate	2.07	1.00 – 4.29	0.05
All-cause eating disability	Stage of dementia		2.27	1.25 – 4.14	0.01
	Comorbidity category	covariate	2.54	1.39 – 4.62	0.01
	Duration of admission	covariate	0.41	0.18 – 0.92	0.03
	Staff dementia education	covariate	1.83	1.03 – 3.26	0.04
Eating excess disability	Stage of dementia		1.99	0.88 – 4.51	0.10
All-cause composite disability	Stage of dementia		2.53	1.50 – 4.27	0.001
	Comorbidity category	covariate	2.13	1.28 – 3.53	0.003
	Quality of environment	covariate	0.39	0.23 – 0.65	0.001
Composite excess disability	Stage of dementia		1.90	0.98 – 3.68	0.06
	Comorbidity category	covariate	2.28	1.17 – 4.41	0.02
	Cognitive enhancer	covariate	0.44	0.21 – 0.92	0.03
	Antidepressant	covariate	2.02	1.06 – 3.88	0.03
	Quality of environment	confounder	0.46	0.24 – 0.90	0.02

#### Proportional hazards assumption

Two methods were employed to assess the assumption of proportional hazards inherent in Cox regression. For each of the six final models describing the relationship between disability and stage of dementia Schoenfeld residuals were used to obtain a test statistic

and complementary log-log plots were visually inspected to see if they were parallel. The test statistic results are summarized in Table 4.26 while the complementary log-log plots are graphed in Figure 4.14.

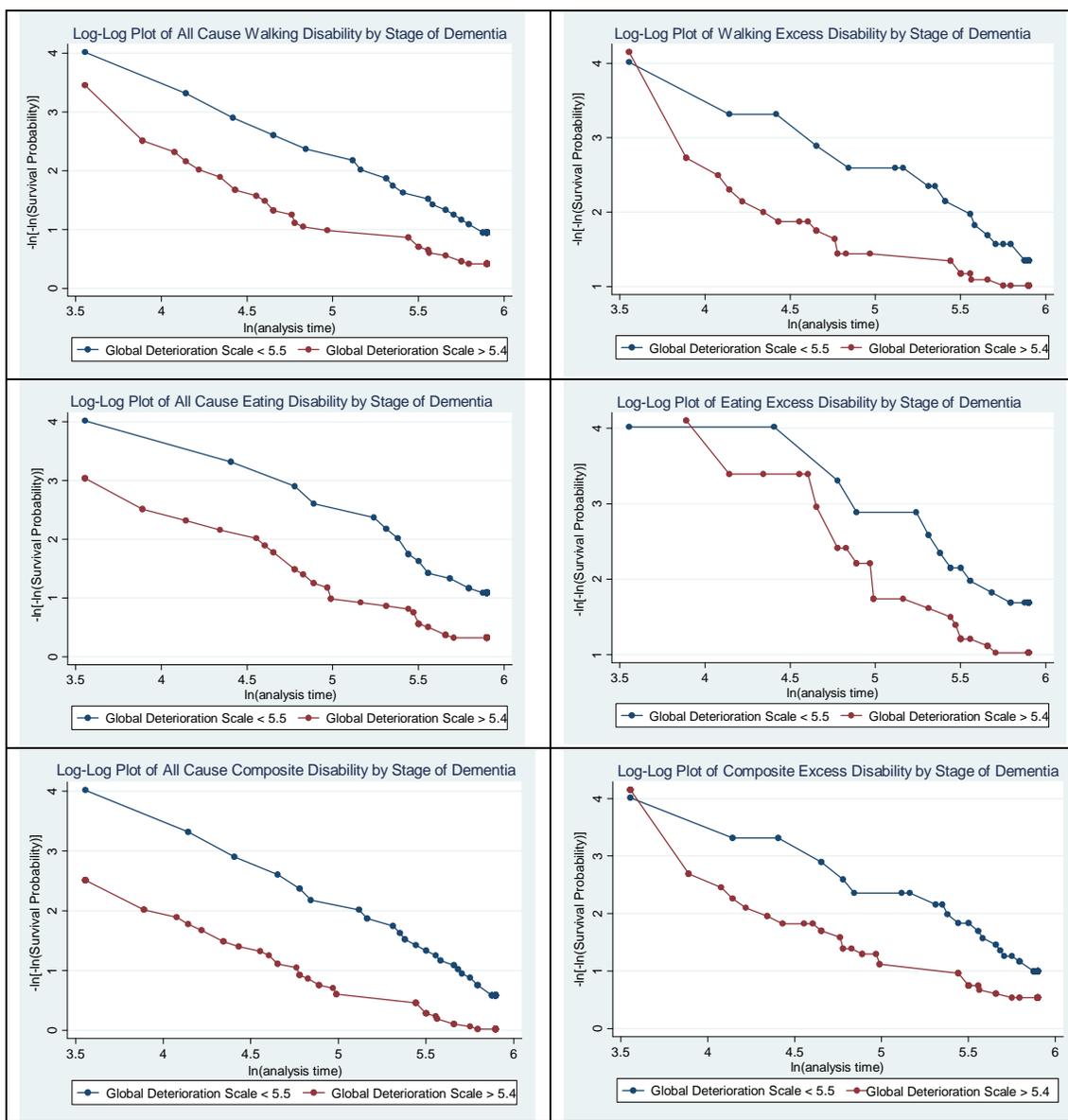
**Table 4.26 Schoenfeld residual test results for each of the final models of disability by stage of dementia**

Outcome for each final model	Schoenfeld proportional hazards test p- value
All-cause walking disability	0.34
Walking excess disability	0.20
All-cause eating disability	0.53
Eating excess disability	0.57
All-cause composite disability	0.12
Composite excess disability	0.53

The Schoenfeld residual proportional hazards test for each of the six final models suggest that there is no evidence against the null hypothesis of proportional hazards for any of the final models. Visual inspection of the complementary log-log plots below in Figure 4.14 corroborates the Schoenfeld residual test results suggesting that the proportional hazards assumption holds for each of the final models: each of the six plots displays roughly parallel lines. The only cross over occurred for early time points in three of the graphs.

Otherwise there was roughly a constant difference between each pair of lines without too much evidence of funneling.

**Figure 4.14 Log-log plots of disability outcomes by stage of dementia**



### *Time-Varying Covariates*

#### Relocation

Relocation from one living environment to another was considered as a potential time-varying covariate since residents did relocate during the study. Some moved between rooms within the same nursing unit (n=12), some moved between nursing units within the same care centre (n=6), and some moved between care centres (n=8). Five of these residents moved twice in one year. Of the residents who moved, 43% experienced a composite outcome compared with 56% who did not move. Furthermore, in only one instance did a move occur within 6 weeks of a loss of either walking or eating ability. Since functional loss did not appear to be associated with relocation, time-varying covariate analysis was not completed for the environmental variables.

Analysis of all of the psychotropic drug variables has focused on the drugs being taken at baseline, however occasionally drugs were discontinued or introduced after the baseline data collection with subsequent functional loss in the ability to walk or eat. Therefore all four drug variables were analyzed further as time-varying covariates in the Cox regression models for each of the six outcomes.

#### Cognitive Enhancer Drugs

Six residents had the baseline cognitive enhancer discontinued during the course of the study and one resident had a cognitive enhancer prescribed once the study was underway. There were two events that took place following the discontinuation of the cognitive

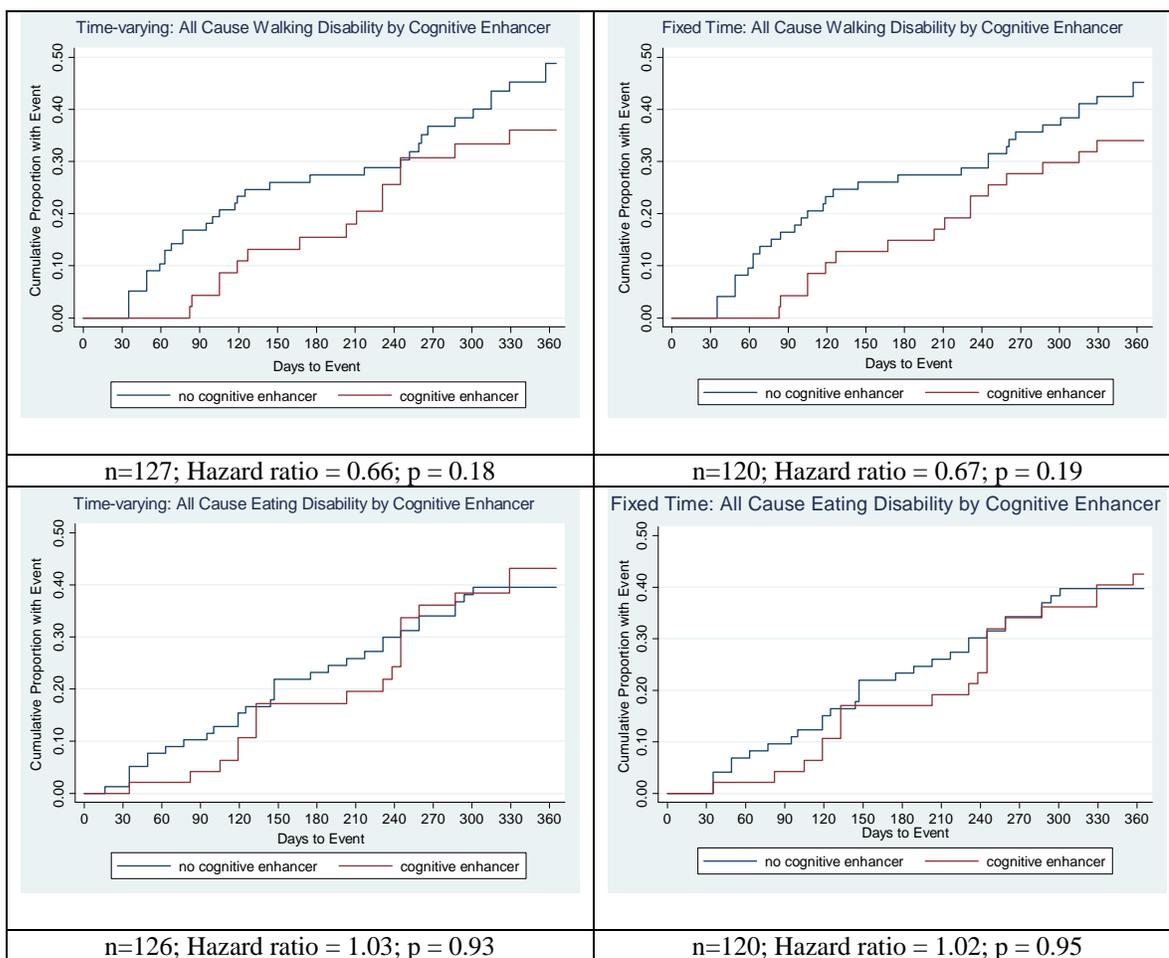
enhancer drugs: one walking event and one eating event. Both were coded as due to dementia. In Table 4.27 the time-varying Cox regression analysis of outcomes for cognitive enhancer use is compared to the fixed time analysis.

**Table 4.27 Fixed and time-varying cognitive enhancer drugs in bivariate Cox regression**

Covariate	Outcome	Status	Hazard ratio	95% CI	p-value
Cognitive enhancer	All-cause walking disability	Varying	0.66	0.36 – 1.21	0.18
		Fixed	0.67	0.37 – 1.22	0.19
	Walking excess disability	Varying	0.38	0.15 – 0.92	<b>0.03</b>
		Fixed	0.35	0.14 – 0.85	<b>0.02</b>
	All-cause eating disability	Varying	1.03	0.58 – 1.83	0.91
		Fixed	1.02	0.58 – 1.80	0.95
	Eating excess disability	Varying	0.76	0.33 – 1.77	0.53
		Fixed	0.69	0.30 – 1.60	0.39
	All-cause composite disability	Varying	0.67	0.40 -1.15	0.15
		Fixed	0.65	0.39 -1.10	0.11
	Composite excess disability	Varying	0.43	0.21 – 0.91	<b>0.03</b>
		Fixed	0.39	0.18 – 0.81	<b>0.01</b>

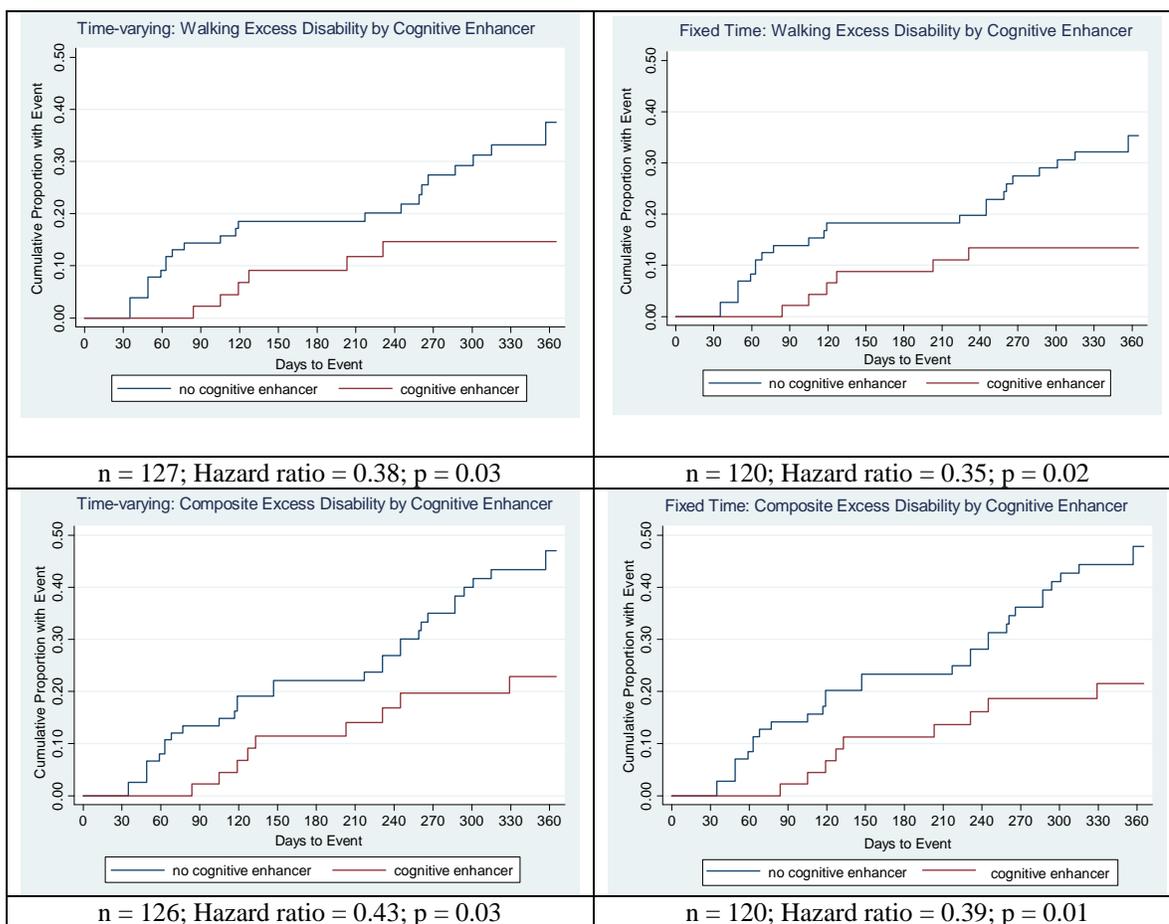
The graphs in Figure 4.15 below compare the time-varying with the fixed bivariate analysis of all-cause walking disability and all-cause eating disability with cognitive enhancer use. Data summarized in the table above and illustrated in the graphs below demonstrate that there was a minimal effect on the hazard ratios and p-values by correcting the misclassified events through time-varying analysis.

**Figure 4.15 Kaplan-Meier failure curves of time-varying and fixed time cognitive enhancer use for all-cause walking disability and all cause eating disability**



Excess disability in walking and the associated composite excess disability outcome in relation to cognitive enhancer drug use were the only statistically significant findings in the Cox regression analysis of all the psychotropic drugs. These time-varying and fixed time Kaplan-Meier failure curves appear in Figure 4.16 below.

**Figure 4.16 Kaplan-Meier failure curves of time-varying and fixed time cognitive enhancer use for walking excess disability and composite excess disability**



When the time-varying cognitive enhancer variable was included in the multivariate modeling process for the walking excess disability outcome, the findings changed for all of the variables in the model. Comorbidity became a covariate and the quality of the environment became a confounder, while cognitive enhancer and antidepressant drugs were no longer part of the model. Furthermore the relationship between walking excess

disability and stage of dementia became stronger. A comparison of the final model with fixed time for the cognitive enhancer at baseline, and the final model with time-varying cognitive enhancer are summarized in Table 4.28 below.

**Table 4.28 Final models for walking excess disability comparing the fixed and time-varying cognitive enhancer variable**

Final Models	Variables in each model	Effect of variables	Hazard ratio	95% Confidence interval	p-value
Walking excess disability (fixed)	<b>Stage of dementia</b>		<b>1.34</b>	<b>0.64 – 2.80</b>	<b>0.44</b>
	Comorbidity category	none			
	Cognitive enhancer	covariate	0.34	0.14 – 0.83	0.02
	Antidepressant	covariate	2.07	1.00 – 4.29	0.05
	Quality of environment	none			
Walking excess disability (time-varying)	<b>Stage of dementia</b>		<b>1.99</b>	<b>0.94 – 4.21</b>	<b>0.07</b>
	Comorbidity category	covariate	2.48	1.16 – 5.32	0.02
	Cognitive enhancer	none			
	Antidepressant	none			
	Quality of environment	confounder	0.46	0.22 – 0.98	0.04

When the time-varying cognitive enhancer variable was included in the multivariate model for the *composite excess disability* outcome very little changed. The hazard ratios and the confidence intervals were very similar. The quality of the environment remained a confounder while comorbidity and baseline antidepressant use remained covariates. A comparison of the final fixed time model with the time-varying cognitive enhancer model is summarized in Table 4.29 below.

