

**University of Alberta**

Exploration of Institutional Dementia Care: Social Engagement and the Use of

Physical Restraints

by

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## Abstract

Social engagement has been established as an important indicator of quality of life. For individuals with dementia, entering an institution can accelerate their exclusion from the social world of their healthy peers (Kitwood, 1997). This study examined social engagement and physical restraint use in 72 elderly individuals diagnosed with dementia (35 males and 37 females) who were being cared for in a psychiatric in-patient setting. The specific research questions were: 1) how frequently are individuals with dementia constructively engaged, passively engaged, self-engaged, or not socially engaged at all with other individuals in their environment; 2) does social engagement differ across the weekday, evening, or weekend nursing shift; and 3) which individual variables uniquely and jointly predict social engagement? Direct observation of social interactions resulted in the following breakdown: 12% constructive engagement, 5% passive engagement, 38% self-engagement, and 46% non-engagement. A repeated measures ANCOVA indicated engagement did not differ across the three shifts. Hierarchical linear regression analyses were used to show that: 1) greater independence in ADLs predicted constructive engagement but restraint use and behavioral disturbances did not; 2) Physical restraint use predicted self-engagement uniquely and jointly with ADL dependency and behavioral disturbances; and 3) Restraint use predicted non-engagement only when combined with ADL dependency. This study showed that physical restraint use contributes to the social exclusion experienced by individuals with dementia. In

addition, individuals with dementia who have the greatest care needs are engaged in the least amount of constructive social interactions.

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## Chapter I

### Introduction

This study explores the relationship between social engagement and the use of physical restraints for individuals diagnosed with a dementia who reside in an institutional setting. While these two phenomenon may appear to have very little in common, this dissertation provides a theoretical argument and empirical evidence to suggest otherwise. Outside of very few empirical studies (e.g., Flomar & Wilson, 1989; Castle, 2006) the relationship between these two variables has not been well established.

Any discussion of dementia in the literature will inevitably touch on the loss of cognitive and functional abilities as well as the personal, familial, and societal burden of the disease. Information written on the topic of dementia frequently begins by stressing the burgeoning impact this disease has on society (e.g., Chou, LaMontagne & Hepworth, 1999; Connell, Janevic, & Gallant, 2001; Mauskopf, Racketa, & Sherrill, 2010; Pinquart & Sörensen, 2003). For example, the estimated costs of treating individuals with dementia is high (Bloom, Pouvourvill, & Straus, 2003; Kinosian, et al., 2000; Kang, Lee, Kim & Park, 2007; Oremus & Aguilar, 2011), the efficacy of current drug interventions is limited (AD2000 Collaborative Group, 2004; Chang-Quan et al., 2011; Franco, & Messinger-Rapport, 2006; Martinon-Torres, Fioravanti, & Grimley, 2004), and dementia has been linked to extensive caregiver burden (Black, & Almeida, 2004; Cooper, Balamurali, & Livingston, 2007; Torti, Gwyther, Reed, Friedman, & Schulman, 2004). In 2010, the Alzheimer Society of Canada launched the report

“Rising tide: Impact of dementia on Canadian society” that provided the most up to date figures on the incidence, prevalence and economic burden of dementia for Canada. In 2008 there were an estimated 480,600 people with dementia in Canada rising to 1,125,200 in 2038. In 2008 an estimated 231 million hours of informal care was provided annually for people with dementia in Canada, rising to 756 million hours in 2038. The economic burden of dementia in Canada was an estimated \$15 billion in 2008 and rising to \$153 billion in 2038.

Deterioration of cognitive and functional abilities are not the only symptoms associated with dementia that affect the individual with dementia and their caregivers. Behavioral disturbances are estimated to occur in 40-90% of individuals diagnosed with dementia and may consist of wandering, agitation, aggression, and sleep disturbance (Beck, Rossby, & Baldwin, 1991; Burgio, 1996; Gauthier et al., 2010; Conn & Thorpe, 2007). Behavioral disturbances clearly contribute to early institutionalization of individuals in long-term care centers, acute care hospitals, and psychiatric facilities (Agüero-Torres, Strauss, Viitanen, Winblad & Fratiglioni, 2001; Lever et al., 1994; Fisher & Swingen, 1997; Nejtek, Hardy, Hall, & Winter 2011; Verhey, 2006).