**Table 4.29 Final models for composite excess disability comparing the fixed and time-varying cognitive enhancer variable**

Final Models	Variables in each model	Effect of variables	Hazard ratio	95% Confidence interval	p-value
Composite excess disability (fixed)	<b>Stage of dementia</b>		<b>1.90</b>	<b>0.98 – 3.68</b>	<b>0.06</b>
	Comorbidity category	covariate	2.28	1.17 – 4.41	0.02
	Cognitive enhancer	covariate	0.44	0.21 – 0.92	0.03
	Antidepressant	covariate	2.02	1.06 – 3.88	0.03
	Quality of environment	confounder	0.46	0.24 – 0.90	0.02
Composite excess disability (time-varying)	<b>Stage of dementia</b>		<b>2.16</b>	<b>1.12 – 4.15</b>	<b>0.02</b>
	Comorbidity category	covariate	2.48	1.29 – 4.77	0.01
	Cognitive enhancer	none			
	Antidepressant	none			
	Quality of environment	confounder	0.51	0.27 – 0.97	0.04

### Neuroleptic Drugs

Three residents had a neuroleptic discontinued and three residents had a neuroleptic prescribed during the period of observation. Three other residents had two changes in their neuroleptic drug status. Although there were two walking events and three eating events among this subset of residents, the timing of the changes in the neuroleptic drug resulted in only two instances of incorrectly attributing an excess disability eating event to the presence or absence of the neuroleptic. In these two cases the neuroleptic was misclassified as present, when in fact it was discontinued at least three months prior to each event. The misclassification of the two eating events explains why there is a difference in the pairs of hazard ratios for the two eating outcomes listed in Table 4.30 below, while the absence of any misclassification of walking events explains why there is little difference in the pairs of hazard ratios for the two walking outcomes.

**Table 4.30 Fixed and time-varying neuroleptic drugs in bivariate Cox regression**

Covariate	Outcome	Status	Hazard ratio	95% CI	p-value
Neuroleptic	All-cause walking disability	Varying	1.04	0.59 – 1.84	0.89
		Fixed	0.98	0.56 – 1.74	0.95
	Walking excess disability	Varying	0.76	0.36 – 1.62	0.48
		Fixed	0.72	0.34 – 1.54	0.40
	All-cause eating disability	Varying	0.84	0.47 – 1.50	0.55
		Fixed	1.00	0.56 – 1.76	0.99
	Eating excess disability	Varying	0.96	0.43 – 2.14	0.92
		Fixed	1.34	0.61 – 2.93	0.47
	All-cause composite disability	Varying	0.93	0.56 – 1.53	0.77
		Fixed	1.05	0.64 – 1.73	0.84
	Composite excess disability	Varying	0.78	0.41 – 1.50	0.46
		Fixed	0.96	0.51 – 1.82	0.91

### Benzodiazepine Drugs

Three residents had a benzodiazepine discontinued during the course of the study and two residents had a benzodiazepine prescribed after the study had commenced. Four of these five residents experienced no event; however one resident had a walking event and an eating event which were misclassified by relying on the baseline status of benzodiazepine drug usage. She began to receive Ativan 65 days after entering the study and 62 days prior to falling and sustaining a hip fracture. Following her return to the nursing home post-surgery she was observed to be fed by one of the nurse aides. Time-varying analysis correctly attributes these walking and eating events to the presence of the benzodiazepine. Following the change in benzodiazepine status, these walking and eating events coded as excess disability, account for the differences observed between the fixed and varying covariate analyses summarized in Table 4.31 below.

**Table 4.31 Fixed and time-varying benzodiazepine drugs in bivariate Cox regression**

Covariate	Outcome	Status	Hazard ratio	95% CI	p-value
Benzodiazepine	All-cause walking disability	Varying	1.40	0.70 – 2.80	0.35
		Fixed	1.14	0.55 – 2.36	0.72
	Walking excess disability	Varying	1.65	0.71 – 3.86	0.25
		Fixed	1.27	0.52 – 3.11	0.60
	All-cause eating disability	Varying	1.08	0.51 – 2.31	0.84
		Fixed	0.75	0.34 – 1.66	0.47
	Eating excess disability	Varying	1.09	0.37 – 3.17	0.88
		Fixed	0.61	0.18 – 2.05	0.43
	All-cause composite disability	Varying	1.29	0.69 – 2.42	0.43
		Fixed	1.04	0.55 – 2.00	0.90
	Composite excess disability	Varying	1.63	0.77 – 3.42	0.20
		Fixed	1.26	0.58 – 2.74	0.56

### Antidepressant Drugs

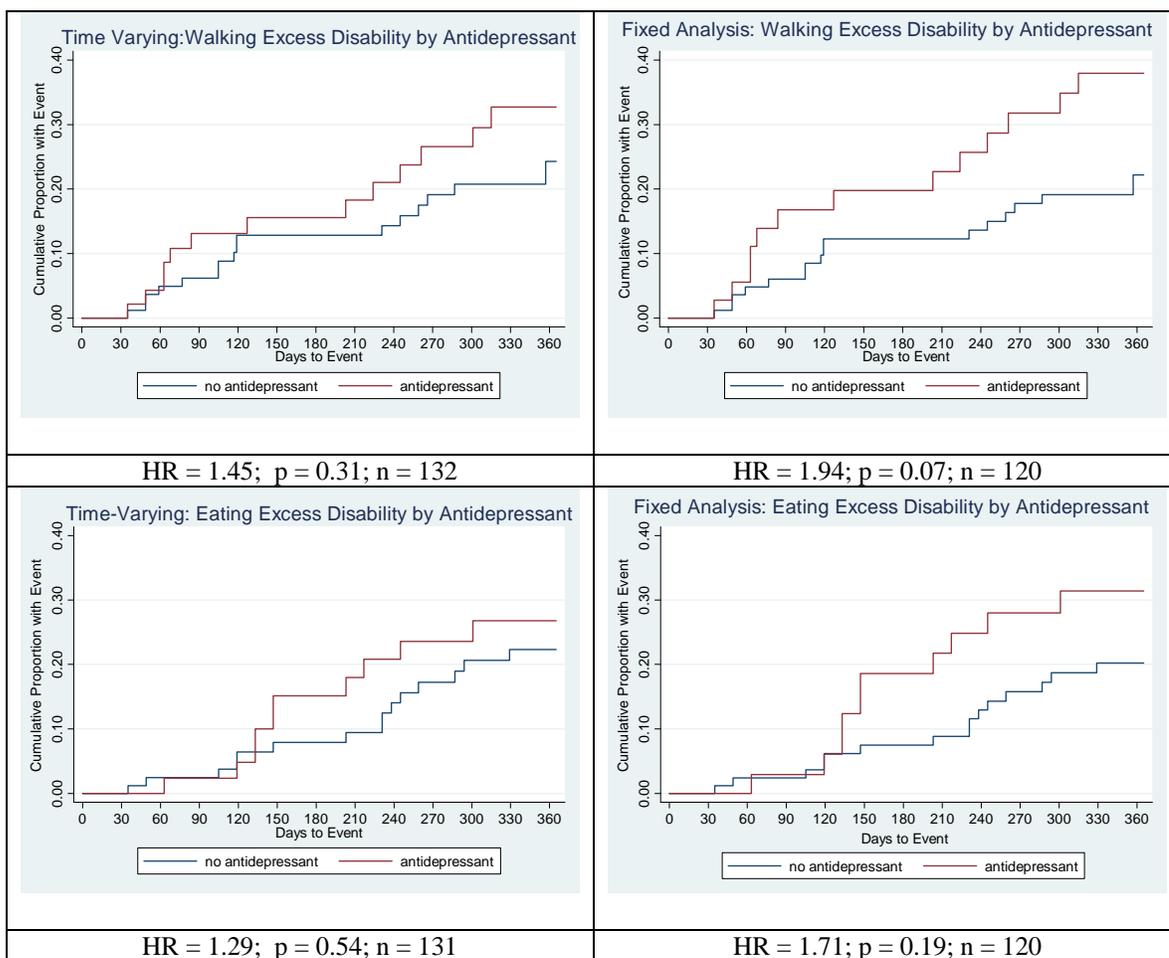
Twelve residents had an antidepressant prescribed once the study was underway. No one had an antidepressant discontinued. Of these twelve residents, four experienced at least one event for which the time-varying analysis corrected the misclassification. Three of these events were all-cause walking disability and three were all-cause eating disability. As is evident in Table 4.32 the time-varying antidepressant analysis moderated the effect size. This was particularly true for the three excess disability outcomes.

**Table 4.32 Fixed and time-varying antidepressant drugs in bivariate Cox regression**

Covariate	Outcome	Status	Hazard ratio	95% CI	p-value
Antidepressant	All-cause walking disability	Varying	1.30	0.73 – 2.30	0.37
		Fixed	1.36	0.76 – 2.45	0.31
	Walking excess disability	Varying	<b>1.46</b>	0.71 – 3.01	0.31
		Fixed	<b>1.94</b>	0.94 – 3.99	0.07
	All-cause eating disability	Varying	1.29	0.73 – 2.28	0.38
		Fixed	1.36	0.75 – 2.44	0.31
	Eating excess disability	Varying	<b>1.24</b>	0.56 – 2.76	0.60
		Fixed	<b>1.71</b>	0.77 – 3.80	0.19
	All-cause composite disability	Varying	1.25	0.76 – 2.07	0.38
		Fixed	1.31	0.78 – 2.21	0.31
	Composite excess disability	Varying	<b>1.30</b>	0.69 – 2.45	0.42
		Fixed	<b>1.79</b>	0.95 – 3.37	0.07

The Kaplan-Meier failure curves which are plotted in Figure 4.17 compare the time-varying and fixed analysis of antidepressant use for both the walking excess disability and eating excess disability outcomes. These graphs illustrate the moderating effect of the time-varying analysis on the hazard associated with the antidepressant.

**Figure 4.17 Kaplan-Meier failure curves of time-varying and fixed time antidepressant use for walking excess disability and eating excess disability**



When the time-varying antidepressant variable was included in the multivariate model for composite excess disability the findings were essentially unchanged for all of the variables except the antidepressant. The quality of the environment remained a confounder, and comorbidity and baseline cognitive enhancer use remained covariates, however the time-varying antidepressant variable was no longer a covariate. A

comparison of the fixed time model for the antidepressant at baseline with time-varying antidepressant model appears in Table 4.33 below.

**Table 4.33 Final models for composite excess disability comparing the fixed and time-varying antidepressant variable**

Final Models	Variables in each model	Effect of variables	Hazard ratio	95% Confidence interval	p-value
Composite excess disability (fixed)	Stage of dementia		1.90	0.98 – 3.68	0.06
	Comorbidity category	covariate	2.28	1.17 – 4.41	0.02
	Cognitive enhancer	covariate	0.44	0.21 – 0.92	0.03
	<b>Antidepressant</b>	<b>covariate</b>	<b>2.02</b>	<b>1.06 – 3.88</b>	<b>0.03</b>
Composite excess disability (time-varying)	Quality of environment	confounder	0.46	0.24 – 0.90	0.02
	Stage of dementia		2.02	1.05 – 3.91	0.04
	Comorbidity category	covariate	2.29	1.18 – 4.42	0.01
	Cognitive enhancer	covariate	0.46	0.22 – 0.98	0.04
	<b>Antidepressant</b>	<b>none</b>			
	Quality of environment	confounder	0.51	0.27 – 0.98	0.04

### *Summary of the Results*

Forty-nine (41%) residents who were followed every two weeks over the course of a year experienced a loss in the ability to walk and 49 (41%) experienced a loss in the ability to eat. More than half of these functional losses (61% walking and 51% eating) were due to excess disability.

The mean number of attributions identified and actions reported for both walking and eating disability were not significantly different for each category of respondent with one

exception. Family members identified significantly more attributions for the loss of ability to walk than did staff members (p-value = 0.02).

There were fewer respondents (26%) who attributed a walking disability to dementia compared with those who attributed a walking loss to excess disability. When a loss of walking ability was attributed to excess disability the actions reported were more oriented to assessment and treatment than when a walking disability was attributed to dementia.

Both family and staff members were more likely to attribute the loss of the ability to eat to dementia (56% and 63% of attributions respectively) than to the loss of the ability to walk (26% of attributions by both). Supportive interventions such as socialization, supervision, and encouragement to eat were reported on 25 occasions for eating disability attributed to dementia but on only 12 occasions for disability attributed to something other than dementia. In contrast, more vigilant types of intervention such as communication, information seeking, and monitoring were reported more often (on ten occasions) when eating disability was attributed to something other than dementia than when eating disability was attributed to dementia (on zero occasions).

Adjusting for the score on the Charlson Comorbidity Index and the quality of the environment as measured by the Professional Environmental Assessment Protocol, residents who were more advanced in their stage of dementia were estimated to experience twice (2.1 times) the hazard of a *loss in the ability to walk for any reason*

compared with residents who were less advanced in their stage of dementia (95% confidence interval 1.18 to 3.83, p-value = 0.01).

Adjusting for the score on the Charlson Comorbidity Index and the quality of the environment as measured by the Professional Environmental Assessment Protocol, and incorporating the time-varying cognitive enhancer variable into the model, residents who were more advanced in their stage of dementia were estimated to experience twice the hazard of *excess disability in walking* compared with residents who were less advanced (95% confidence interval 0.94 to 4.21, p-value = 0.07).

Adjusting for the score on the Charlson Comorbidity Index, the duration of admission in the nursing home, and the dementia education of the staff members, residents who were more advanced in their stage of dementia were estimated to have 2.3 times the hazard of experiencing a *loss in the ability to eat for any reason* compared with residents who were less advanced (95% confidence interval 1.25 to 4.14, p-value = 0.01). Residents who were more advanced in their stage of dementia were estimated to have twice the hazard of experiencing *excess disability in eating* compared with residents who were less advanced (95% confidence interval 0.88 to 4.51, p-value = 0.10).

Adjusting for the score on the Charlson Comorbidity Index and the quality of the environment as measured by the Professional Environmental Assessment Protocol, residents who were more advanced in their stage of dementia were estimated to have two

and a half times the hazard of experiencing a *loss in the ability to walk or to eat for any reason* compared with residents who were less advanced (95% confidence interval 1.50 to 4.27, p-value = 0.001).

Adjusting for the score on the Charlson Comorbidity Index, the use of a cognitive enhancer at baseline, time-varying antidepressant use, and the quality of the environment as measured by the Professional Environmental Assessment Protocol, residents who were more advanced in their stage of dementia were estimated to have twice the hazard of experiencing *excess disability in either walking or eating* compared with residents who were less advanced in their stage of dementia (95% confidence interval 1.05 to 3.91, p-value = 0.04).

## CHAPTER FIVE – DISCUSSION

In the interest of improving the quality of life of the growing number of people with middle stage dementia, this study investigated the experience of walking and eating disability in a cohort of 120 people with middle stage dementia who live in nursing homes in a western Canadian city. The aim was to identify, to differentiate between, to predict, and to understand the disability associated with dementia, which is progressive and irreversible, and excess disability which has the potential to be improved. The study showed that excess disability in walking and eating can be identified and predicted, and was distinct from disability related to dementia. Furthermore, this distinction was evident in the experience of the transition from ability to disability as described by family members and nursing staff that interacted regularly with the members of the cohort.

This chapter opens with the definition, differentiation, and discussion of the three types of disability that were investigated in this study. This is followed by a discussion of the predictors of the three types of disability. Then the transition from ability to disability is discussed in relation to the attributions and actions of family and staff members. Next methodological considerations will be discussed including the strengths and limitations of the study, and the implications for future research. The chapter concludes with a discussion of the practice, education, and policy implications of the study. As the discussion unfolds, the three main constructs of the Functional Transitions Model will be

addressed: disability in people with dementia, excess disability in people with dementia, and the functional transitions experienced by people with dementia (Slaughter et al., 2007).

### **Disability**

This section of the discussion characterizes three distinct and clinically meaningful subtypes of disability. Because the inability to walk or to eat at baseline was an exclusion criteria for participation in the study these instances of disability represent incident cases. All-cause disability, excess disability, and composite disability will be discussed below in terms of the definition of disability, the incidence of disability, and how these findings relate to similar findings in the literature.

#### *All Cause Disability*

Disability is defined as “an inability or limitation in performing socially defined roles and tasks expected of an individual within a sociocultural and physical environment” (Nagi, 1991, p. 315). In this study any observed loss of ability to walk or to eat for any reason is termed either all-cause walking disability or all-cause eating disability. The operational definition of an all-cause walking disability denotes when a resident is observed either to use a wheelchair to mobilize to the dining room or to remain in bed. The operational definition of an all-cause eating disability denotes when a resident does not eat during a meal, or receives the physical assistance of another person to eat part or all of a meal.

The Kaplan-Meier estimate of the proportion of residents with middle stage dementia who experienced a new onset of walking disability for any reason during the course of a year is 0.41. The proportion is identical for those who experienced a new onset of eating disability for any reason. It is somewhat surprising that the incidence of walking disability was the same as the incidence of eating disability since, with the hierarchical profile of loss of activities of daily living for people with dementia, walking loss generally occurs during the middle stage of dementia while eating loss occurs during the late stage (Morris et al., 1999; Njegovan et al., 2001). One would have expected less eating disability in this sample of people with middle stage dementia.

This higher than expected incidence of eating disability may be explained by looking more closely at the definition of disability and the timing of the losses in ability. An all-cause eating disability was defined as not eating at mealtime, or receiving physical assistance to eat part or all of a meal. Although the definition was clear, the operationalization of the definition was ambiguous at times. For example, during one observation a resident would be physically assisted to eat, while during a subsequent observation the same resident would slowly eat a small portion of a meal with many prompts over an extended period of time. In this study the frequent observation intervals revealed that the onset of the loss of the ability to eat was gradual rather than a sudden and complete loss of ability. Other epidemiological studies have not gathered data in less than one month intervals. Much of the data has been based on secondary analysis of

administrative data sets or on the reports of formal or informal caregivers. Thus the subtle and gradual changes in ability would not have been detected in these studies.

In a prospective study of disability in basic activities of daily living the distinction between difficulty and dependence as two components of the disability continuum was investigated (Gill et al., 1998). Community-dwelling older adults (n=1065) were followed monthly over three years. Those who were independent but with difficulty in basic activities of daily living experienced hospitalization, nursing home admission, and mortality outcomes that were intermediate to those who were independent without difficulty and those who were dependent. The researchers concluded that difficulty and dependence offer complementary information in the continuum of disability. In the current study it may be that the definition of walking disability was tapping the dependence component of disability while the definition of eating disability was tapping the difficulty component.

Although the incidence of walking disability was estimated to be the same as the incidence of eating disability over the course of a year, the timing of the losses in ability was not. The median time of onset of an all-cause walking disability was 144 days while the median time of onset of an all-cause eating disability was 175 days. This difference of a month in median time of onset is consistent with the expectation that eating disability would occur later than walking disability.

Only a few of the longitudinal studies of function of people with dementia reported changes in the specific activities of walking and eating (Brickman et al., 2002; Carpenter et al., 2006; Chen et al., 2007; Covinsky et al., 2003; Njegovan et al., 2001) and only one of these included a sample of people with middle-stage dementia who lived in a nursing home (Carpenter et al., 2006). One investigation included data only on disability in eating (Brickman et al., 2002) and four included data on disability in walking and eating (Carpenter et al., 2006; Chen et al., 2007; Covinsky et al., 2003; Njegovan et al., 2001). A summary of the findings of these studies follows.