There is a large volume of literature that explores the use of psychotropic medications and various non-pharmacological interventions to treat these cognitive, behavioral, and psychiatric symptoms associated with dementia (see Saddichha & Pandey, 2008; Snowden, Sato, & Roy-Byrne, 2003 for a review). The amount of literature detailing medical interventions, especially drug therapy, is not surprising given that individuals with dementia are often treated in medical

settings (e.g., hospitals, nursing homes, and psychiatric facilities). Meta-analyses have pointed out that the medical interventions have at best, moderate effect sizes in treating behavioral disturbances and functional dependency (Ballard & O'Brien, 1999; Cheung & Stapelberg, 2011; Howard, Ballard, O'Brien, & Burns, 2001; Trinh, Hoblyn, Mohanty, & Yaffe, 2003; Schneider, Dagerman, Higgins, & McShane, 2011). Studies discussing the effectiveness of non-pharmacological interventions have had mixed results, but suggest a trend toward positive outcomes (e.g., Ballard, Khan, Clack, & Corbett, 2011; Finnema et al., 2000; Forbes, 1998; Kolanowski, Litaker, & Buettner, 2005; Lai, Chi, & Kayser-Jones, 2003; Richeson, 2003, Robinson et al., 2007; Saddhichha & Pandey, 2008; Snowden et al., 2003).

Alongside the plethora of information currently describing the biological degenerative progression of the disease and the commonly accepted treatments, there is a smaller but growing body of literature concerned with the social and psychological impacts of dementia. Social psychological approaches to understanding and treating dementia are noteworthy given the absence of any medical cure for this disorder. Kitwood (1996) argued that while science has improved our understanding of the biological mechanisms at play in the disease process, the structural changes observed in brain tissue of the individual with dementia does not necessarily correspond with functional changes observed in that individual. He pointed out that there can be substantial neuropathology without dementia and serious cognitive and functional impairments despite relatively spared brain structure. Kitwood suggested that the medical model falls

short in its quest to treat individuals with dementia by excluding an appreciation of the individual's social psychological experience and well-being. He recommended a model of dementia care that encompasses an appreciation of both the biological and social psychological aspects of dementia.

Similarly, there is a growing body of literature devoted to the improvement and measurement of what has been coined "quality of life" for individuals residing in the institutional setting (see Kwasky, Harrison, & Wall 2010; Werezak & Morgan, 2003 for a review). As such, we now understand from the research literature that the quality of life of the institutionalized person with dementia varies depending on a number of individual and organizational factors (e.g., Chen, Ryden, Feldt, & Savik, 2000; Chung, 2004; Edvardsson, Sandman, & Rasmussen, 2010; Kelley, 1997; Kolanowski, Buettner, Litaker, & Yu, 2006; Kolanowski, Fick, Campbell, Litaker & Boustani, 2009; Lemke & Moos, 1989; Mor et al., 1995; Voelkl, Fries, & Galecki, 1995). However, the picture remains unclear as to which individual and organizational factors and under which circumstances these factors best predict a positive and validating experience for people with dementia. Once those factors are better understood, altering or enhancing the social and physical environment in which people with dementia are being cared for will hopefully improve their quality of life.

Social engagement is a component of the social psychological model outlined by Kitwood (1996; 1997) that has been singled out as an important indicator of quality of life not just for individuals with dementia but for all people (e.g., Ballard et al., 2001; Forbes, 1998; Mor et al., 1995). The absence or lack of

social engagement has also been identified as a predictor of mortality in the research literature (e.g., Bennett, 2002; Forbes, 1998; Hjaltadottir, Hallberg, Ekwall, & Nyberg, 2011; Kiely, Simon, Jones, & Morris, 2000).