Njegovan et al., (2001) report that the pattern of loss of ability to walk and to eat over a five year period in 5874 older Canadians is related to progressive cognitive decline, however only 14% of the sample had a dementia diagnosis at baseline and there was no separate analysis for this diagnostic subgroup. The functional abilities of another cohort of 230 people with mild to moderate Alzheimer disease with a mean age of 73 years were evaluated prospectively by caregivers at six month intervals. After six years 50% of the cohort needed to be fed (Brickman et al., 2002). The young age and early stage of this cohort with dementia explains why the sample did not require assistance with eating until much later than the residents in the current study.

Two retrospective cohort studies of functional decline during the last year of life included people with late stage dementia (Chen et al., 2007; Covinsky et al., 2003). The participants in Chen et al.'s study needed extensive assistance in eating and were almost

totally dependent in walking at baseline. Therefore these data are not comparable with the findings in the current cohort of people with middle stage dementia. In the other retrospective end-of-life cohort study, 56% of 583 community-dwelling older adults with cognitive impairment, who met the criteria for a nursing home admission, lost the ability to walk during the last two years of life, and 49% lost the ability to eat (Covinsky et al., 2003). These proportions of functional loss are roughly similar to those in the current study in that the proportion losing the ability to walk is not very different from the proportion losing the ability to eat. However, Covinsky et al.'s findings are not directly comparable to the functional outcomes in the current study because participants in the former did not necessarily have a dementia diagnosis, they were not necessarily independent in the ability to walk or to eat at the beginning of the two year study period, and they were followed for two years rather than one.

In another prospective longitudinal study of 7001 nursing home residents with moderate dementia, functional change in locomotion and eating were assessed using the Minimum Data Set-Activities of Daily Living scale at baseline, three months and six months (Carpenter et al., 2006). In a six month period 27% showed a decline in the ability to walk while 29% showed a decline in the ability to eat. Carpenter et al.'s sample and findings are comparable with those of the current study: residents with middle-stage dementia who lived in a nursing home lost the ability to walk and to eat in approximately the same proportion.

*Excess Disability*

Excess disability is defined as the discrepancy between existing and potential functional capacity which is greater than that warranted by any irreversible cognitive, physical, or affective impairment (Brody, 1971; Kahn, 1965; Rogers et al., 2000). In the current study excess disability in walking and eating was operationally defined in two ways. Firstly excess disability was coded based on the concordance of the family and staff member attributions, and secondly was based on the transient nature of the disability. Thus if both interview respondents attributed the functional loss to something other than dementia or if, in the absence of an interview, the ability was regained, then the event was coded as excess disability.

This is not the first study to define disability in function based on the duration of disability episodes. Gill et al. (2008) characterize five distinct subtypes of disability (transient, short-term, long-term, recurrent, and unstable) in a community-dwelling sample of 2503 relatively young older adults who did not have dementia. With the exception of the definition for long-term disability, the definitions of all of these types of disability are based on the timing of a recovery of ability in basic activities of daily living.

In the current study the proportion of people with middle stage dementia who experienced a new onset of excess disability in walking over the course of a year is

estimated to be 0.27 while the proportion of people who experienced a new onset of excess disability in eating is estimated to be 0.24. As was the case for all-cause disability, the proportions of residents experiencing walking and eating excess disability are similar. Thus just over half of all of the disability events are estimated to be due to excess disability.

It is not possible to compare these findings with other studies because no others have attempted to estimate the incidence of excess disability in walking or eating in people with dementia. Several studies report the prevalence of excess disability at the time of a dementia diagnosis although the specific type of functional loss is not usually identified. Using Reifler et al.'s definition of excess disability (a treatable problem superimposed on dementia; 1987, p. 207), Walstra et al. (1997) claim to have identified 78 (66%) people with excess disability in a sample from a memory clinic. In fact they identified 78 people with diagnoses that were treatable, including 38 people with new diagnoses, but these were not instances of excess disability as defined in the current study. Only five of these outpatients with Alzheimer disease in Walstra's study demonstrated functional improvement following the treatment of their medical conditions. This relatively low frequency of functional improvement may be explained in part by the limitation of an exclusively biomedical approach to disability in people with dementia in an outpatient medical clinic which does not include a psycho-socio-environmental therapeutic approach.

In the Canadian Study of Health and Aging, a population-based study of older adults, the prevalence of excess disability was estimated in people with dementia in six basic activities of daily living (bathing, dressing, grooming, toileting, urinary continence, and bowel incontinence) (Thomas, 2001). Conditions that are commonly associated with the development of physical disability in older adults were adjusted in the analysis, and then the disability of those with dementia was compared to those without dementia. After adjusting for age, sex, cognitive function, a set of medical diagnoses, sensory impairment, gait abnormalities, a history of falling, and depression, the prevalence of disability for those with dementia and for those without dementia was estimated to be, respectively, 16% and 11% for bathing, 14% and 5% for dressing, 8% and 6% for grooming, 6% and 4% for toileting, 20% and 18% for urinary incontinence, and 3% and 4% for bowel incontinence. Based on these findings it was concluded that people with dementia experienced disability in excess of the disability experienced by people without dementia for these activities. Thomas' conceptualization of 'excess disability' differs from the current study in that the notion of excess is relative to other people without dementia rather than relative to uncomplicated functional loss due to dementia.

#### *Composite Disability*

Functional loss in walking and eating was combined to create a pair of 'composite' disability outcomes. Since the event-free survival analysis in this study does not account for repeated events the all-cause composite disability is defined as the first episode of all-cause disability experienced by a resident, be it walking or eating all-cause disability.

Similarly, composite excess disability is defined as the first episode of excess disability experienced by a resident, be it walking or eating excess disability.

Precedents have been set for measuring function as a composite outcome. In fact most studies of functional change in people with dementia report a change in the total score on measures of basic activities of daily living, instrumental activities of daily living, or both (Aguero-Torres et al., 2002b; Berg et al., 1988; Brickman et al., 2002; Feldman et al., 2001; Green et al., 1993; Hogan et al., 1994; Holmes et al., 2003; Holtzer et al., 2003b; Huff et al., 1990; Jacobs et al., 1994; Lucca et al., 1993; McCann et al., 2000; Morris et al., 1993; Nyenhuis et al., 2002; Perrault et al., 2002; Reimer et al., 2004; Schmeidler et al., 1998; Sloane et al., 2005; Suh et al., 2004). These studies all used composite measures of function.

The use of composite outcomes provides the advantage of statistical efficiency but has the disadvantage of interpretation difficulty (Ross, 2007). The use of a single composite outcome composed of several contributing outcomes increases the number of events that can be studied and thus increases the statistical power of a study. In the current study combining walking and eating disability did increase the number of events for survival analysis from 49 all-cause walking disability events and 49 all-cause eating disability events, to 64 all-cause composite disability events. Not all functional losses were included in the composite outcome because some residents experienced functional loss in both walking and eating.

The main disadvantage of a composite outcome or a composite measure is the difficulty in interpreting the outcome or measurement score. For example composite ratings of functional ability can include several constituent activities ranging from the use of the telephone to the ability to drive, in the case of instrumental activities (e.g., Instrumental Activities of Daily Living Scale, Lawton, 1969), and from the ability to bathe to the ability to eat in the case of basic activities (e.g., Index of ADL, Katz et al., 1963). The resulting total score provides a general or global measure of the functional status of the person which may be useful for program evaluation, however the total score on a composite measure does not provide sufficient specificity required to guide clinical practice in relation to the constituent activities.

Unless the constituent factors of a measure have demonstrated psychometric properties that are related to the construct to be measured, the total composite score has limited conceptual meaning. Although no measure or score is being used in the current study, the combination of walking and eating disability outcomes generates a composite disability outcome with uncertain meaning. The walking outcome is distinct from the eating outcome. While both are motor outcomes walking relies on gross motor skills while eating relies on fine motor skills requiring coordination and concentration.

Although the composite outcome of 'first disability outcome' is not as readily interpretable as 'walking disability' or 'eating disability', nevertheless the estimate of

composite excess disability does have some clinical utility. It captures the activities that families see when they visit their relatives in nursing homes. Compared to bathing, dressing, or toileting, walking and eating are the basic activities of daily living that may still be preserved in nursing home residents with dementia and that are easily and publically accessible for monitoring by both families and members of the health care team.

The one year Kaplan-Meier estimate of the proportion of residents who experienced an all-cause composite disability is 0.53, while the one year Kaplan-Meier estimate of the proportion of residents experiencing a composite excess disability is 0.38. Once again there are no comparable estimates of this type of disability in the literature. Disability estimates that have been reported are either for one activity of daily living or are for a composite outcome which includes many more activities than just walking and eating. The proportion of residents experiencing some type of disability and excess disability in one year is substantial and will be discussed further in the section entitled “implications for practice, education and policy.”

### **Predictors of Disability**

This study contributes to the literature by identifying predictors of functional disability in people with dementia. In particular the study assesses the influence of resident-specific and facility-specific variables that predict both disability and excess disability in people with middle-stage dementia living in nursing homes.

### *Stage of Dementia*

As expected, the hazard of experiencing any of the three all-cause disability outcomes was significantly greater for residents who were more advanced in their stage of dementia than for those who were less so. In the bivariate Cox regression analysis more advanced dementia, as measured by a score of greater than 5.4 on the Global Deterioration Scale, was a statistically significant predictor of all-cause disability for the walking, eating, and composite outcomes. This finding is consistent with extensive previous research and the generally accepted understanding that losses in functional ability increase as Alzheimer disease and related dementias progress to more advanced stages (Albert et al., 1992; Berg, 1988; Eisdorfer et al., 1992; Hughes et al., 1982; McConnell et al., 2003; Morris et al., 1999; Njegovan et al., 2001; Reisberg, 1982, 1986, 1988a, 1988b; Saxton et al., 1990; Sheridan et al., 2007; Volicer et al., 1994).

Since the progression of dementia is associated with progressive functional loss, stage of dementia was treated a priori as a privileged variable in the multivariate modeling process. Thus all of the other potential predictor variables were assessed for their effect on the relationship between the stage of dementia and the six disability outcome variables. After adjusting for all of the covariates in the multivariate analysis, the relationships between the stage of dementia and the three all-cause disability outcomes remained statistically significant.

However, in the bivariate Cox regression analysis a more advanced stage of dementia was not a statistically significant predictor of excess disability for the walking or eating outcomes, although there was a trend towards significance for the composite excess disability outcome. After adjusting for all of the covariates in the multivariate analysis, the relationships between the stage of dementia and the three excess disability outcomes remained not statistically significant, although once again there was a trend towards significance for the composite excess disability outcomes. The absence of a statistically significant relationship between stage of dementia and any of the excess disability outcomes in the presence of strong statistically significant relationships in the all-cause disability outcomes supports the identification of excess disability as a distinct and separate construct from disability associated with dementia. This distinction is particularly striking since the 'all-cause' disability outcomes included both disabilities due to dementia and due to excess disability. It might have been expected that the inclusion of the excess disability events in the all-cause disability outcome would moderate the relationship between all-cause disability and stage of dementia.

Although the hazards for both disability to walk and disability to eat are significantly increased with more advanced dementia, stage of dementia appears to have a somewhat stronger influence on all-cause eating disability than all-cause walking disability. It is estimated that residents with more advanced dementia have 2.3 times the hazard of experiencing an all-cause eating and 1.8 times the hazard of experiencing an all-cause walking disability compared with those who have less advanced dementia. The interview

data support this trend as family and staff member respondents attributed eating disability to dementia for 56% and 63% of the residents discussed, while both groups attributed walking disability to dementia for only 26% of the residents discussed.

Until recently walking has been considered to be an automatic process involving reflexes and requiring little involvement from the motor cortex (Dietz, 1997). Consistent with this thinking, some measures of dependence in activities of daily living for people with dementia include eating but do not include walking (Gelinis et al., 1999; Stern et al., 1994b). Neurophysiological evidence from the last ten years suggests that the motor cortex is more instrumental in walking than previously thought (Capaday, 2002; Nielsen, 2003). Walking is now thought to be based on an integration of spinal reflexes, sensory feedback, motor cortex activity, and transcortical reflex pathways (Nielsen, 2003). Furthermore, executive function and attention may play a role in gait disturbance (Yogev-Seligmann et al., 2008). Clinicians are beginning to appreciate the implications of this evidence for clinical practice (Sheridan et al., 2007; Yang et al., 2006). In particular the increased risk of falls in people with dementia (Buchner et al., 1987; Imamura et al., 2000; Morris et al., 1987; Weller et al., 2004) may be explained by the role of higher order cognitive function in walking that is adversely affected by the cognitive impairment associated with Alzheimer disease (Sheridan et al., 2007; Yang et al., 2006; Yogev-Seligmann et al., 2008).

Eating on the other hand is an activity of daily living that has been conceptualized to require cognitive processing comprising spontaneous initiation, planning and organization, and performance (Gauthier et al., 1997, G  linas et al., 1999). Apraxia, or impairment in the ability to execute complex coordinated movements, is a motor disorder resulting from brain impairment and is classified by a two-system model of action: a conceptual system and a production system (Leiguarda et al., 2000). This inability to effectively plan and carry out a motor act has been observed in people with early-stage Alzheimer disease with minimal cognitive deficits (Edwards et al., 1991; Tippett, et al., 2006). Impaired eye-hand coordination (Ghilardi et al., 2000) and slowing of reaction times (Elble et al., 2000) in people with Alzheimer disease has led one researcher to conclude that pronounced motor deficits associated with early-stage Alzheimer disease are under-characterized (Tippett et al., 2006). While both walking and eating are activities that involve the motor cortex for praxis or performance, eating activity may depend on neural processes more than walking activity for the initiation, planning and organizational aspects of the activity. This may account for the somewhat stronger influence of stage of dementia on all-cause eating disability than all-cause walking disability.

### *Comorbidity*

The presence of comorbid conditions was a statistically significant predictor of all of the six types of disability in the bivariate analysis (eating excess disability was marginally significant with a p-value of 0.07.), and in almost all of the disability types in the

multivariate analysis. A score of two or more on the Charlson Comorbidity Index approximately doubled the hazard of experiencing any of the six types of disability compared with residents who scored 0 or 1 on the index. This finding is not surprising since comorbidities are well known to be a source of excess disability for all older adults (Verbrugge et al., 1989) as well as for people with dementia (Aguero-Torres et al., 2002a; Larson, 1997; Reifler et al., 1987; Shaw et al., 2004; Taylor et al., 2001).

#### *Quality of the Environment*

The dichotomous scores on the Professional Environmental Assessment Protocol differentiated nursing homes with environmental design features that were more versus less supportive of people with dementia (Norris-Baker et al., 1999). In the bivariate Cox regression analyses residents who lived in nursing homes scoring  $>79$  on the Professional Environmental Assessment Protocol experienced half of the hazard of walking and composite all-cause disability compared with those who lived in nursing homes scoring  $\leq 79$ . After adjusting for stage of dementia and comorbidity, residents who lived in nursing homes with more design features that are supportive of people with dementia were estimated to experience 39% of the hazard of all-cause composite disability compared with those who did not live in a supportive environment. After further adjustments which also included cognitive enhancer use and antidepressant use, residents who lived in more supportive nursing homes were estimated to experience 46% of the hazard of composite excess disability compared with those who did not live in a supportive environment.

The finding of better functional outcomes for people with dementia living in more supportive physical and social environments is consistent with that of other studies. Kane et al. (2007) compared the outcomes of residents living in an unconventional small-house nursing home and two conventional nursing homes at 6 month intervals over two years. In addition to significant differences in the quality of life of the residents living in the two types of nursing homes, after adjusting for cognition and Alzheimer disease, the incidence of decline of late-loss activities of daily living, as measured by the Minimum Data Set, in the two conventional nursing homes was three and four times that for the unconventional nursing home ( $p = 0.03$  and  $p = 0.01$  respectively). In a similar prospective longitudinal study, Reimer et al. (2006) compared the outcomes of residents living in a specialized nursing home with those of residents living in traditional nursing homes at three month intervals over one year, although their sample was composed exclusively of residents with middle to late-stage dementia. Competence in activities of daily living as measured by the Functional Assessment Staging instrument (Reisberg, 1988a) declined significantly less for residents living in the specialized nursing home during the year of follow-up compared with residents living in the traditional nursing homes ( $p = 0.02$ ). The current study, along with the studies of Kane et al. and Reimer et al., provides evidence that less supportive environments can contribute to the excess disability of people with dementia.

### *Cognitive Enhancer Drugs*

In the current study 39% of the residents were taking a cognitive enhancer drug at baseline. The bivariate Cox regression analyses revealed that residents who received a cognitive enhancer drug were estimated to experience a third of the hazard of walking excess disability and 0.4 times the hazard of composite excess disability compared with those who did not receive a cognitive enhancer drug. The multivariate Cox regression analyses replicated these findings. After adjusting for stage of dementia and antidepressant use, residents who received a cognitive enhancer drug were estimated to experience a third of the hazard of walking excess disability compared to those who did not receive a cognitive enhancer. Furthermore, after adjusting for stage of dementia, comorbidity, quality of the environment, and antidepressant use, residents who received a cognitive enhancer drug were estimated to experience 0.4 times the hazard of a composite excess disability compared with those who did not receive a cognitive enhancer drug. The protective effect of the cognitive enhancers is essentially unchanged in the time-varying covariate analysis (Table 4.27). That is, when the events which were misclassified in the fixed-time analysis were correctly classified with time-varying covariate analysis, the cognitive enhancer drugs were still associated with a statistically significant reduction in the hazard of walking excess disability.

These findings are consistent with evidence from randomized controlled trials (Feldman et al., 2001; 2003; Reisberg et al., 2003; Tariot et al., 2004; Winblad et al., 1999; 2006) and secondary analyses of the same (Burns et al., 2004; Kurz et al., 2004) which suggest

that acetylcholinesterase inhibitor drugs and N-methyl-D-aspartate inhibitor drugs have a modest benefit of maintaining the functional ability of people with middle-stage (moderate to severe) Alzheimer disease.

The protective effect of the cognitive enhancer drugs appears to apply to excess disability but not to all cause disability. Perhaps the benefit of cognitive enhancers is mediated through a reduction in the risk of falling. The interview data support this hypothesis. During the interviews with staff and family members, falls and their sequellae were the most frequently cited reasons for walking excess disability: walking disability was attributed to falls, unsteadiness, and fractures by 44% of the respondents. The higher incidence of falls in people with dementia compared with cognitively normal people also supports this hypothesis (Shaw, 2007). Several mechanisms may be operating synergistically to increase the risk of falling for people with dementia compared with older adults in general. Central neurodegenerative changes may impair attentional control (Hauer et al., 2003; Sheridan et al. 2007) and, as discussed previously, motor control (Nielsen, 2003); central autonomic dysfunction may contribute to the increased prevalence of orthostatic hypotension in people with dementia (Passant et al., 1997; Prettyman, 1998); and behaviours such as wandering and agitation may increase the risk of falling. The protective effect of cognitive enhancer drugs may attenuate the neurodegenerative changes and the agitated behaviours.