The literature also demonstrates that a lack of social engagement is thought to be a consequence of residing in an institutional setting (Bruce, 2004; Kitwood, 1996; Hill, Kolanowski, & Kürüm, 2010; Mor et al., 1995). For example, interactions between staff and individuals with dementia has been shown to be very low outside the daily routines associated with personal care such as bathing, dressing, and feeding (Armstrong-Esther, Browne, & McAfee, 1994; Bowie & Mountain, 1993; Chen et al., 2000; Kolanowski & Litaker, 2006; Norbergh, Asplund, Rassmussen, Nordahl, & Sandman, 2001, Perrin, 1997; Zimmerman et al., 2007). Interactions between staff and individuals with dementia are further compromised by the individual's inability to communicate through effective means due to a severe cognitive impairment (Bourgeois, Dijkstra, Burgio, & Allen, 2004; Cohen-Mansfield & Mintzer, 2005; Fisher & Swingen, 1997). Furthermore, the behavioral disturbances associated with dementia may also compromise the staff-patient relationship whereby the patient is perceived to be excessively difficult or aggressive and is therefore avoided (e.g., Beck et al., 1991; Talerico, Evans, & Strumpf, 2002). Other factors including the severity of cognitive impairment, functional disability, and behavioral disturbances are correlated with the degree of social isolation for individuals with dementia (Chen et al., 2000; Lemke & Moos, 1989; Kolanowski et al., 2006; Zimmerman et al., 2003).

In many cases, functional disabilities and/or behavioral disturbances such as aggression, agitation, or wandering can lead to the use of a physical or mechanical restraint in an effort to keep the individual with dementia safe from falls or from harming others (Castle & Engberg, 2009; Huizing, Hatners, Jonge, Candel & Berger, 2007; Mion et al., 2010). Physical restraints continue to be used with the institutionalized elderly, especially those with cognitive impairments, despite a growing body of research suggesting they contribute to health complications associated with immobility, negative affect, and injury or death due to the constriction of a limb or strangulation (e.g., Capezuti, Brush, Won, Wagner, & Lawson, 2008; Castle & Engberg, 2009; Evans & Strumpf, 1989; Evans, Wood, & Lambert, 2003; Luo, Lin, & Castle, 2011; Miles & Irvine, 1992; Rubin, Dube, & Mitchell, 1993). When functional disabilities or behavioral disturbances such as aggression, agitation, or wandering are treated with the use of physical restraint, the individual with dementia may become less able to engage in the social environment (Castle 2006; Folmar & Wilson, 1989). The purpose of this current study was not to explore in depth the reasons physical restraints are commonly used in this population. Nor was the intent of this study to explicate when, what type, or if physical restraints should be used at all. Of principal interest was to explore the relationship between the use of physical restraints and observed social engagement among individuals with dementia currently being treated in an institutional setting.

While there have been a number of studies that have explored either physical restraints (e.g., Evans & Strumpf, 1989; Evans, et al., 2003; Miles &

Irvine, 1992; Phillips et al., 2003; Rubin, et al., 1993; Scherder, Bogen, Eggermont, Hamers, & Swaab, 2010) or social engagement in the institutionalized elderly (e.g., Chen, et al., 2000; Chung, 2004; Kolanowski et al., 2006; Norbergh, et al., 2001), very few studies to date have combined observed social engagement and physical restraints to explore their potential relationship (e.g., Folmar & Wilson, 1989). Furthermore, there has been a paucity of research that has explored the possible organizational variables that influence social engagement. Organizational variables such as staffing changes during the day, evening, and weekend nursing shifts will therefore also be considered in the current study (e.g., Bourbonniere, Strumpf, Evans, & Maislin, 2003).

In keeping with Kitwood's (1996; 1997) theory, the current study defines social engagement as the frequency and quality of social contact between individuals with a dementia diagnosis, their co-residents, family members, and paid staff members. The research questions that were explored in this study included: (a) Using behavioral observations, how frequently are individuals with dementia actively socially engaged, passively socially engaged, self-engaged, or not socially engaged at all with others in their environment; (b) do organizational variables such as time of day affect the frequency and quality of the social engagement? In other words does social engagement differ across the weekday, evening, or weekend shift; (c) which individual variables (i.e., degree of cognitive impairment, frequency of behavioral disturbances, activities of daily living (ADL) dependency, or use of physical restraints uniquely and jointly predict social engagement? A better understanding of the relationship between the individual

and organizational variables outlined above and social engagement will hopefully encourage researchers and clinicians to continue to explore alternative, less restrictive interventions than physical restraint use.

### **Organization of the Dissertation**

Chapter II begins with a literature review which is organized in the following way: (a) A brief description of the different types of dementia and the related behavioral disturbances and functional deficits as outlined in the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revised* (DSM-IV-TR; 2000); (b) the tenets of the social psychological theories of dementia submitted by Tom Kitwood (1997) and others; (c) a discussion of the literature regarding the primary dependent variable of the study, social engagement; (d) an examination of the individual and organizational factors that influence social engagement; (e) a critical review of the literature concerned with the use of physical restraints and finally; and (f) the potential for physical restraints to influence the social psychological experience of individual's diagnosed with dementia. Chapter III encompasses the research methods and design of the study. This chapter includes a thorough description of each of the measures used and the procedure in which the study was conducted. Chapter IV contains the analysis of the data as it pertains to the three research questions. A summary of the purpose of the study, the research questions, and the results are provided in Chapter V followed by a discussion of the conclusions and implications for practice and recommendations for future research.

## Chapter II

### Literature Review

#### **Biological approach to the diagnosis of dementia.**

Dementia is considered a clinical syndrome based on central nervous system dysfunction (Bondi, Salmon, & Kasniak, 2009; Cummings & Benson, 1992; Cummings & Mega, 2003; Lerner, 2012). It involves acquired cognitive impairment affecting multiple cognitive domains, behavioral alterations, and functional impairments. There are a number of distinct clinical subtypes of dementia that reflect a wide range of etiologies and pathophysiologic mechanisms underlying these disorders. Each individual diagnosed with dementia is said to experience the disease process in a different manner and the expression of symptoms such as behavioral disturbances and psychiatric features (e.g., hallucinations and delusions) can depend upon many intrinsic and extrinsic variables (Bondi et al., 2009; Cummings, 2003).

The most widely applied standardized guideline for the diagnosis of dementia in North America is the *Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revised* (DSM-IV-TR; 2000) and includes an impairment in social and occupational functioning in addition to an impairment in memory and at least one other domain of cognitive functioning. The specific domains of cognitive deficits include aphasia, apraxia, agnosia, and disturbance in executive functions such as planning, organizing, sequencing and abstract thinking. Finally, in order to receive a diagnosis of dementia one must not be experiencing a delirium (e.g., clouding of consciousness due to a medical

condition) or symptoms better accounted for by another Axis I psychiatric disorder (e.g., Major Depressive Disorder). A diagnosis of dementia based on the DSM-IV-TR criteria is accompanied by a qualifier that stipulates the probable type of dementia (e.g. Alzheimer type, Vascular, Huntington's Disease). Although a clinical presentation of a dementia may point to one type over another, most dementia diagnoses cannot be made with absolute certainty until autopsy. On the other hand, some dementias due to conditions such as Huntington's disease can be confirmed by genetic testing (Tröster & Arnett, 2006).

By far the most commonly diagnosed dementia is Alzheimer Disease (AD). It is a neuro-degenerative disease characterized by progressive cognitive impairment, synaptic dysfunction, and the presence of neuritic plaques and neurofibrillary tangles in the cortical regions of the brain particularly the entorhinal cortex and CA1 region of the hippocampus (Albert, 2011; Brack & Brack, 1991; Breitner et al., 1999; Lerner, 2012). The two subtypes of AD are based on the age of onset. An early-onset subtype of AD accounts for approximately 1% to 6% of all cases and ranges roughly from 30 years to 60 or 65 years (Bekris, Yu, Bird, & Tsuang, 2010). The much more common late onset subtype of AD occurs in individuals older than 60 or 65 years. Both subtypes may occur in people with a positive family history of AD. According to Bekris et al. (2010) approximately 60% of the early onset cases have multiple cases of AD within their families, and of these familial early onset cases, 13% are inherited in an autosomal dominant manner with at least 3 generations affected.