A recent small controlled study of the gait of people with Alzheimer disease who received Galantamine treatment compared with normal controls also supports this hypothesis. An improvement in the gait performance was observed in people with Alzheimer disease who received Galantamine treatment compared with normal controls (Assal et al., 2008). The researchers proposed that the cholinesterase inhibitor may enhance the ability of people with Alzheimer disease to adapt their gait patterns to unexpected situations. Perhaps this is further evidence of the attenuation of the neurodegenerative changes with the cognitive enhancers.

On the other hand, the possible protective effect of the cognitive enhancer drugs on walking excess disability may be a spurious finding, since other studies have found that cholinesterase inhibitors are associated with an *increased* risk of falls (French et al., 2006) and fractures (French et al., 2005). However, those associations may point to the cholinesterase inhibitor being a marker for dementia rather than the cholinesterase inhibitor itself being the risk factor.

### *Psychotropic Drugs*

Overall 65% of the residents in the current study received at least one neuroleptic, benzodiazepine, or antidepressant at baseline (42% neuroleptics, 18% benzodiazepines, and 30% antidepressants). This use of psychotropics is among the highest reported in similar studies from around the world and compares with a US study of Alzheimer's special care units in which 65% of residents in the sample received at least one

psychotropic drug (33% neuroleptics, 37% benzodiazepines, and 30% antidepressants) (Zeisel et al., 2003), and a study of nursing home residents in Helsinki, Finland in which 80% were taking psychotropic drugs (46% neuroleptics, 54% benzodiazepines, and 45% antidepressants) (Hosia-Randell et al., 2005). Other studies report the proportion of nursing home residents using psychotropics to be 47% in Australia (Snowdon et al., 2006), and 48% in Ontario, Canada (Conn et al., 1999).

The relatively high proportion of residents taking psychotropic drugs in the current study may be explained in part because of the characteristics of the sample. All of the residents were in the middle stage of dementia which is known to be the stage when behavioural and psychological symptoms peak (Schreinzer et al., 2005). Others have explained an increased use of neuroleptics and antidepressants in the past decade by the introduction of atypical neuroleptics and selective serotonin reuptake inhibitors which are reported to have fewer adverse effects than the earlier generation neuroleptics and antidepressants. For example clinical practice guidelines recommend the use of the atypical neuroleptics and the new generation of antidepressant drugs (Herrmann et al., 2007). The characteristics of nursing homes have also been found to affect the prescription of psychotropic medications (Hughes et al., 2000).

In the current study none of the three categories of psychotropic drugs had a statistically significant association with any type of disability outcome in the bivariate Cox regression analyses. It is surprising that the use of neuroleptic drugs did not increase the hazard of

disability since the typical neuroleptics are known to be associated with an increased risk of falls because of their adverse effects (Ames et al., 2005; Lanctôt et al., 1998; Lee et al., 2004). Furthermore a systematic review of atypical neuroleptics cautions that “limited evidence supports the perception of improved efficacy and adverse-event profiles (of atypical) compared with typical antipsychotic drugs” (Lee et al., 2004, p. 75).

There is no evidence that the antidepressant drug category was a predictor of any disability outcomes in the bivariate Cox regression analyses although antidepressant use was a marginally significant predictor of composite excess disability. When antidepressant use was included in the time-varying covariate analysis for composite excess disability this marginally significant finding disappeared. However, in the multivariate Cox regression analysis, after adjusting for stage of dementia, comorbidity category, cognitive enhancer use, and quality of the environment, the use of antidepressants at baseline was estimated to double the hazard of composite excess disability ( $p = 0.03$ ). This finding is not surprising since other research has found that depression in people with dementia is significantly associated with functional disability (Espiritu et al., 2001; Hargrave et al., 2000; Holtzer et al., 2005; Kales et al., 2005; Li et al., 2001; Pearson et al., 1989; Potter et al., 2007).

The findings from the current study suggest that the use of antidepressants (not necessarily depression) predicts functional loss. It is unclear whether the antidepressant variable is a marker for depression and the disabilities associated with depression, or

whether antidepressant use is associated with an increase in the hazard of excess disability, due to the adverse effects of these drugs. Perhaps both explanations are operating. People with dementia may be more susceptible to adverse effects given their concomitant physical and cognitive frailty (Thompson et al., 2007). The adverse effects of antidepressants in people with dementia can be implicated in falls. For example the commonly used selective serotonin reuptake inhibitors have the adverse effects of sedation and dizziness, while the less commonly used tricyclic antidepressants have the adverse effects of orthostatic hypotension, cardiac arrhythmias, and anticholinergic symptoms (Bhatia et al., 1997).

#### *Education of the Residents*

Data on the educational status of the residents relied on family members' knowledge of their relatives' educational accomplishments. Although family members were not always sure of the highest grade completed by the residents, family members usually knew if the residents had completed high school or not. In the current study residents who completed high school were estimated to have a third of the hazard of eating excess disability compared with those who did not.

While the resident education variable may be considered a proxy for socio-economic status, education is also thought to protect the brain either by postponing the emergence of cognitive symptoms with an increased "brain reserve" or by prolonging "mental fitness" with an engagement in more cognitively demanding activities (Schmand et al.,

1997; Stern et al., 1999). However the benefit of education has not been a consistent finding in the literature. Other investigators have found higher educational attainment either to be associated with a slightly accelerated rate of cognitive decline in people with Alzheimer disease (Wilson et al., 2004) or to not be associated with cognitive decline at all (Van Dijk et al., 2008). No other studies were found that have examined the association between education and the preservation of ability in the activities of daily living of people with dementia.

There is no clear reason why the protective effect of education should be operating for eating excess disability but not for any of the other disability outcomes. Since there were only four residents in the group who completed high school and experienced an eating excess disability, it may be that this is a spurious finding that attained statistical significance by chance.

#### *Profit Status of Nursing Homes*

In the current study, living in a for-profit nursing home was estimated to double the hazard of experiencing an all-cause walking disability compared to living in a not-for-profit nursing home. This finding is consistent with a body of literature suggesting that resident outcomes do vary with the profit status of the nursing home (Aaronson et al., 1994; Castle et al., 1998a; McGregor et al., 2006). In studies in the United States not-for-profit nursing homes scored better than for-profit nursing homes with a lower use of restraints (Castle et al., 1998a) and a lower rate of pressure sores (Aaronson et al., 1994).

British Columbian for-profit long-term care facilities demonstrated higher hospitalization rates for pneumonia, anemia, and dehydration compared to not-for-profit nursing homes (McGregor et al., 2006). Quebec for-profit nursing homes had a lower composite quality of care score compared with not-for-profit nursing homes (Bravo et al., 1999).

It may be that staffing levels are the mediating variable in the association between the profit status of nursing homes and resident outcomes. Not-for-profit nursing homes have been associated with higher staffing levels than for-profit nursing homes in both the United States (Harrington et al., 2001; Hillmer et al., 2005) and in Canada (McGregor et al., 2005). For example in a study of nursing homes in British Columbia, not-for-profit status was associated with an estimated 0.34 hours per resident-day of more direct care than for-profit status (McGregor et al., 2005).

#### *Nursing Home Staffing Levels*

In the current study none of the staff-to-resident ratios were associated with any of the disability outcomes. There was considerable variability in the number of registered nurses / licensed practical nurses available to the residents. The professional nurse-to-resident ratios ranged from 0.02 to 0.07, or stated in other words, professional nurse assignments ranged between 14 and 50 residents.

By grouping registered nurses and licensed practical nurses into one category, the ability to identify the unique contribution of each of these types of nurses to disability outcomes

was lost. Perhaps this is one reason why there was no association found between the professional nurse-to-resident ratios and the disability outcomes in the current study since others have found registered nurse turnover to be an important variable related to resident outcomes (Zimmerman et al., 2002). During the interviews with care managers these two categories of professional nurses were often given identical resident assignments and similar responsibilities. This apparent lack of differentiation between these two categories of nurses by the care managers led to the research decision to group the two nurse categories together into one professional nurse category for data analysis. Others have also calculated a composite variable for nursing care hours (McGregor et al., 2005).

The variability in staffing levels was considerably less for the nurse aides who were assigned to the direct care of between six and nine residents. The nurse aide-to-resident ratios were not associated with the hazard of any of the disability outcomes. In a United States study of nurse aide staffing and quality of care a similar range of staffing ratios was reported: the highest staffed homes reported 7.6 residents per nurse aide across day and evening shifts, while the lowest staffed homes reported 9 to 10 residents per nurse aide (Schnelle et al., 2004). Level of staffing was associated with the quality of care processes implemented by nurse aides. The more highly staffed nursing homes performed better on 13 of 16 care *processes* compared to the most poorly staffed nursing homes (Schnelle et al., 2004). It is unknown whether the nursing homes with higher proportions of nurse aides experience better resident *outcomes*.

The role of rehabilitation and activity staff has not been studied extensively, however one Canadian study found that higher activity aide-to-resident ratios had beneficial effects on residents' cognitive function and social language skills (Reid et al., 2003). In the current study the rehabilitation staff-to-resident ratios were not associated with the hazard of any of the disability outcomes. The staff members in this composite category included staff from physical therapy, occupational therapy, recreation therapy, and volunteer coordination disciplines. The staff-to-resident ratios for this staff category varied considerably between nursing homes with assignments ranging between 14 and 100 residents per staff member.

During almost all of the care manager interviews the current labour shortage was cited as managers lamented their perceived inadequate staff-to-resident ratios (Aiken et al., 2002; MacGillivray, 2001; Nevidjon et al., 2001). Almost all managers explained that they had several vacancies for registered nurses and nurse aides while some managers also had vacancies for rehabilitation therapists. The variability in staff-to-resident ratios between facilities was not necessarily related to organizational priorities or decisions about funding allocation. Instead, it may have been related to the unstable labour market. This may account for the absence of a relationship between staffing levels and resident disability outcomes. Nursing homes that performed well and those which did not experienced similar difficulties in recruiting and retaining staff.

### *Facility Size*

While facility size was not associated with any disability outcomes that achieved statistical significance, the effect size is noteworthy. The hazard of experiencing both all-cause and excess disability in walking was approximately double for residents living in larger facilities. That is, residents who lived in nursing homes with more than 60 beds were estimated to experience 1.9 times the hazard of an all-cause walking disability and 2.4 times the hazard of a walking excess disability compared with residents who lived in nursing homes with 60 beds or less. The doubling of the hazard associated with larger nursing homes was in the opposite direction to that expected since the evidence in the literature suggests that larger nursing homes are associated with *improved* resident outcomes (Bravo et al., 1999; Castle et al., 1998; Leon et al., 1999; McGregor et al., 2006).

The manner in which the beds were counted in the current study may account for these discrepant findings. The facility size was calculated based on the total number of beds in the individual nursing homes where the residents in the sample resided. If the number of beds were to be based on the number of beds operated by the nursing home organizations participating in the study, the findings would be reversed since the smallest nursing homes participating in the study were operated (and subsidized) by the largest nursing home operators in the health region. Residents in a Canadian study experienced better outcomes in nursing homes that were multisite or amalgamated to a larger organization compared with residents living in single-site nursing homes (McGregor et al., 2005).

### *Staff Dementia Education*

The 15 nursing homes in the current study were classified as either receiving or not receiving dementia education, such as the Supportive Pathways Education Program (Collins, 2007), at least once in the previous year. Although dementia education was not a significant predictor of any disability outcomes in the bivariate analyses, it is a covariate in the multivariate model for the all-cause eating disability outcome. After adjusting for stage of dementia, comorbidity, and the duration of admission to the nursing home, the residents who lived in nursing homes without any staff dementia education in the previous year were estimated to experience 1.8 times the hazard of experiencing an all-cause eating disability, compared with residents who lived in nursing homes with staff dementia education in the same period.

Although there are those who question the effectiveness of education to change staff performance and resident outcomes (Mace, 1996), there is evidence from controlled trials to suggest that education targeting nursing home staff can increase residents' nutritional intake and weight (Mamhidir et al., 2007), while another study which targeted functional ability as an outcome did not find differences between the staff education intervention and the control groups (Proctor et al., 1999). In the current study the dementia education offered to staff did not specifically target the eating or walking abilities of the residents therefore it is unlikely that the dementia education directly led to the reduction in the

hazard of eating disability. Instead the dementia education variable may have been a marker for continuous quality improvement in the nursing homes.

#### *Age, Sex and Type of Dementia*

The only potential predictor variables that were not at all associated with any of the disability outcomes in the bivariate Cox regression models were age, sex, and type of dementia. For this reason these variables are not included in any of the multivariate regression models. Epidemiological studies generally adjust for age and sex (Aschengrau et al., 2003). In this study of older adults living in a nursing home the mean age was 86 years (SD = 6.5). The ages of the residents may not have been sufficiently varied to discriminate between a younger and an older age group. Likewise, the majority (78%) of participants in the study were women. The sample may not have included sufficient numbers of men to be able to discriminate between the sexes.

There are two possible reasons why the dementia diagnosis variable was not associated with any of the disability outcomes. First of all the accuracy of the dementia diagnosis variable is suspect since these diagnoses were abstracted from residents' health records. There was increased confidence in the accuracy of a diagnosis on the occasions when a consultation report from geriatric psychiatry, geriatric medicine, or neurology was available. Occasionally there were conflicting diagnoses with Alzheimer disease and mixed dementia appearing on the same health record. In these instances specialist opinions were given priority over the opinions of family physicians.

Secondly, the absence of any differentiation between the two diagnostic categories in the bivariate Cox regression analysis is not surprising given the likely overlap in the diagnoses. The thinking about diagnosing dementia is evolving: mixed dementia is now considered to be more common than previously thought, while pure Alzheimer disease and pure vascular dementia are considered to be relatively uncommon (Rockwood, 1997; Zekry et al., 2002). In the current study the diagnosis variable was dichotomized with Alzheimer disease and mixed dementia in one category, and vascular dementia and unspecified dementia in the other.

### **Transitions from Ability to Disability**

When residents were observed by the researcher on three consecutive observations to be unable to walk or to eat independently, then the family and staff participants discussed their thoughts with the researcher in terms of their attributions of cause and the actions taken in response to the functional losses. The data generated during the observations and interviews are a window on the experience of the transition process.

#### *Transitions: A Process or an Event*

Oftentimes the losses of the ability to walk and the ability to eat were less like discrete events and more like processes. A gradual loss of ability punctuated by good days and bad days was evident in the losses of both walking and eating, although this was more often evident with eating disability than walking disability. The transition from walking

to using a wheelchair was a less ambiguous, more clearly defined event which was more suited to survival analysis; however the experience of functional loss as a process rather than an event is consistent with what is described in the literature as the gradual progression of Alzheimer disease.

### *Attributions*

Respondents attributed walking and eating disability to a broad range of potential causes. The most frequent attributions for walking disability were weakness/fatigue and falls/unsteadiness with 16 respondents identifying each of these attributions, followed by pain and dementia with 12 respondents identifying each of these. The most frequent attributions for eating disability were dementia and a poor appetite with 19 and six respondents respectively identifying these as a potential causes.

### Attributions to Dementia

Attributions to dementia accounted for approximately 25% of the attributions for the loss of the ability to walk, but accounted for over 50% of the attributions for the loss of the ability to eat. Thus the respondents had many more ideas about what might be causing the loss of the ability to walk than they did for the loss of the ability to eat. Falls, unsteadiness, weakness, fatigue, and pain are much more understandable causes for the loss of ability to walk than is dementia. Disability in eating is a very different experience than disability in walking. It may be that the respondents could not think of anything other than dementia to explain this somewhat unusual behaviour.

It is possible that the attribution to dementia was underrepresented by some family members due to the lack of understanding that dementia affects multiple functional domains. Family members are less familiar with the downward trajectory of physical function than are staff members who have witnessed the progressive loss of function in people with dementia many times. Several family members stated that their relative's physical disability was not due to dementia because they did not perceive any concurrent decline in their cognitive function. Other family members wondered whether dementia was affecting more than memory as they saw motor function changes unfold in their relatives. It is possible that the attributions to something other than dementia (excess disability) were over represented with the walking disability.

There was more concordance or agreement between staff and family members regarding the dementia attribution for eating disability than for walking disability. Six of the 16 residents whose eating disabilities were discussed during interviews had both family and staff members attributing the disability to dementia. In contrast both family and staff members attributed the loss of walking ability to dementia for only two of the 23 residents who were discussed during the interviews. The practice implications for concordance (or lack thereof) are discussed later in the chapter in the section entitled 'Implications for Practice.'

### Attributions to Environmental Factors

With few exceptions, the losses in walking and eating ability were attributed to resident-specific rather than to environmental factors. Only six respondents attributed disability to environmental factors including the reduced visits by a family member, dishes being cleared from the table too quickly, a disturbing table partner, and a boring environment. Attribution theory suggests that there is a general tendency for people to overestimate the role of personal factors and to underestimate the role of environmental factors in causing behaviour (Ross, 1977). This tendency has been termed the “fundamental attribution error”. It has been suggested that the bias of attributing events to the characteristics of individuals rather than to environmental factors may be due to observers paying selective attention to the most conspicuous, accessible, and easily processed information, which is information associated with the individual (Taylor et al., 1975). In contrast, processing environmental information that qualifies the attribution to individual characteristics requires more time and effort and may not always be undertaken.

### Attributional Uncertainty

During the interviews staff members were confident in their attributions while family members were uncertain and sometimes speculative. The attribution literature suggests that people who experience causal uncertainty are motivated to resolve it by intentional information seeking that may require effort (Weary et al., 1994, 1997). In the current study more family members than staff members responded to the functional loss of the residents by consulting a physician, communicating with various interested parties, and

seeking information. Evidently these family members were trying to increase their knowledge and thereby reduce their uncertainty. In another study, family caregivers' causal uncertainty of their relatives' behaviour led them to seek a doctor's opinion and to monitor the person with dementia prior to developing an attribution (Polk, 2005).

In the current study, family member's tentativeness in their attributions may explain why they identified significantly more attributions for the loss of walking ability than did staff. Family members may speculate all the possible reasons that could conceivably explain the behaviour but do not have the knowledge to rule out some of the possibilities in the same way that staff members do. For example, family members attributed walking disability to a possible neurological event or to a possible infection more than staff members did. Staff members were able to verify or discard such possibilities by drawing on their previous knowledge, by using their physical assessment skills, or by accessing a physician. For this reason family members may have generated what could be termed 'hypotheses' rather than attributions for the loss of ability. Family members' untested hypotheses were more numerous than staff members' attributions.

Another explanation for the more numerous attributions of family members may be that they were more invested than staff members in trying to restore the loss of ability. Perhaps they were more motivated to engage in a problem-solving exercise and therefore they spent more time and effort to identify possible causes for the disability. The fact that

family members' interviews were longer than staff members' interviews supports this explanation.

The attribution literature also offers some support for this explanation and expands on it. A series of social psychology experiments were conducted to assess the relationship between causal uncertainty and the use of stereotypes (Weary et al., 2001). It was hypothesized that those who experience causal uncertainty are more motivated to understand their social world and are therefore more likely to process social information in a thoughtful fashion rather than using stereotypes. The investigators did not find any evidence against this hypothesis. They concluded that causal uncertainty was related to a reduced use of stereotypes (Weary et al., 2001). Extrapolating this finding to the current study, the causally uncertain family members may have been more motivated than staff members to understand the reason for the loss of functional ability and therefore were less likely to apply a simplistic stereotype in their search for a cause. In contrast, the more certain staff members may have been more prone to explain a loss of functional ability by simply categorizing the functional loss as dementia-related. That is, staff members may have been cognitive misers (Fiske et al., 2001) by stereotyping the residents with dementia because it required too much effort to consider the individual circumstances of the resident.

### *Actions Taken in Response to Functional Loss*

As with the attributions, the actions reported in response to walking and eating loss were wide ranging. While there were obvious differences in the actions taken in response to losses in walking (e.g., wheelchair interventions) and eating (e.g., nutritional supplements), there also were some similarities. Actions that were reported for both walking and eating loss included increasing supervision and monitoring, enhancing socialization, referring to a mental health consulting service, and adjusting psychotropic and other drugs.

It appears that the reported actions were not exclusively dedicated to maximizing the independence of the residents but also addressed more comprehensive issues of well-being. While some reported actions in response to eating loss were intended to support the residents' own physical ability to move food from the dish to the mouth (e.g., reminding and encouraging or offering finger food), other reported actions were focused on avoiding weight loss (e.g., nutritional supplements and physically assisting to eat) or enhancing the ability to swallow (e.g., modifying food textures and dentures). Likewise some actions taken in response to walking loss were intended to enhance the ability to walk (e.g., foot care), however other reported actions were intended to improve the safety of the resident (e.g., hip protectors) or to support alternate methods of mobilizing (wheelchair interventions). Thus the reported actions reflected wide ranging agendas which went beyond enabling the residents to maintain their functional abilities.

Family members cited the actions of informal communication and formal consultation more often than the staff members did. The relative importance of communication for family members may be accounted for by their perceived need for updates, information, and support from the health professionals. Research on the involvement of families in the care of nursing home residents reveals the need of family members for a positive ongoing relationship with staff members (Duncan et al., 1994; Hertzberg et al., 2000; Wackerbarth et al., 2002) and that formal and informal social support from nursing staff seems to protect against the psychological distress experienced by family members of residents with dementia (Ducharme et al., 1997; Lévesque et al., 1999).

A comparison of the actions reported by respondents who attributed the loss of ability to dementia versus those who attributed the loss to something else revealed some differences between the actions taken in response to the walking and eating disability. The actions reported by family and staff members who attributed either walking or eating disability to dementia were more often related to supportive interventions such as socialization and supervision. In contrast the actions reported by those who attributed a disability to something other than dementia were more often oriented towards assessment and treatment. This finding provides evidence for the logical connection between the attributions made and the actions taken in response to particular walking or eating disabilities. Functional loss that is attributed to dementia is less likely to lead to assessment and treatment to improve the functional ability of residents. Thus there is the

potential for disagreement regarding the actions to be taken when there are discordant attributions.

Since few interview respondents attributed the loss of function to the environment it is not surprising that few respondents reported taking actions which targeted the environment. In a randomized controlled trial to determine the short-term effects of a home environmental intervention on caregivers and the function of people with dementia, part of the intervention involved helping caregivers reframe their attributions of events (Gitlin et al., 2001). The investigators reported that this was “important to enable behavioural change and the use of environmental strategies” (p. 6).

As has been discussed at length, the environment can support the functional ability of people with dementia or it can contribute to disability. There is an opportunity to expand the repertoire of interventions taken by staff and family members to include environmental interventions. For example, in a systematic review of the literature on feeding difficulty in people with dementia the following interventions targeting the environment have demonstrated utility in assisting older adults with dementia to eat: changing meal service systems and routines, changing the focus of the nurse aide assignments, changing table arrangements and dining rooms, dining room décor and music (Watson et al., 2006).

The prioritized preferences of family members for nutritional interventions to improve the oral intake of nursing home residents were assessed in a survey (Simmons et al., 2003). In order of preference the interventions that family members chose were: to improve the quality of the food, to improve the quality and quantity of feeding assistance, to provide multiple small meals and snacks throughout the day, to seat the resident in a preferred dining location, to provide an oral liquid nutritional supplement between meals, and to provide a medication to stimulate the appetite. All of these interventions were cited by respondents in the current study and comprised 45% of the total number of reported eating interventions.

Although five family members attributed eating disability to swallowing and chewing difficulties in the residents, and seven family members reported modifying food textures and dentures, all of the residents in the sample who experienced an eating disability were able to consume food orally when they were physically assisted to eat. In the middle stage of dementia the transition in eating ability is primarily centred on getting food into the mouth rather than on being able to swallow. This probably explains why tube feeding was never mentioned during the interviews.

### **Methodological Considerations and Implications for Research**

Several methodological considerations will be discussed in this section beginning with a summary of the strengths followed by a discussion of the limitations of the study. The section will conclude with a discussion of the implications for further research.

### *Strengths of the Study*

Particular strengths of the study include the collection of data over the course of a full year, the higher than usual frequency of repeated data collection, the observation of functional performance rather than relying on proxy reports, the gathering of functional performance data in a natural setting rather than in a testing situation, the absence of loss to follow-up, the absence of missing data, the concurrent exploration of the real time transitions from ability to disability, and the inclusion of environmental and resident-specific risk factors beyond the usual comorbid medical risk factors.

One of the well documented weaknesses of cohort studies is the ‘inevitable’ loss to follow-up (Kristman et al., 1979). Participant attrition negatively impacts both the internal and external validity of a cohort study (Barry, 2005; Ribisl et al., 1996). There was no loss to follow-up in this study. This absence is not a common occurrence.

Retention of the participants was facilitated by the nature of the population being studied.

In contrast to populations which are very difficult to follow, such as adolescents or substance abusers, nursing home residents live in carefully monitored environments.

Whenever a resident relocated to a different nursing home, it was possible to continue data collection in the new setting. Documented retention strategies such as flexible hours for data collection, an emphasis on maintaining a positive rapport with all categories of participants, and the frequent and unobtrusive observations (Tansey et al., 2007), are all likely to have contributed to this success.

### *Limitations of the Study*

The methodological considerations and associated limitations of this study include the reliance on the residents' health records for several of the predictor variables, the operational definition of excess disability, dichotomizing the outcome variables, dichotomizing the predictor variables, the omission of several potentially important predictors of disability, the collection of observational data, the timing of the observations, the interview questions and prompts, the zero time point of reference for the event-free survival analysis, the potential issue of multiple comparisons during the data analysis, the external validity of the study, and the absence of reliability verification for scoring the standardized measures. These methodological considerations and limitations are discussed below.

### Health Records as a Data Source

A reliance on the residents' health records as a source of data for some of the predictor variables is fraught with the issues of inaccuracy, incompleteness, and being outdated. Resident-specific variables that were abstracted from the health record included age, dementia diagnosis, comorbidities, duration of admission, scores on the Mini-Mental State Examination, drugs taken at baseline and throughout the year of observation. The accuracy issue pertains particularly to the dementia diagnosis, the completeness issue pertains particularly to the list of comorbidities, and the currency issue pertains particularly to the Mini-Mental State Examination score. Relying on the data available in

the health record was unavoidable given the context of a doctoral study with the associated time, financial, and human resource limitations.

### Operational Definition of Excess Disability

There are limitations with an operational definition of excess disability which is based on the concordance of interview respondents and on the transience of the disability. Firstly, the family members' limited understanding of the progression of dementia influenced their attributions. They did not always understand that a decline in physical function could be caused by dementia independently of a perceptible change in cognitive function. As a result the family member attributions of a functional loss to excess disability may have been over reported. Compensation for this potential classification bias was accomplished by defining excess disability only when both the family and staff members agreed on attributing a functional loss to something other than dementia.

Secondly, recovery was not a reliable guide to excess disability because, as was frequently noted by the interview respondents, people with dementia have "good days" and "bad days." This phenomenon has been documented in the literature in terms of fluctuating cognition although fluctuating cognition is more characteristic of Lewy Body dementia than of Alzheimer disease, vascular, or mixed dementia (Ballard et al., 2001b; Bradshaw et al., 2004). On this basis excess disability could have been both under or over-reported. That is, excess disability could have been under-reported if the resident happened to have an exceptionally good day on the day of observation. Alternatively

excess disability could have been over-reported if the resident happened to have an exceptionally bad day on the day of observation. The impracticality of observing the residents daily led to the possibility of this misclassification bias.

Thirdly, the incidence of excess disability could have been underestimated in instances when the resident temporarily lost the ability either to eat or to walk after one observation but recovered the ability before the subsequent observation. The relatively frequent biweekly observations reduced the chance of this misclassification bias but did not eliminate it.

Fourthly, while a sustained loss of function was less likely to be due to excess disability, family or staff members may have attributed the loss to dementia when in fact the resident had an excess disability that was not identified and treated. Thus excess disability may not have been coded when it was present. This misclassification bias would have led to a more conservative estimate of excess disability.

#### Dichotomizing Outcome Variables

In this study functional loss was treated as an event for the purpose of the event-free survival analysis but was explored as a process during the observations and interviews.

Some residents did not experience a functional loss during the study period but their functional abilities did decline nonetheless. One limitation of the binary data and its analysis is that it does not capture the gradual deterioration in function that was observed

in many of the residents over the course of a year. Triangulating the methods for data collection compensated for this limitation since the observational and interview data did reflect the gradual and dynamic nature of the transitions associated with functional loss. This complemented the relatively simplistic binary outcome data.

An alternate approach to data collection could have been to identify residents when they first experienced difficulty with an activity and when they first experienced total dependence in an activity. This method of studying disability was employed by Gill et al. (1998). Such an approach would have required different operational definitions of disability, and distinctions that would have been even more difficult to code during data collection.

#### Dichotomizing Predictor Variables

One strategy for analyzing measured variables is to convert them into categorical variables by grouping research participants into two or more groups. Although the stratification of predictor variables enables the identification of low-risk and high-risk groups the disadvantages of this strategy include the loss of information and variable findings for different cut points (Altman et al., 1994). Often variables are dichotomized using the median as the pre-specified cut point, however the median will vary with the sample recruited to the study and may not represent a clinically meaningful distinction between groups. The use of the median can also result in Type II error: failing to detect a difference in the subgroups when in fact there was one.

Some have attempted to identify ‘optimal’ cut points by minimizing the p-value of the chi-square statistic, however this can result in an inflation of the Type I error rate: detecting a significant difference in the subgroups when in fact there was no difference (Altman et al., 1994; Faraggi et al., 1996). When the ‘minimum p-value approach’ (also known as the ‘maximally selected chi-square statistic’) is used then the p-value can be corrected using a simple formula (Altman et al., 1994; Miller et al., 1982).

In the current study the recommendation of Altman et al. (1994) to avoid the use of the minimum p-value approach was followed. Where possible, biological reasoning, knowledge of the measurement techniques, simplicity, and pre-specified quartile cut points were used. The cut points for the measured variables did influence the predictor status of the variables. An opportunity for future research will be to explore alternate cut points for the variables that significantly predicted disability, including the Charlson Comorbidity Index, the Global Deterioration Scale, and the Professional Environmental Assessment Protocol.

#### Omission of Predictor Variables

This study did not assess the universe of possible sources of excess disability. For example possible contributors to excess disability in people with dementia which were not assessed include sensory impairment (Allen et al., 2003), pain (Miller et al., 2000) and delirium (Fick et al., 2002). Vision and hearing impairment, pain, and delirium were

not routinely assessed by clinicians for all residents and therefore data regarding these parameters were not readily available on the health record. Although data were collected based on the difficulty residents appeared to have with hearing during the initial face-to-face interviews, these data were not analyzed because they were confounded by receptive aphasia that was present in some residents.

Neither did the current study assess the contribution of cognitive impairment as a potential predictor of excess disability, although functional decline in people with Alzheimer disease has been consistently related to cognitive impairment (Aguero-Torres et al., 1998; Green et al., 1993; McConnell et al., 2003). It was decided a priori that administering the Mini-Mental State Examination yet again to residents who had previously responded to this instrument, in many cases more than once, might be considered intrusive by the resident, the authorized representative, or both. In the opinion of the investigator, the response rate for study participation would have been compromised if the Mini-Mental State Examination were to have been administered directly to the residents.

The wisdom of this decision was validated, first of all, during the initial interviews with the authorized representatives when consent to participation in the study was obtained, and secondly during the health record reviews. Prior to consenting to participate in the study several authorized representatives asked if the resident would be exposed to the 'memory questions' again. They spontaneously commented that the resident had already

answered these questions more than once and that they did not want the resident exposed to them again. Secondly, without exception there was at least one copy of the Mini-Mental State Examination on each the residents' health records. Scores for the most recent Mini-Mental State Examination were collected for the purpose of characterizing the sample, however these data were not included in the regression analyses because the mental status assessments were often not current. Given that all of the residents in the study had some degree of cognitive impairment, and that stage of dementia is a marker for the degree of cognitive impairment, the omission of cognitive impairment as a potential predictor variable was not judged to be a serious one.

#### Collecting Observational Data

In some care centres there were resident research participants eating in several different dining rooms at once, necessitating the researcher to move between two or three dining rooms to gather data. Given that 120 residents were observed 27 times over the course of a year, residents were often only observed eating portions of a meal. After a resident ate at least two spoonfuls of a meal the researcher would move on to another dining room or would commence the health record review. Occasionally it was observed that a resident who began the meal by eating independently was physically assisted to eat by a nurse aide at the end of the meal.

There may be several explanations for this observation. Firstly it suggests the possibility of an iatrogenic process in which residents who eat slowly are unnecessarily assisted to

eat by nurse aides. This may induce or accelerate disability in residents who are at risk of losing the ability to eat independently. Alternatively, residents may tire of the eating process or be distracted such that they genuinely do require assistance. Rather than finding ways to support the residents' functional abilities it may be more expedient for the nurse aides to feed the residents given the myriad of constraints on their time. Furthermore the nurse aides and registered nurses may lack the knowledge to know how to compensate for the residents' eating disability by obtaining adapted cutlery and dishware, for example. Occupational therapists or dieticians may not be available or have sufficient time to assist with such ability enhancing interventions.

Another Canadian study involving the observation of residents with dementia during mealtimes yielded similar findings: some staff members did not provide the more highly functioning residents with opportunities to eat independently, and the ability and initiative of residents to eat varied from meal to meal (Gibbs-Ward et al., 2005). The investigators concluded that mealtimes are dynamic processes in which both internal and external influences affect the residents' behaviours.

The observed variation in eating behaviour during the same meal points to the limitation of the researcher not observing residents eat their entire meals. The decision whether or not to code a resident as eating independently at a particular meal was ambiguous. For the purpose of this study, whenever a resident was observed to be physically assisted to eat by anyone (staff member, family member, visitor, or fellow resident) then an eating

disability was coded. This decision rule was consistent with the initial guide for coding eating disability. It is unlikely that the decision rule led to classification bias because if the researcher witnessed the resident being physically assisted to eat once during a biweekly observation, then in all likelihood the resident was also being fed at other times. Furthermore, it is unlikely that anyone would initiate feeding a resident if the resident was successfully eating independently.

#### Timing of Observations

The potential variation in a resident's eating ability from breakfast to supper, which may be due to fatigue at the end of the day, highlights the limitation of not consistently observing residents at the same meal for each of the 27 observations. Approximately 80% of the data were collected during the same mealtime although the specific mealtime varied systematically from one nursing home to another. In some nursing homes data were collected at breakfast, some at lunch, some at supper, some on weekdays, and some on weekends. Ideally all residents would have been observed at the same meal all of the time, however practical considerations precluded this from happening. The timing of data collection at a particular nursing home depended on the distance to travel and the ease of travel throughout the city. Rush hours, affecting breakfast and suppertime observations, were avoided for those nursing homes that were farther away. In one nursing home observations were rescheduled from breakfast to supper because a resident that was recruited later in the study did not get out of bed until the afternoon. The consistency of a single data collector observing a particular meal on a particular day at a particular nursing

home over the course of a full year 100% of the time was compromised by the unpredictable vicissitudes of out-of-town travel associated with research conferences and family crises. The general rule guiding the data collection was that data were to be collected at each nursing home every two weeks  $\pm$  two days, although most of the time the data were collected at exactly two week intervals. The minor departures from this rule were unlikely to have adversely affected the integrity of the data.

#### Interview Questions and Prompts

When family members were asked the open question: “What do you think may be causing this change in ability?” some had difficulty responding. Some stated outright that they did not know or that they were not experts. However the closed question which served as a prompt, “Is this because of dementia or because of something else?” enabled family members to speculate on what might be the cause. This prompt undoubtedly influenced the nature of the data that were generated. The influence likely varied from respondent to respondent. For some their notions about causality were formed and they discarded the possibility of dementia as a reason for the disability. For other respondents who explained that they had not given the matter much thought, the initial question and the subsequent prompt may have led to responses that were more like hypotheses than fully formed attributions. Still other respondents embraced the suggestion of dementia as a possible attribution perhaps because they were unable to come up with one on their own and were trying to please the researcher.

The issue of leading questions has received much attention in the literature, possibly due to a naive empiricism (Kvale, 1994). There has been a preoccupation with absolute truth and a concern for response accuracy (Schober et al., 1997) with research focused on the factors that determine why individuals respond differently to leading questions (Schooler et al., 1986). Attribution researchers have participated in this discussion with a particular concern that the responses of research participants are somehow influenced by the researcher introducing the idea of causality (Enzle et al., 1978). This has spawned an entire research agenda targeting 'spontaneous' causal thinking (Weiner, 1985). For example research findings suggest that a spontaneous attributional search may be elicited by an unexpected event (Lau, 1984), nonattainment of a goal (Bettman et al., 1983), or concrete rather than abstract information (Anderson et al., 1983).

The post-positivist stance of the current study embraces interview data as accurate representations of the respondent's views, meanings and experiences (Bronowski, 1956). It is accepted that they may not be fully formed, they may be socially constructed within the context of an interview, or they may change. When family and staff members were asked whether a functional loss was because of dementia or because of something else they were prompted with more than one option. It could be argued that giving the respondents two options which included the universe of all possible responses, was not a leading question. Constructivists would argue that the issue in conducting an interview is not whether an interview question leads, but rather whether an interview question leads in an important direction to yield worthwhile knowledge (Kvale, 1994). In the current study

it was important for the purposes of defining excess disability to know whether the respondents were aware of anything that could account for the functional loss. After responding to the open question “What do you think may be causing this change in ability?” the use of the closed question “Is this because of dementia or because of something else?” enabled the respondents to directly address the issue of excess disability.