AD is associated with neuronal loss in the cortical structures of the brain and subsequent atrophy (Caselli & Tariot, 2010; Cummings & Mega, 2003). A transitional or prodromal phase between normal function and Alzheimer dementia is commonly referred to as mild cognitive impairment (MCI) (Albert, 2011). The progression maps roughly to the presentation of cognitive dysfunction: memory systems are usually affected first; deterioration of other cognitive domains follows, starting with the most complex ones such as problem-solving, reasoning, and judgment (Bianchetti & Trabucchi, 2001; Bondi et al., 2009; Larner, 2012). Studies that have investigated the effects of AD on neuropsychological performance suggest that the primary cognitive deficits include (a) aphasia or the inability to use and understand language, (b) memory impairment, (c) agnosia which is the inability to recognize faces, and (d) apraxia which is the inability to perform well-learned motor tasks such as writing or handling an eating utensil (Bondi et al., 2009; Heindel, Salmon, Schults, Walicke, & Butters, 1989; Huber, Shuttleworth, Paulson, Bellchambers, & Clapp, 1986).

The primary behavioral or “non-cognitive” symptoms include agitation (anxiety, irritability, motor restlessness, pacing, wandering, aggression, shouting and sleep disturbances), psychosis (hallucinations and delusions), and mood disorders (depression and anxiety) (Ballard, O’Brien, James & Swan, 2001; Dupuis, Wiersma, & Loiselle, 2012; Gauthier et al., 2010). Also included under the umbrella of behavioral symptoms are sexual disinhibition, eating problems, and abnormal vocalizations which include shouting, screaming, and demanding attention (Ballard et al., 2001).

Vascular Dementia (VaD) occurs when an individual suffers from some type of disease or trauma to the brain such as a stroke. The diagnosis of VaD is made based on similar cognitive criteria set out for the diagnosis of AD with the addition of either focal neurological signs (e.g., extremity weakness, gait abnormalities) or laboratory evidence of cerebrovascular disease (Chui, 2007; Cummings, 2003). The typical course of VaD is characterized by a stepwise progression where the affected individual will experience a sudden decline in cognitive functioning followed by a period of relative stability only to experience another cerebrovascular event and subsequent drop in functioning (Chui, 2007; Kempler, 2005). The behavioral symptoms associated with VaD can be similar to those seen in AD, but there is some evidence to suggest that there is more emotional lability, psychosis, and depression common to VaD (Kempler, 2005).

Also common is the presence of VaD mixed with other neurodegenerative disorders such as AD (Gearing et al., 1995; Langa, Foster, & Larson, 2004; Mayeux et al., 2011). Mixed dementia has been described in various ways including AD with vascular pathology (either macroscopic infarcts or smaller vascular lesions), AD with vascular risk factors, or AD with any other neurodegenerative illness (Zekry & Gold, 2010). For example, an etiologically mixed presentation may also include features of Dementia with Lewy bodies or a non-neurological medical comorbidity or medication use that could have a substantial effect on cognition (McKann et al., 2011). Neuro-imaging studies indicate that mixed dementia is common (see Mayeux et al., 2011 for a review). How AD and VaD or other neurodegenerative pathologies interact to affect

behavioral and cognitive functioning is less well understood (Mathias & Burke, 2009; Nagata et al., 2007).

Frontotemporal dementia (FTD) is a term that describes a group of progressive dementias associated with distinctive neuropathology of the frontal and temporal lobes of the brain (Brun et al., 1994; Josephs et al., 2011; Lerner, 2012; Neary & Snowden, 1996). It encompasses three main clinical syndromes: behavioral variant frontal temporal dementia, progressive non-fluent aphasia, and semantic dementia (Josephs et al., 2011). The symptoms of FTD often appear before age 65 with genetic inheritance appearing to play an important role (Gustafson, 1993; Hodges, 2007; Stevens et al., 1998). According to Kempler (2005) the characteristic symptoms of FTD may include personality changes, social disinhibition, and loss of insight. Cognitive symptoms include problems with attention, abstraction, planning, and problem solving (Josephs et al., 2011; Neary & Snowden, 1996). In contrast to AD, memory and often language and visual-spatial functions remain relatively spared in FTD (Green, 2000; Rascovsky et al., 2002).