#### Zero Time for Survival Analysis

The “beginning of time” in event-free survival analysis or the “fiducial point” is the time when everyone is at risk for experiencing the event to be studied (Singer et al., 2003). This time may be meaningfully tied to the occurrence of a precipitating event which places all of the study participants at risk, or it may be conveniently and arbitrarily set when the study begins. In the current study the possibility of a meaningful fiducial point was considered. The time of symptom onset (Fiske et al., 2005; Sano et al., 1995), the time of first seeking medical attention for dementia-related symptoms, the time of receiving a dementia diagnosis, the time of entry to the nursing home, and the time of scoring a defined point on a dementia staging instrument (Berg et al., 1988) were all possible candidates.

During the recruitment interviews with the family members an attempt was made to identify the time of symptom onset and the time of receiving a dementia diagnosis. However it soon became evident that the data were either compromised by recall bias or

were unavailable. The dates of nursing home admission were available, but they were influenced by a wide range of factors beyond the functional abilities of the residents. Thus the ‘beginning of time’ was set, as is usually the case, at the time when members of the cohort were recruited to the study and follow-up began.

### Multiple Comparisons

Multiple statistical comparisons were carried out during the analysis as part of the original plan to answer the research questions. Planned statistical comparisons do not require correction for multiple comparisons in the way that post hoc comparisons do (Norman et al., 2000). The planned comparisons in the current study were completed as part of the assessment of the potential predictor variables in relation to the six disability outcomes. Although the assessment of effect modification in the six multivariate Cox regression models did constitute post hoc statistical comparisons, the number of these post hoc comparisons was reduced to one comparison per model by using the likelihood ratio test. This is an overall test that was used to assess the null hypothesis of no effect modification by all of the interaction terms simultaneously in each of the multivariate regression models (Ramsey et al., 2002). That is, each of the six full multivariate models which included interaction terms were compared with the six simple nested models without any interaction terms. In this way the necessity of correcting for multiple comparisons was averted.

### External Validity

In a cohort study external validity is thought to depend as much on the stability of the population over time as on the choice of the study populations (Szklo, 1998). Thus the high participation rate and the low attrition rate enhanced the generalizability of the findings in the study. Seventy-two percent of the 167 residents who were referred to the study became participants and 92% of the 130 residents who were referred to the study and met the inclusion criteria became participants. Since the researcher did not initially approach the authorized representatives for their consent to be contacted by her, the proportion of potential participants who declined to be contacted is unknown. While there is no reason to believe that the sample of residents who were referred to the study by the nursing unit managers is any different from the general population of residents meeting the study inclusion and exclusion criteria, population data are not available to confirm the representativeness of the sample. That the exclusion criteria for participation in the study were minimal supports the external validity of the study. Alzheimer disease, vascular dementia, and mixed dementia are the most common types of dementia, and most nursing home residents are usually able to walk and eat independently in middle-stage dementia. The stability of the sample was optimized with no loss to follow-up and only six (5%) deaths.

### Verification of the Reliability of Standardized Measures

There is potential for measurement bias due to the absence of reliability checks for scoring the Global Deterioration Scale, the Charlson Comorbidity Index, and the

Professional Environmental Assessment Protocol. This limitation was unavoidable since the university regulations precluded the researcher / doctoral student from working collaboratively with another researcher or a research assistant to check the reliability of scoring these instruments.

#### *Other Opportunities for Future Research*

The five predictors of composite excess disability (more advanced stage of dementia, more comorbidities, absence of a cognitive enhancer, antidepressant use, and an unsupportive dementia care environment) each approximately double the hazard of composite excess disability. It would be possible to develop a simple, unweighted scale to assess the risk of developing excess disability in people with Alzheimer disease, vascular dementia, or mixed dementia. Each of the five dichotomous predictors could be scored 0 or 1 for a total scale score ranging from 0 to 5. Items could be dichotomized based on the categories for each of these variables in the current study. Initial scale development could be tested using the dataset of the current study to score the risk of excess disability of the 120 residents on the 0 to 5 scale. Then the scores could be dichotomized to identify those at low (0 to 3) risk and at high (4 or 5) risk. A Kaplan-Meier analysis could be completed to assess the ability of the instrument to discriminate between low and high risk groups. The optimal cut point for the sensitivity and specificity of the instrument could be assessed using a receiver operating characteristic curve which plots the sensitivity as a function of 1 – specificity. Furthermore, the area under the receiver operating characteristic curve could be calculated to ascertain the

ability of the instrument to discriminate between those at higher risk and those at lower risk for excess disability. Further reliability and validity work would require new datasets. Such a scale could be useful as a clinical and a research instrument to identify nursing home residents at risk for excess disability and for whom proactive measures could be taken to mitigate the risk.

The hazard of experiencing both walking disability outcomes is estimated to approximately double for residents living in larger facilities although this finding does not achieve statistical significance. If the number of beds were recalculated based on the number of beds operated by the nursing home organization, rather than based on the number of beds in the individual facility where participating residents lived, then it might be possible to replicate the findings of McGregor et al. (2006) who found that residents who live in nursing homes that are nested within larger organizations are more likely to have better outcomes than those who live in single-site nursing homes (McGregor et al., 2006).

An alternate approach to the analysis of the size of facility would be to calculate the number of residents living in the specific care areas or nursing units rather than the number of residents living in the entire nursing home. Evidence suggests that smaller dementia care units are associated with better resident outcomes compared to larger units accommodating more residents (Calkins, 2001a; Morgan et al., 1998; Sloane et al., 1998). One explanation for this finding is that smaller units may reduce the likelihood of

overstimulation and increase the opportunity for relationships to be developed with the residents. Future research could involve adding a nursing unit size variable to the dataset to see if smaller nursing units are associated with improved disability outcomes.

### **Implications for Practice, Education, and Policy**

Understanding the pattern of functional loss associated with dementia as distinct from functional loss associated with excess disability in people with Alzheimer disease will help family caregivers, clinicians, and health policy makers to more effectively anticipate the care needs of a growing number of Canadians with middle stage Alzheimer disease. This section of the discussion will open with the implications of the findings for clinical practice. In particular the implications for interdisciplinary team collaboration, assessment, and intervention will be followed by a discussion of the ethical issues that arise in maintaining the functional ability of frail older adults who are at risk of losing the ability to walk and eat independently. Then the implications of the findings for educating of staff, physicians and families will be discussed. The section will conclude with a discussion of the implications of the findings for health policy in relation to the care of people with dementia who live in nursing homes, and in relation to the delivery of long-term care services by various categories of owner-operators.

#### *Implications for Practice*

The results of this study will help to heighten the awareness of the incidence of excess disability among clinicians from all disciplines who work in nursing homes. It is

estimated that more than 50% of all walking and eating disability is due to excess disability. If functional impairment is incorrectly attributed to dementia, then this can result in a missed opportunity to reverse or attenuate a potentially reversible functional loss. There exists an important opportunity to address modifiable factors that contribute to walking and eating disability.

In view of the ambiguity and uncertainty surrounding functional loss in people with dementia, and in view of the significant potential for discordance between staff and family members regarding the cause of functional loss, health professionals need to develop ways of building a common understanding of what might be causing the functional loss experienced by a resident. Family members with a lifetime of experience and knowledge about the person with dementia can contribute a perspective that may help in the assessment and identification of reversible causes of disability. Family members can be especially important members of a dementia care team by compensating for the inability of the person with dementia to provide details that may help with problem solving. Unfortunately family members of residents living in nursing homes are not always included as members of the team with the potential for cooperation between family and staff members in the care of the residents not being fully utilized (Hertzberg et al., 2000). In the current study family members had ideas about what might be causing the functional losses of which the nurses were seemingly unaware. Formal admission and annual family conferences that are institutionalized in most nursing homes in the Calgary Health Region are not sufficient for the teamwork that is necessary to respond to the

functional losses of residents as they occur. Nursing staff with leadership skills are essential for building functional teams that include interested and involved family members as active participants on the team (Duncan et al., 1994; Maas et al., 1994; Wilken et al., 1992).

### Assessment

In the light of over half of the instances of walking and eating disability in people with middle-stage dementia being due to excess disability, potential sources of excess disability should be carefully considered before attributing the loss of function to dementia. The process of identifying reversible causes of excess disability in walking or eating should include a careful assessment of possible exacerbations of comorbid chronic conditions, the possible emergence of new acute medical problems, an assessment of depression and the possible side effects of antidepressants, and an assessment of the elements of the social and physical environment that may be contributing to the disability. Family members may be reassured that assessments and interventions are targeting potentially reversible causes of disability such as pain, difficulty chewing, or a noisy dining room. The list of possible causes of disability in walking and eating that was generated by the interview respondents in this study may be a useful guide for the assessment work of dementia care teams.

### Intervention

#### *Walking Disability*

Actions ranging from pain control to rehabilitation therapy were reportedly taken by interview respondents to improve the walking ability of residents. Four recent reviews of the literature pertain to the mobility interventions for people with dementia (Christofoletti et al., 2007; Eggermont et al., 2006; Hauer et al., 2006; Heyn et al., 2004). Physical activity or exercise training is the most frequent strategy reported to enhance function and prevent falls (Hauer et al., 2006). Three of the systematic reviews concluded that motor interventions can have a positive impact on physical and functional abilities as well as on cognition and well-being (Christofoletti et al., 2007; Eggermont et al., 2006; Heyn et al., 2004). Interventions are more likely to be feasible with residents who have dementia if they are integrated into the day-to-day routines of the resident. Several studies have successfully incorporated music (Clair et al., 2006; Mathews et al., 2001), social dancing (Palo-Bengtsson et al., 1998), conversation (Tappen et al., 2000), socialization (Arkin, 1999, 2003), or continence care (Schnelle et al., 2002) into a mobility intervention. Although cognitive impairment has been perceived to be a barrier to rehabilitation in older adults, there is evidence that cognitively impaired older adults can achieve and maintain functional gain with exercise training (Thomas, 2005).

### *Eating Disability*

Numerous interventions to facilitate the ability of residents with dementia to eat independently are suggested in the literature (Amella et al., 2008; Barratt et al., 2004; LeClerc et al., 1998). However a recent systematic review cautions that the research underpinning many of these interventions lacks methodological rigour (Watson et al.,

2006). Some of these interventions include modifying food textures for people with difficulty swallowing, and offering finger food to those who no longer know how to use cutlery (Biernacki et al., 2001; LeClerc et al., 1998). These two interventions were reported by 44% of the interview respondents in the current study. Family members reported residents' successes with independently eating hand held snacks after they had lost their ability to eat the usual nursing home fare. The norms for the dining experience in many nursing homes do not include finger foods, although sandwiches and fruit are often available as snack foods between meals. There is an opportunity to integrate foods that are easier to handle into the regular menus of dementia care facilities.

The most commonly reported actions taken by family members in response to a loss in eating ability were related to modifying the social environment. These included encouraging eating, enhancing mealtime socialization, and changing dining tables to increase mealtime supervision. Together these modifications to the social environment in response to a loss of ability to eat accounted for 24 (41%) of the actions reported by family members and 14 (25%) of the actions reported by staff members. Evidence in the literature supports the effectiveness of modifications to the social environment (Beattie et al., 2004). Amella et al. asserts that "one of the most powerful interventions that clinicians can use to assist persons with moderate to late-stage dementia is to modify both the environment and the interactions" (2008, p. 364).

Since none of the family or staff members reported actions taken to modify the physical environment to enhance eating ability, as discussed earlier, there are opportunities to expand the repertoire of interventions that encourage residents with dementia to remain independent in their eating by also targeting the physical environment (Van Ort et al., 1995; Kayser-Jones et al., 1997; McDaniel et al., 2001). Nurses could be more deliberate in the use of physical space during mealtimes by minimizing noise and other distractions. For example televisions should be turned off during mealtime. The selective use of music rather than turning on a radio may promote a peaceful atmosphere in the dining room. Two quasi-experimental studies on the use of 'quiet' or 'relaxing' music in the dining room of dementia care areas demonstrated a reduction in agitated behaviour (Denney et al., 1997; Goddaer et al., 1994). Residents who are particularly distractible could be seated to eat their meals in quieter areas separate from the main dining room. The presence of non-institutional features such as tablecloths rather than trays was associated with higher food and fluid intake in a sample of 407 residents with dementia (Reed et al., 2005).

### Ethical Issues

There are ethical issues of trying to maintain the mobility of a person who, in the absence of excess disability, is losing the ability to walk due to an advanced stage of dementia. Increased independence in functional ability may not always lead to higher levels of well-being for the person with dementia. The cost of increased function may be too great when balanced with increased anxiety and a lowered sense of security and safety (Woods,

1999). Secker (2003) argues that independence can be understood as a subjectively self-assessed lived experience that is distinct from actual dependence in activities of daily living. For example residents whose walking is particularly hazardous may be able to mobilize in a wheelchair while experiencing a sense of independence and well-being. Future research is indicated in relation to the ethical aspects of decisions to introduce a wheelchair to residents with dementia.

Much of the discussion of ethical issues in eating pertains to people with dementia who refuse to be fed or who are unable to swallow (Norberg et al., 1987; 1988; Wilmot et al., 2002). These issues did not arise for the participants in the current study who were just beginning to lose the ability to feed themselves. Difficulty swallowing was rarely identified by interview respondents as one of the causes of eating disability. Instead the ethical issues were more to do with choosing to support and maintain eating ability versus feeding the person. Staff members' responsibilities to promote physical well-being and to provide care (the principle of beneficence) may conflict with a respect for the autonomy of the person (Manthorpe et al., 2003). Indeed the interpretation of the behaviours of the person who is not eating and the knowledge of the choices available for intervening will influence how this dilemma is resolved (Manthorpe et al., 2003). In this regard, day-to-day ethical decision-making usually rests with nurse aides who often have little training in nutrition and dementia (Barratt et al., 2004).

### *Implications for Education*

Based on the attribution data that were collected during the interviews with family members, some families need help to understand that dementia can affect both the resident's cognitive and physical function. If sources of excess disability have been ruled out and it appears that the disability is, in fact, due to dementia then family education may be indicated. Dementia education resources such as reading material, websites, or education sessions that target family members should be readily available in nursing homes to support the efforts of the health professionals in educating family members regarding dementia broadly, and regarding the contribution of dementia to the loss of physical function more specifically.

Staff members working in nursing homes need greater expertise and skill in providing geriatric care and dementia care to frail older adults rather than custodial care only (Cohen-Mansfield et al., 2005). There is evidence that staff education can reduce turnover rates of nurse aides (McCallion et al., 1999; Noel et al., 2000). The inconsistent evidence supporting the benefit of nursing staff education for resident outcomes has been discussed earlier in the chapter. A study of the outcomes of training family physicians working in long-term care facilities found that despite good participant satisfaction there were no positive effects on their actual work (De Lepeleire et al., 2006). Comprehensive approaches to translating evidence into practice which go beyond continuing education are likely to be what is necessary for adopting and sustaining innovations that will

improve resident outcomes (Aylward et al., 2003; Berta et al., 2005). This is an opportunity for future research.

### *Implications for Policy*

Given that the proportion of the population with dementia will increase as the Canadian population ages, the prevention and management of excess disability in people with dementia must become a policy priority. This study has identified the substantial magnitude of excess disability in people with middle-stage dementia and has identified the predictors of excess disability. Measures taken to prevent, assess, and treat excess disability will improve the well-being of nursing home resident with middle-stage dementia.

### Resources in Nursing Homes

One of the challenges of excess disability is recognizing that it exists. An assessment of excess disability depends upon the availability of skilled professionals working in nursing homes with access to the necessary resources. Professional nurses and family physicians, with additional specialty training in gerontological nursing and geriatric medicine, are in a good position to assess and treat excess disability. The necessary resources to support their work include access to diagnostic services including diagnostic imaging which is frequently required when a fall occurs, and geriatric psychiatry and geriatric medicine consultation for particularly challenging situations.

The current shortage of registered nurses and family physicians affects all health care sectors however the crisis in human capital is most serious in long-term care with few health professionals choosing geriatrics or geriatric mental health specialties (Abramson et al., 2002; Diachun et al., 2006; Kovner et al., 2002). Even fewer choose to work in nursing homes where the residents are the most frail and present with the most complex assessment and treatment challenges (Chan, 2002; MacKnight et al., 2003). Furthermore nurse aides who are usually the first to notice a decline in the functional ability of nursing home residents are underpaid, undervalued, and in short supply (Stone et al., 2001; Beck et al., 2002). Health policy is required that will provide incentives to attract both health professionals and unlicensed workers to care for older adults in nursing homes.

This study has identified three modifiable factors that contribute to the hazard of excess disability in walking and eating: they are the quality of the social and physical environment, the use of antidepressants, and the use of cognitive enhancer drugs. A discussion of the policy implications for each of these follows.

### Supportive Environments

The hazard of excess disability in walking and eating is doubled in the absence of supportive design features in the nursing home environment. This finding adds to the existing literature demonstrating improved outcomes for nursing home residents who live in social and physical environments that are supportive of people with dementia (Kane et al., 2007; Reimer et al., 2004). The character of the social environment of a nursing home

is largely influenced by nurse aides who provide the hands-on care, supervision and emotional support to residents. Although retaining trained staff is essential for the continuity of care and relationships that nursing home residents experience, staff turnover is a significant problem (Bostick et al., 2006). Investment in recruiting, training, and retaining this category of staff will be strategic in creating more supportive dementia care environments.

There is also a need to modify existing physical environments and to create new environments that capitalize on the design features that have been reported in the literature to support people with dementia (Brawley et al., 2001; Calkins, 2001; Day et al., 2000; Lawton et al., 2000). Any policies designed to improve the social and physical supportiveness of nursing home environments will benefit all residents in nursing homes whether they have a dementia diagnosis or not.

#### Antidepressants and Depression

Depression is a common occurrence in people with Alzheimer disease and vascular dementia: in a review of the literature prevalence rates were estimated at 10% and 25% respectively (Potter et al., 2007). In the current study 30% of the sample was taking an antidepressant and it was estimated that the use of antidepressant drugs doubled the hazard of experiencing an excess disability in walking or eating. This increased hazard of functional loss emphasizes the importance of preventing depression in nursing home residents and treating depression where possible using nonpharmacological interventions.

A recent consensus statement for mental health in nursing homes recommends that all residents be screened for depression within a month of admission and then every six months thereafter (American Geriatrics Society et al., 2003). Furthermore nonpharmacological interventions are the recommended first-line treatment for residents who do not meet the criteria for major depression but who have significant symptoms of depression, dysthymia, or minor depression. These treatments include “social contact intervention” and the “provision of meaningful activities such as a sheltered workshop, volunteering, religious activities, or activities that maintain residents’ past roles” (American Geriatrics Society et al., 2003, p. 1291). The consensus statement did affirm that antidepressants are indicated for major depression in conjunction with nonpharmacological treatments.

Unfortunately it is the norm for mental health consulting services which target nursing home residents to be primarily oriented towards diagnosing and recommending pharmacological treatment. One psychiatric liaison service was able to significantly reduce the neuroleptic and health service use by people with dementia living in care facilities (nursing and residential homes) compared with people living in care facilities who received usual care (Ballard et al., 2002). The clinician-researchers concluded that while the resource efficient psychiatric consultation service did reduce the use of neuroleptics and health services, the overall quality of care did not change as reflected in resident well-being and physical function scores. In their opinion “a more extensive

intervention is probably required to achieve global improvements in the quality of care provision” (p. 144).

Cohen-Mansfield et al. (2005) has urged policy makers, clinicians and caregivers to allocate resources for the nonpharmacological care of residents in nursing homes with psychiatric syndromes. The current priorities for resource allocation have led to the disturbing practice of sedating people with dementia who are suffering from undiagnosed pain, from boredom, or from loneliness, rather than treating these causes of distress first. The way in which services develop depends upon finances, culture, and attitudes towards older adults and disabled people (Snowdon, 2007). It is recommended that the current allocation of mental health resources, which are oriented to systems of diagnosis and pharmacological treatment, be reconsidered to include resources for the provision of nonpharmacological care.

### Cognitive Enhancers

The current study estimates that the use of a cognitive enhancer drug reduces the hazard of composite excess disability by 60%. As discussed previously, this finding contributes to the evidence suggesting that cognitive enhancers do help to maintain the functional ability of people with middle to late-stage dementia temporarily. However the use of cognitive enhancer drugs remains controversial based on the questionable clinical importance of the modest improvements in outcome and the relative costliness of these drugs (Hogan, 2006; Khang et al., 2004). The findings of the current study add those of

others calling for the funding of cognitive enhancer drugs to nursing home residents with middle-stage dementia (Gauthier, 2004).

#### For-profit Nursing Home Outcomes

In the current study residents living in private for-profit nursing homes experienced twice the hazard of all-cause walking disability and all-cause composite disability compared with residents living in public or non-profit nursing homes. As discussed previously, this finding of worse resident outcomes for those living in for-profit nursing homes is consistent with the findings of other research.

Although many older adults with Alzheimer disease and related dementias require facility-based care once their dementia has progressed to the middle to late-stage, nursing homes are not considered an essential service under the Canada Health Act (1984). Thus public funding of nursing homes is at the discretion of each province with the out-of-pocket spending varying accordingly (Canadian Institute for Health Information, 2005). The public-private mix of nursing home ownership varies widely across Canada with typically both ownership categories providing health care and accommodation (Canadian Institute for Health Information, 2005). In the Calgary Health Region nursing home services are provided by public (19%), voluntary non-profit (24%), and private for-profit nursing homes (57%) (R. Simpson, personal communication, April 14, 2008). Legislated regulations are necessary to assure the provision of quality services to all nursing home residents and in particular to residents living in for-profit nursing homes.

## **Conclusions**

This study is the first to quantify the extent and predictors of excess disability in walking and eating for people with middle-stage dementia living in nursing homes. Forty-one percent of the residents experienced a walking disability in one year and the same proportion experienced an eating disability. In one year just over 50% of the residents were disabled in the composite outcome of either walking or eating. More than half of the disability experienced by people with middle-stage dementia living in a nursing home was estimated to be due to disability in excess of what would be expected from dementia alone.

After adjusting for the various individual and environmental predictors of disability, residents who were more advanced in their stage of dementia were estimated to experience approximately twice the hazard of any of the all-cause disability outcomes studied. In contrast, the relationships between the stage of dementia and the three excess disability outcomes were not statistically significant in any of the bivariate or multivariate Cox regression analyses. The absence of statistical significance in the relationships between stage of dementia and any of the excess disability outcomes, in the presence of strong statistical significance in all of the relationships between stage of dementia and the all-cause disability outcomes, lends some support to the identification of excess disability as a distinct and separate construct from disability associated with dementia. The predictors of composite disability in walking and eating included the stage of dementia,

comorbidity, and the quality of the environment, while the predictors of composite *excess* disability in walking and eating included these three variables in addition to the use of antidepressant drugs and the lack of use of cognitive enhancer drugs.

This study contributes to the understanding of the responses to the transition from ability to disability in both walking and eating. Fewer staff and family members attributed the loss of the ability to walk to dementia compared with those who attributed the loss to excess disability. When a loss of the ability to walk was attributed to excess disability the reported actions were more oriented to assessment and treatment rather than to safety measures and psychotropic drug use. In contrast, both staff and family members more often attributed the loss of the ability to eat to dementia than to excess disability. Supportive actions such as socialization, supervision, and encouragement were more often reported when a loss of ability to eat was attributed to dementia, while more vigilant types of intervention such as communication, monitoring, and information seeking were more often reported when an eating disability was attributed to excess disability.

The recommendations arising from the implications for practice, education, and policy have the potential to improve the functional status of residents with middle-stage dementia who live in nursing homes. Although there are costs associated with the prevention and reversal of excess disability, maintaining the function of residents will

result in an improvement in the well-being of nursing home residents with middle-stage dementia, and a reduction in the costs associated with caring for more disabled residents.

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## APPENDIX 1



FACULTY OF | UNIVERSITY OF  
MEDICINE | CALGARY

**DEPARTMENT OF FAMILY  
MEDICINE**

#1707, 1632 – 14<sup>th</sup> Ave. NW  
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ndrummon@ucalgary.ca

### **AUTHORIZED REPRESENTATIVE CONSENT FORM**

**TITLE:** Physical Disability of People with Memory Problems Who Live in a Nursing Home

**SPONSOR:** Alberta Heritage Foundation for Medical Research

**INVESTIGATORS:** Susan Slaughter, Neil Drummond, Michael Eliasziw, Debra Morgan

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here or information not included here please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

#### **BACKGROUND**

When people move into a nursing home their abilities to do things for themselves may change. Sometimes these changes are because of illnesses and sometimes these changes are because of being in an unfamiliar place. In this research study people who live in a Calgary nursing home will be visited every second week for a year to see how much they can do for themselves. If any changes occur it will be important to know what the changes are, when the changes happen, and why the changes are happening.

#### **WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this study to identify and measure the changes in ability to walk and ability to eat that may occur in people with memory problems who live in a nursing home. The timing of any changes in function and what is done about these changes will be noted.

## APPENDIX 1

### **WHAT WOULD I HAVE TO DO?**

- Over the next year I will need permission to visit your relative every second week to observe signs of functional change in walking and eating. On the first visit I will also need to complete a more detailed assessment of function.
- I will call you when I notice a change in your family member's functional ability so that we can have a brief conversation about the change. This conversation could be over the phone or we could plan to meet face-to-face, depending on what is most convenient for you. I would like to record our conversations on a tape recorder.
- I will need your permission to have a similar conversation with a member of the nursing home staff.
- I will also need your permission review your family member's health record or to have a research assistant review the health record every time I see your family member. The information needed includes: symptoms, health assessments, diagnoses, medications, tests and treatments.

### **WHAT ARE THE RISKS?**

There are no risks to you or your relative through being involved in the study, except the sharing of thoughts and feelings and the time taken for the visit.

### **WILL I BENEFIT IF I TAKE PART?**

If you agree to take part in this study there may or may not be a direct medical benefit for your relative. The functional abilities of your relative may improve during the study but there is no guarantee that this research will help. The information obtained from this study may help to provide better treatments in the future for people with disabilities who live in nursing homes.

### **DO I HAVE TO PARTICIPATE?**

No, you do not have to take part if you prefer not to, and you may ask me to stop visiting any time without affecting the care the resident will receive. If new information becomes available which might affect your willingness to take part in the study I will tell you about it as soon as possible.

### **WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for participating, and you do not have to pay anything.

### **WILL MY RECORDS BE KEPT PRIVATE?**

Only my supervisor, the research assistant and I will have access to the information gathered for this research study. You will be identified by a study number, not by your name. Scientific reports will not include anybody's name. These reports will only talk about groups of people, not individual people.

## APPENDIX 1

### **SIGNATURES**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Neil Drummond (403) 210-9246

If you have any questions concerning your rights as a possible participant in this research, please contact the Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

**APPENDIX 2**

Resident Participant ID Number \_\_\_\_\_

**AUTHORIZED REPRESENTATIVE INTERVIEW SCHEDULE**  
(complete at time of recruitment)

Date of Interview: dd/mm/yy \_\_\_/\_\_\_/\_\_\_

1. How are you related to the person with dementia?

Daughter

Son

Husband

Wife

Other \_\_\_\_\_

2. When was your relative diagnosed with a memory problem? \_\_\_/\_\_\_/\_\_\_

Did a family doctor or a specialist diagnose the memory problem? family MD spec.

Did the doctor call the memory problem Alzheimer disease? Yes No

If not, what did the doctor call the memory problem? \_\_\_\_\_

3. Is English the first language your relative spoke? Yes No

If not, how well does your relative speak English now? \_\_\_\_\_

4. I will be asking your relative some questions to get an idea of how advanced her Alzheimer disease is. Could you please tell me the correct answers to the following questions that I will be asking your relative?

- spouse's name \_\_\_\_\_
- names of brothers & sisters \_\_\_\_\_
- names of children \_\_\_\_\_
- father's first name \_\_\_\_\_
- mother's first name \_\_\_\_\_
- highest grade in school attended. \_\_\_ Was that grade completed? Yes No
- names of schools attended \_\_\_\_\_
- names of teachers \_\_\_\_\_
- name of childhood friend \_\_\_\_\_
- highest job ever held \_\_\_\_\_
- favorite TV show \_\_\_\_\_
- favorite radio program \_\_\_\_\_

5. During the past week, on how many days did you visit your ... (mother, father, husband, wife)? \_\_\_\_\_

6. During the past week, how many hours in total did you spend visiting with your ....?  
\_\_\_\_\_

7. Was this past week a typical week for visiting? Yes No





Resident ID: \_\_\_\_\_

CORRECT	# OF ERRORS OR INCORRECT	RESPONSE NOT RATEABLE	REFUSAL	NOT ASKED DUE TO PHYSICAL &/OR PERCEPTUAL IMPAIR
0	1	7	8	9

**AXIS 4: ORIENTATION**

1.	I'd like you to remember my name. My name is _____ Could you repeat that please?	0 1	(Cannot repeat rough approximation of name after 3 repeats)	7 8 9
2.	What is your name?	0 1	(Does not state name)	7 8 9
3.	Have you ever been married:	IF YES:		
3a.	What is (was) your spouse's name?	0 1	(Does not state a name)	7 8 9
4.	Do you have any children?	IF YES:		
4a.	What are their names?	0 1	(Does not state a name)	7 8 9
5.	What is today's date?	0 1	(Does not know date or gives incorrect date)	7 8 9
6.	What season is it? (Accept as correct if within one month of season change)	0 1	(Does not know season or gives incorrect season)	7 8 9
7.	What hour of the day is it? (Accept as correct if within one hour either side of time)	0 1	(Does not know time or gives incorrect hour)	7 8 9

**BCRS AXIS 4: ORIENTATION** (Circle only one, i.e., the most appropriate level)

- 1 No deficit in memory for time, place, identity of self or others.
- 2 Subjective impairment only. Knows time to the nearest hour. Knows location.
- 3 Any mistake in time of two hours or more, day of the week of 1 day or more, date of 3 days or more.
- 4 Mistakes day of the month by 10 days or more, and/or confuses month of the year by 1 month or more.
- 5 Unsure of month and/or year and/or season, unsure of locale.
- 6 No idea of date. Identifies spouse but may not recall name. Knows own name.
- 7 Cannot identify spouse. may be unsure of personal identity.

Resident ID: \_\_\_\_\_

CORRECT	# OF ERRORS OR INCORRECT	RESPONSE NOT RATEABLE	REFUSAL	NOT ASKED DUE TO PHYSICAL &/OR PERCEPTUAL IMPAIR
0	1	7	8	9
<b>AXIS 3: PAST MEMORY</b>				
8.	Where were you born?		(Place of birth is not stated or incorrect or does not know)	RECORD BIRTHPLACE _____
		0 1		7 8 9
9.	What was your father's first name?		(Does not state a male name, does not mention a name, or does not know)	RECORD FATHER'S NAME _____
		0 1		7 8 9
9a.	What was your mother's first name?		(Does not state a female name, does not mention a name, or does not know)	RECORD MOTHER'S NAME _____
		0 1		7 8 9
10.	What is the highest grade or year of regular school you ever attended? (Did you finish that year of school?)		(Does not recall how much schooling)	RECORD HIGHEST YEAR COMPLETED _____
		0 1		7 8 9
11.	IF EVER ATTENDED SCHOOL What is the name of one specific you went to?		(Cannot name a specific school)	7 8 9
		0 1		
11a.	What was the name of one of your teachers?		(Does not state name)	7 8 9
		0 1		
11b.	What was the name of one of your childhood friends?		(Does not state name)	7 8 9
		0 1		
12.	Did you ever do any work for pay? What was the highest job you ever held?		IF YES: (Cannot recall occupation)	SPECIFY HIGHEST JOB _____
		0 1		7 8 9

**BCRS AXIS 3: PAST MEMORY** (Circle only one, i.e., the most appropriate level)

- 1 No subjective or objective impairment in past memory.
- 2 Subjective impairment only. Can recall two or more primary school teachers.
- 3 Some gaps in past memory upon detailed questioning. Able to recall at least one childhood teacher and/or one childhood friend.
- 4 Clear-cut deficit. The spouse recalls more of the patient's past than the patient. Cannot recall childhood friends and/or teachers but knows the names of schools attended. Confuses chronology in reciting personal history.
- 5 Major past events sometimes not recalled (e.g., names of schools attended). Characteristically, at this stage patients recall some schools attended, but not others.
- 6 Some residual memory of past (e.g., may recall country of birth or former occupation, may or may not recall mother's name, may or may not recall father's name). Generally, patients do not recall any of the schools which they attended.
- 7 No memory of past (cannot recall country, state, or town or origin, cannot recall names of parents, etc.).

**REMINDER:** Transpose the accurate past history information in to the subsequent assessment forms.

Resident ID: \_\_\_\_\_

CORRECT	# OF ERRORS OR INCORRECT	RESPONSE NOT RATEABLE	REFUSAL	NOT ASKED DUE TO PHYSICAL &/OR PERCEPTUAL IMPAIR
0	1	7	8	9

**AXIS 2: RECENT MEMORY**

13. What is your address? 0 1 (Gives incorrect address or doesn't know) 7 8 9

IF NOT ALREADY GIVEN, ASK:

14. What is your postal code? 0 1 (Gives incorrect postal code or doesn't know) 7 8 9

15. What is your telephone number? 0 1 (Gives incorrect telephone number or doesn't know) 7 8 9

IF NOT ALREADY GIVEN, ASK:

16. What is the area code? 0 1 (Gives incorrect area code or doesn't know) 7 8 9

17. Which meal did you eat last? 0 1 (Gives incorrect meal or doesn't know) 7 8 9

18. What is your favourite T.V. show or radio program? 0 1 (Does not state a program) 7 8 9

19. Who is Prime Minister now? 0 1 (Does not recall name of Prime Minister) 7 8 9

**BCRS AXIS 2: RECENT MEMORY** (Circle only one, i.e., the most appropriate level)

- 1 No objective or subjective evidence of deficit in recent memory.
- 2 Subjective impairment only (e.g., forgetting names more than formerly).
- 3 Deficit in recall of specific events evident upon detailed questioning, (e.g. about recent meals, current reading, recent appointments, etc.). No deficit in the recall of major recent events.
- 4 Cannot recall major events of previous weekend or week. Scanty knowledge (not detailed) of current events, favourite TV shows, etc. May not know telephone number and/or telephone area code and/or postal code.
- 5 Unsure of weather, and/or may not know current Prime Minister and/or current address.
- 6 Occasional knowledge of some recent events. Little or no idea of current address, weather, etc. Given the current Prime Minister's first name, may recall his last name.
- 7 No knowledge of any recent events.

Resident ID: \_\_\_\_\_

CORRECT	# OF ERRORS OR INCORRECT	RESPONSE NOT RATEABLE	REFUSAL	NOT ASKED DUE TO PHYSICAL &/OR PERCEPTUAL IMPAIR
0	1	7	8	9

**AXIS 1: CONCENTRATION** (Begin at level respondent is at and go up or down depending on answer.)

20. I would like you to take 7 away from 100  
 ...now take 7 away from the number you get  
 ...keep subtracting 7 until I tell you to stop.

# OF ERRORS  
 0 1 \_\_\_\_\_ 7 8 9  
 IF CORRECT GO TO QUESTION 25

(93)	(86)	(79)	(72)	(65)	(58)	(51)
(44)	(37)	(30)	(23)	(16)	(9)	(2)

(count 1 error when difference is not 7)

21. I would like you to take 4 away from 40  
 ...now take 4 away from the number you get  
 ...keep subtracting.

0 1 \_\_\_\_\_ 7 8 9  
 IF CORRECT GO TO QUESTION 25

(36)	(32)	(28)	(24)	(20)	(16)	(12)	(8)	(4)
------	------	------	------	------	------	------	-----	-----

(count 1 error when difference is not 4)

22. I would like you to take 2 away from 20 and keep subtracting 2.

0 1 \_\_\_\_\_ 7 8 9  
 IF CORRECT GO TO QUESTION 25

(18)	(16)	(14)	(12)	(10)	(8)	(6)	(4)	(2)
------	------	------	------	------	-----	-----	-----	-----

(count 1 error when difference is not 2)

23. Would you count backwards from 10 to 1? 0 1 \_\_\_\_\_ 7 8 9  
 IF CORRECT GO TO QUESTION 25

24. Now would you count forward from 1 to 10? 0 1 \_\_\_\_\_ 7 8 9

25. Do you still remember my name? 0 1 (Does not recall even gross approximation of name) 7 8 9

**BCRS AXIS 1: CONCENTRATION** (Circle only one, i.e., the most appropriate level)

- 1 No objective or subjective evidence of deficit in concentration.
- 2 Subjective decrement in concentration ability.
- 3 Minor signs of poor concentration (e.g., subtraction of serial 7s from 100).
- 4 Definite concentration deficit for persons of their background (e.g., marked deficit on serial 7s, frequent deficit in subtraction of serial 4s from 40).
- 5 Marked concentration deficit (e.g., giving months backwards or serial 2s from 20).
- 6 Forgets the concentration task. Frequently begins to count forward when asked to count backwards from 10 by 1.
- 7 Marked difficulty counting forward to 10 by 1s.