Dementia with Lewy Bodies (DLB) is considered to be the second most common neuro-degenerative dementia in the elderly (Kempler, 2005). Specific neuropsychological, neuropsychiatric, and motor features are associated with this disease and differentiate it from AD however there are more similarities than differences between DLB and AD (Cummings & Mega, 2003; Green, 2000; Merdes et al., 2003). Deficits in memory, clouding of consciousness, visual hallucinations, and disruptions in executive functions are the most common

characteristics of this dementia (McKeith et al., 1996). Also a defining feature of DLB (but not of AD) is the motor symptoms that are often shared with Parkinson's disease (PD) which include rigidity, bradykinesia, and dystonia (Darvish & Freedman, 1996; Goetz, Emre, & Dubois, 2008; Kempler, 2005; McPherson & Cummings, 2009; Merdes et al., 2003). Because dementia is a common feature in PD, the time of onset is used to differentiate DLB from Parkinson Disease with dementia (PDD). For those individuals where dementia develops prior to parkinsonism or during the first year of disease, a designation of DLB is given. In those where dementia develops over a year after the onset of motor signs, the condition is considered PDD. However, the overlap between DLB and PDD is substantial and there is uncertainty diagnosing individuals who have both motor symptoms and early cognitive impairment (see Johansen, White, Sando, & Aasly, 2010 for a review). As such, they are often considered to be on a spectrum rather than being completely distinct conditions (Ballard, Kahn & Corbett, 2011).

There is also a category of loosely associated dementias whose neuropathology originates in the subcortical regions of the brain (e.g., substantia nigra, caudate nucleus, and putamen) and usually presents initially as a movement disorder (Heindel et al., 1989; McPherson & Cummings, 2009). Huntington's disease, which is characterized primarily as a subcortical dementia, is differentiated by the presence of chorea. Chorea (an involuntary movement disorder) and an alteration in the physical appearance in these individuals is due primarily, if not exclusively, to dysfunction in the subcortical structures of the

brain (Brandt, 2009; Darvish & Freedman, 1996). The cognitive and functional impairment associated with subcortical dementias varies depending on the subcortical to cortical neuronal pathways affected by the disease (Cummings, 1990).

### **Social psychological theories of dementia.**

The definitions of dementia discussed above provide only the neuropsychiatric perspective driven primarily by the biological model. By contrast, in his seminal book *Dementia Reconsidered, the Person Comes First*; the late psychologist Tom Kitwood (1997) discussed a theory of dementia that invokes a decidedly social psychological perspective. Kitwood's theory of personhood and wellbeing in dementia has been well represented in the literature focusing on the improvement and measurement of the quality of life for individual's living in institutions for the elderly (e.g., Chung, 2004; Finnema et al., 2000; Fritsch, Kwak, Grant, Lang, Montgomery, & Basting, 2009; Hubbard, Cook, Tester, & Downs, 2002; McKee, Houston, & Barnes, 2002; Moore, 1999; Norbergh et al., 2001; Potkins et al., 2003; Teitelman, Raber, & Watts, 2010; Werezak & Morgan, 2003; Wilkie, McCaffrey, Jones, & Comeau, 2007). The impetus for Kitwood's theory arose from his personal and empirical observations of individuals diagnosed with dementia, especially those living within the institutional setting. He concluded that when moved into an institution, the elderly were at risk for expulsion from the social world of their peers. Social exclusion is even more pronounced in those diagnosed with dementia because of the nature of the disease process (e.g., loss of communication skills) and because of the

medical model in which they are being cared for. According to Kitwood (1997) and Kitwood and Bredin (1992), when combined, these two factors contribute to “depersonalization”. Traditional institutions operate on a medical model of care that has been criticized for a tendency to reduce the individual with dementia to a set of neuro-biological symptoms focusing on skill deficits rather than remaining abilities (Bender, 2003; Kitwood, 1997; Moore, 1999).