# OF ERRORS

RESPONSE

NOT ASKED DUE TO



## APPENDIX 5

## CHARLSON COMORBIDITY INDEX

<i>Items</i>	<i>(weighting)</i>
Myocardial infarct	(1)
Congestive heart failure	(1)
Peripheral vascular disease	(1)
Cerebrovascular disease	(1)
Dementia	(1)
Chronic Pulmonary Disease	(1)
Connective Tissue Disease	(1)
Ulcer disease	(1)
Mild liver disease	(1)
Diabetes	(1)
Hemiplegia	(2)
Moderate or severe renal disease	(2)
Diabetes with end organ damage	(2)
Any tumor	(2)
Leukemia	(2)
Lymphoma	(2)
Moderate or severe liver disease	(3)
Metastatic solid tumor	(6)
AIDS	(6)

## APPENDIX 6

## REVISED CHARLSON COMORBIDITY INDEX

*Items (weighting):*

- congestive heart failure (1)
- dementia (1)
- chronic pulmonary disease (1)
- moderate or severe renal disease (2)
- any tumor (1.25)
- metastatic solid tumor (2)
- valvular disease (2)
- hearing disability (2.75)
- urinary problems (1.75)

*Definitions of Items:*

congestive heart failure: coded present in patients who have exertional or paroxysmal nocturnal dyspnea and who have responded symptomatically (or on physical examination) to digitalis, diuretics or afterloading reducing agents. It does not include patients who are on medication but have no symptomatic response and no evidence of improvement of physical signs.

dementia: coded present in patients with chronic cognitive deficit

chronic pulmonary disease: coded present in patients who are dyspneic at rest, despite treatment, those who require constant oxygen, those with CO<sub>2</sub> retention and those with baseline PO<sub>2</sub> below 50 torr.

moderate or severe renal disease: coded present in patients with serum creatinines of >3mg%, patients on dialysis, those who had a transplant, and those with uremia.

any tumor: coded present in patients with solid tumors without documented metastases, but initially treated in the last 5 years, including breast, colon, lung and a variety of other tumors.

metastatic solid tumor: coded present in patients with metastatic solid tumors, including breast, lung, colon and other tumors.

valvular disease: coded present in patients with significant aortic stenosis or insufficiency, significant mitral stenosis or insufficiency, prosthetic aortic or mitral valves, symptomatic mitral valve prolapse, asymmetric septal hypertrophy requiring treatment, or tricuspid insufficiency.

hearing disability: coded present in patients who can only hear shouting or certain words, in those who read lips, understand gestures, or are totally deaf.

urinary problems: coded present in patients with frequent or complete urinary incontinence, in those who wear a diaper, an indwelling catheter, or a urinary condom.

## APPENDIX 7

Resident Participant ID Number \_\_\_\_\_

## OBSERVATION FLOWSHEET

DATE								
<b>FUNCTION</b>								
<b>Walking</b> Ambulates within care centre without a person assisting (note if uses aides such as walker or cane or nursing time of any sort required)								
Describe:								
<b>Eating</b> Eats without a person assisting (note if set up needed or nursing time of any sort required)								
Describe:								

0 independent

1 independent with special devices

**APPENDIX 8**

Resident Participant ID Number \_\_\_\_\_

**FUNCTIONAL LOSS INTERVIEW SCHEDULE**  
(complete after each event with family and staff)

Date of Interview: dd/mm/yy \_\_\_/\_\_\_/\_\_\_

Week Number: \_\_\_

1. Have you noticed any changes in the physical ability of \_\_\_ (person with dementia)?

- Yes    No      If Yes: What have you noticed?

---

---

2. What do you think may be causing this change in physical ability?

- Alzheimer disease (or dementia)  
 Something other than Alzheimer disease/dementia

---

---

3. What actions, if any, have been taken because of this change in physical ability?

- None  
 Actions by family member

---

---

---

- Actions by someone else

---

---

---

## APPENDIX 9



### DEPARTMENT OF FAMILY MEDICINE

#1707, 1632 – 14<sup>th</sup> Ave. NW  
Calgary, AB, Canada T2N 1M7

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### STAFF CONSENT FORM

**TITLE:** Physical Disability of People with Memory Problems Who Live in a Nursing Home

**SPONSOR:** Alberta Heritage Foundation for Medical Research

**INVESTIGATORS:** Susan Slaughter, Neil Drummond, Michael Eliasziw, Debra Morgan

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#### **BACKGROUND**

When people move into a nursing home their abilities to do things for themselves may change. Sometimes these changes are because of illnesses and sometimes these changes are because of other things like being in an unfamiliar place. In this research study people who live in a Calgary nursing home will be visited every second week for a year to see how much they can do for themselves. If any changes occur it will be important to know what the changes are, when the changes happen, and why the changes are happening.

#### **WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this study to identify and measure the changes in ability to walk and ability to eat that may occur in people with memory problems who live in a nursing home. The timing of any changes in function and what is done about these changes will be noted.

## APPENDIX 9

### **WHAT WOULD I HAVE TO DO?**

Once in a while I will ask you some questions about any changes you may have noticed in the ability of a resident to walk or to eat. I will ask you what you think might be causing the change in the resident's function and if you know of any actions that are being taken because of this change in function. Our conversation should only take about 5 minutes.

### **WHAT ARE THE RISKS?**

There are no risks to you through being involved in the study, except the sharing of your thoughts and feelings and the time taken for the visit.

### **WILL I BENEFIT IF I TAKE PART?**

If you agree to take part in this study there will not be a direct benefit to you. The information obtained from this study may help to provide better treatments in the future for people with disabilities and memory problems who live in nursing homes. Some people find it helpful to know that someone is interested in their work.

### **DO I HAVE TO PARTICIPATE?**

No, you do not have to take part if you prefer not to. If new information becomes available which might affect your willingness to take part in the study I will tell you about it as soon as possible.

### **WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

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### **WILL MY RECORDS BE KEPT PRIVATE?**

Only my research supervisor, my research assistant and I will have access to the information gathered for this research study. You will be identified by a study number, not by your name. Scientific reports will not contain anybody's name. These reports will only talk about groups of people, not individual people.

### **SIGNATURES**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Neil Drummond (403) 210-9246

**APPENDIX 9**

If you have any questions concerning your rights as a possible participant in this research, please contact the Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

_____	_____
Participant's Name	Signature and Date
_____	_____
Investigator/Delegate's Name	Signature and Date
_____	_____
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

**APPENDIX 10**

Resident Participant ID Number \_\_\_\_\_

**CASE REPORT FORM**

(complete on 3 consecutive weeks after each event)

Data Collection Date: \_\_\_/\_\_\_/\_\_\_  
 Week Number: \_\_\_  
 New Symptoms\*:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Data Collection Date: \_\_\_/\_\_\_/\_\_\_  
 Week Number: \_\_\_  
 New Symptoms:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

New Investigations:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

New Investigations:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

New Referral/Report:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

New Referral/Report:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

New Medical Diagnoses:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

New Medical Diagnoses:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Drug Change(drug, dose, route, time):  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Drug Change:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Physical Environment Change:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Environment Change:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Social Env.Change: (family or staff)  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Social Environment. Change:  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
 \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

Comments:

Comment

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

\* pain, constipation, sleeplessness, increasingly unsteady, more confused, more aggressive, more withdrawn, other

## APPENDIX 11



FACULTY OF | UNIVERSITY OF  
**MEDICINE | CALGARY**

**DEPARTMENT OF FAMILY MEDICINE**

#1707, 1632 – 14<sup>th</sup> Ave. NW  
 Calgary, AB, Canada T2N 1M7

**T** 403.210-9246

**F** 403.210-9205  
 ndrummyon@ucalgary.ca

### **MANAGER CONSENT FORM**

**TITLE:** Physical Disability of People with Memory Problems Who Live in a Nursing Home

**SPONSOR:** Alberta Heritage Foundation for Medical Research

**INVESTIGATORS:** Susan Slaughter, Neil Drummond, Michael Eliasziw, Debra Morgan

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here or information not included here please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

#### **BACKGROUND**

When people move into a nursing home their abilities to do things for themselves may change. Sometimes people start to need help with things like getting dressed or getting to the bathroom. Sometimes these changes are because of illnesses and sometimes these changes are because of other things like being in an unfamiliar place. In this research study people who have recently moved into 6 nursing homes in Calgary will be visited every week for a year to see how much they can do for themselves. If any changes occur it will be important to know what the changes are, when the changes happen, and why the changes are happening.

#### **WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this study to identify and measure the changes in functional ability that occur in people with memory problems during the first year of living in a nursing home and the factors associated with these changes. When the changes in function occur and what is done about these changes will be noted.

## APPENDIX 11

### **WHAT WOULD I HAVE TO DO?**

I will ask you some questions about this nursing home environment. The questions are part of the Professional Environmental Assessment Procedure. This questionnaire should take about 15 to 20 minutes to complete.

### **WHAT ARE THE RISKS?**

There are no risks to you through being involved in the study, except the time taken for completing the questionnaire.

### **WILL I BENEFIT IF I TAKE PART?**

If you agree to take part in this study there will not be a direct benefit to you. The information obtained from this study may help to provide better treatments in the future for people with disabilities and memory problems who live in nursing homes. Some people find it helpful to know that someone is interested in their work.

### **DO I HAVE TO PARTICIPATE?**

No, you do not have to take part if you prefer not to. If new information becomes available which might affect your willingness to take part in the study I will tell you about it as soon as possible.

### **WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for participating, and you do not have to pay anything.

### **WILL MY RECORDS BE KEPT PRIVATE?**

Only my research supervisor, my research assistant and I will have access to the information gathered for this research study. You and the nursing home where you work will be identified by a study number, not by name. Scientific reports will not contain any names. These reports will only talk about groups of people, not individual people.

### **SIGNATURES**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Neil Drummond (403) 210-9246

## APPENDIX 11

If you have any questions concerning your rights as a possible participant in this research, please contact the Ethics Resource Officer, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

**APPENDIX 12**

**PROFESSIONAL ENVIRONMENTAL ASSESSMENT PROTOCOL**

**Staff Questionnaire**

Unit I.D. \_\_\_\_\_

**Maximize Awareness and Orientation**

To what extent do you try to have a consistent daily program every day? So similar types of activities occur at roughly the same time every day? \_\_\_\_\_

How many of the social spaces have a clear identity for specific types of activities--vs. rooms that are used for multiple purposes, and it's hard to tell what's going to take place? \_\_\_\_\_

**Maximize Safety and Security**

If there is equipment like stoves, coffee-maker, etc., to what extent are they available to residents vs. secured? \_\_\_\_\_

**Provision of Privacy**

How is room-mate selection made? Resident choice, staff opinion about how would suit each other, what's open, etc.? \_\_\_\_\_

Being honest, about what % of the time do staff (CNAs and RNs) knock on doors and wait for a response before entering a bedroom? \_\_\_\_\_

Are residents encouraged to be out of their rooms every day, or can they choose where they want to be? \_\_\_\_\_

If a resident chooses to be in their bedroom, are they allowed to keep the bedroom door closed? \_\_\_\_\_

**Stimulation and Coherence**

Over the course of the day, would you say there's a lot of noise from TVs, radios, PA systems, etc.? Includes both level and frequency \_\_\_\_\_

Do you consciously plan when you have more physical active activities, vs. more quiet and calming activities? \_\_\_\_\_

**Support Functional Abilities**

To what extent do you encourage residents to do things on their own (like dressing and grooming) even when it takes substantially longer? \_\_\_\_\_

Are cooking facilities available to residents? How available? \_\_\_\_\_

Are wardrobes routinely locked? For all residents or just some? \_\_\_\_\_

To what extent can residents keep personal grooming supplies and toiletries in their rooms? \_\_\_\_\_

**Opportunities for Personal Control**

How often are multiple and simultaneous activities taking place on the unit? i.e.- do residents have much a choice about what they're doing?

\_\_\_\_\_

Do all residents get up at the same time for breakfast?

\_\_\_\_\_

Are they encouraged to go to bed at a set time?

**Continuity of the Self**

To what extent can and do residents bring in furniture from home?

\_\_\_\_\_

\_\_\_\_\_

**Facilitation of Social Contact**

Can residents sit near the nurses station or other area where they can easily talk with others-- particularly staff?

\_\_\_\_\_

\_\_\_\_\_

## APPENDIX 13: Ethics Approval from Conjoint Health Research Ethics Board



2006-07-04

Dr. Neil Drummond  
Department of Family Medicine  
UCMC North Hill  
Calgary, Alberta

OFFICE OF MEDICAL ETHICS  
Room 93, Heritage Medical Research Bldg  
3330 Hospital Drive NW  
Calgary, AB, Canada T2N 4N1  
Telephone: (403) 220-7890  
Fax: (403) 220-9824  
Email: omb@ucalgary.ca

Dear Dr. N. Drummond:

**RE: Physical Disability of People with Memory Problems Who Live in a Nursing Home**

**Ethics ID: E-20251**

**Student: Ms. Susan Slaughter**

The above-named research, including the Research Proposal, Family Member Consent Form (Version 1, dated: June 15, 2006), Staff Consent Form (Version 1, dated: June 15, 2006), Data Collection Sheet (Baseline Data, Weekly Observation Guide, Event Case Report Form, Coding System for Family Member Interviews), and the Interview Guide (Family Interview Schedule, Interview Schedule) has been granted ethical approval by the Conjoint Health Research Ethics Board of the Faculties of Medicine, Nursing and Kinesiology, University of Calgary, and the Affiliated Teaching Institutions. The Board conforms to the Tri-Council Guidelines, ICH Guidelines and amendments to regulations of the Food and Drugs Act re clinical trials, including membership and requirements for a quorum.

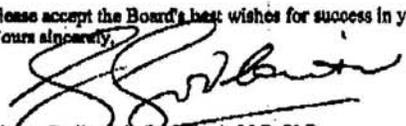
You and your co-investigators are not members of the CHREB and did not participate in review or voting on this study.

Please note that this approval is subject to the following conditions:

- (1) appropriate procedures for consent for access to identified health information have been approved;
- (2) a copy of the informed consent form must have been given to each research subject, if required for this study;
- (3) a Progress Report must be submitted by July 04, 2007, containing the following information:
  - i) the number of subjects recruited;
  - ii) a description of any protocol modification;
  - iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
  - iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
  - v) a copy of the current informed consent form;
  - vi) the expected date of termination of this project.
- 4) a Final Report must be submitted at the termination of the project.

Please accept the Board's best wishes for success in your research.

Yours sincerely,

  
Glenns Godwin, BA(Hons), LLB, PhD  
Chair, Conjoint Health Research Ethics Board

GO/sg  
c.o. Adult Research Committee  
Office of Information & Privacy

Dr. T. Noseworthy (Information)

Research Services

Susan Slaughter (Student)

Foothills Medical Centre  
1403 29 Street NW  
Calgary, Alberta, Canada T2N 2T9  
website [www.calgaryhealthregion.ca](http://www.calgaryhealthregion.ca)



calgary health region  
Foothills Medical Centre

July 05, 2006

Dr. Neil Drummond  
Department of Family Medicine  
UCMC North Hill  
Calgary, Alberta

Dear Dr. Drummond:

**RE: E-20251 - Physical Disability of People with Memory Problems Who Live in a Nursing Home**

Thank you for submitting an application regarding the above project for review by the Adult Research Committee of the Calgary Health Region (CHR). This will confirm that the committee has granted institutional approval for this project, and that the CHR has granted approval under Sections 53 and 54 of the Health Information Act. *This approval is contingent on approval by the Conjoint Health Research Ethics Board.*

It is understood from your submission that your study will be entirely funded through external sources and that the CHR will be reimbursed for all research costs associated with this project. **To facilitate a smooth startup of your project, please notify affected departments in the Region well in advance of your intent to initiate this study.**

Please accept the committee's best wishes for success in your research.

Yours sincerely,

Elizabeth MacKay, MD  
Acting Chair, Adult Research Committee

cc: Dr. T. Noseworthy (information), Conjoint Health Research Ethics Board, Susan Slaughter (Student)



FACULTY OF | UNIVERSITY OF  
**MEDICINE | CALGARY**

October 23, 2006

Dr. Neil Drummond  
 Department of Family Medicine  
 UCMC North Hill  
 Calgary, AB

**OFFICE OF MEDICAL BIOETHICS**

Room 93, Heritage Medical Research Bldg  
 3330 Hospital Drive NW  
 Calgary, AB, Canada T2N 4N1  
 Telephone: (403) 220-7990  
 Fax: (403) 283-8524  
 Email: omb@ucalgary.ca

Dear Dr. Drummond:

**RE: Physical Disability of People with Memory Problems Who Live in a Nursing Home**

**ETHICS ID: 20251**

Your request to modify the above-named protocol has been reviewed and approved.

I am pleased to advise you that it is permissible for you to use the revised protocol and the previously approved consent form, based on the information contained in your correspondence of September 8, 2006.

A progress report concerning this study is required annually, from the date of the original approval 2006-07-04.

The report should contain information concerning:

- i) the number of subjects recruited
- ii) a description of any protocol modifications;
- iii) any unusual and /or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
- iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
- v) a copy of the current informed consent form;
- vi) the expected date of termination of this project;

Thank you for the attention, which I know you will bring to these matters.

Yours sincerely,

Glenys Godlovitch, BA(Hons) LLB, PhD  
 Chair, Conjoint Health Research Ethics Board

GG/tm

cc: Ms. Susan Slaughter



FACULTY OF | UNIVERSITY OF  
**MEDICINE | CALGARY**

December 19, 2007

Dr. Neil Drummond  
 Department of Family Medicine  
 UCMC, North Hill  
 Calgary, Alberta

**OFFICE OF MEDICAL BIOETHICS**

Room 93, Heritage Medical Research Bldg  
 3330 Hospital Drive NW  
 Calgary, AB, Canada T2N 4N1  
 Telephone: (403) 220-7990  
 Fax: (403) 283-8524  
 Email: omb@ucalgary.ca

Dear Dr. Drummond:

**Re: Physical Disability of People with Memory Problems Who Live in a Nursing Home**

**Ethics ID: 20251**

Ms. Susan Slaughter's request to modify the above named research protocol has been reviewed and approved.

I am pleased to advise you that it is permissible for you to collect one additional piece of environmental data using a standardized observational assessment instrument which contains a questionnaire for the nursing home manager in each nursing home and for you to use the additional Manager Consent Form (dated December 18, 2007), based on the information contained in your correspondence of October 15 and December 18, 2007.

A progress report concerning this study is required annually, from the date of the original approval 2006-07-04. The report should contain information concerning:

- (i) the number of subjects recruited;
- (ii) a description of any protocol modification;
- (iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
- (iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
- (v) a copy of the current informed consent form;
- (vi) the expected date of termination of this project;

Thank you for the attention which I know you will bring to these matters.

Yours sincerely,

Glenys Godwin, BA(Hons) LLB, PhD.  
 Chair, Conjoint Health Research Ethics Board

GG/mc

c.c. Ms. Susan Slaughter