A key component of Kitwood’s theory is the definition of personhood as the standing or status bestowed upon the individual by others within the context of social relationships. Kitwood’s notion of personhood in dementia was notably influenced by the work of Carl Rogers (1961) and theologian Martin Buber (Buber, 1937) whom placed great emphasis on the importance of viewing the person within the context of a relationship or in terms of the ‘I-Thou’. The shift to viewing personhood as sustainable outside the individual within the social environment is in stark contrast to the concept of personhood or personal identity put forth by the neuropsychiatric or biological models (Hughes, Louw, & Sabat, 2006).

The biological model broadly suggests personhood, personal identity, and personality lie within the mind and are created through mental states supported by brain functioning. Without brain functioning there can be no mind and thus no person (Post, 2006). Deterioration of the brain is equated with a loss in personhood which occurs largely outside the influence of the physical or social environment. Given the strength of the biological model and its influence on modern medicine, it is not surprising that negative stereotypes of dementia such

as “the death that leaves the body behind” and “a long good-bye” continue to shape our attitudes toward those who are afflicted by dementia and cared for within the medical model. Critics of the traditional biological models of dementia such as Stephen Post (2006) describe these models as *hypercognitive* and suggest that far too much emphasis is placed on the failing mental capacities commonly associated dementia. The attention on cognitive, functional, and behavioral deficits occurs at the expense of respect, recognition, and moral concern for the individual with dementia. In Post’s words “Hypercognitive snobbery is moral blindness” (Post, 2006, p. 223).

Kitwood also argued that both the according of personhood, and the failure to do so, have empirically testable consequences. While the concept of social relationships and the empirical study of these relationships is complex and multi-dimensional, at the very least they consist of social engagement or exchanges between individuals. Social engagement and its antithesis, social isolation, have been empirically measured in the context of institutions for the elderly as an indicator of quality of life (e.g., Castle 2006; Chen et al., 2000; Kolanowski et al., 2006; 2009; Lindsay & Skeat, 1997; Mor et al., 1995; Potkins et al., 2003; Resnick, Fries, & Verbrugge, 1997; Røsvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011; Zeisel et al., 2003; Zimmerman et al., 2003). In general, studies have criticized the traditional nursing home institutions for their overwhelming emphasis on task-oriented routines rather than the development of relationships and socialization between staff and residents (Edvardsson et al., 2010; Hill et al., 2010; Kelley, 1997; Norbergh et al., 2001; Teitelman et al.,

2010; Werezak & Morgan, 2003). Furthermore, there have been a number of studies which have demonstrated the efficacy of specific psycho-social therapies that have improved the socialization and behavioral outcomes among residents with dementia (e.g., Finnema et al., 2000; Fritsch et al., 2009; Forbes, 1998; Kolanowski, Litaker, & Buettner, 2005; Kolanowski, Litaker, Buettner, Moeller, & Costa, 2011; Lai, Chi, & Kayser-Jones, 2003; Luttenberger, Donath, Uter, & Graessel, 2012; O'Connor, et al. 2009; Richeson, 2003).

Errollyn Bruce (2004) explored the role of social exclusion in care homes for the aged in the United Kingdom. The author pointed out that residing in a care home (a term referred to as long-term care in North America) places the elderly at risk for being excluded from the social world. And those residents who have cognitive impairments become the individuals most at risk of social exclusion. The underlying cause of social exclusion according to Bruce (2004) is the loss of power and social position brought about in part by the need for more than the ordinary amounts of assistance with personal care. Personal care is considered to be a range of daily living activities that may include anything from having meals provided to assistance with walking, feeding, and toileting. Three routes of social exclusion in care homes are outlined by Bruce (2004) and include (a) the tendency for the residents of care homes with the most severe cognitive impairments to receive little more than basic physical care, (b) group living creates an environment where some individuals experience more isolation and rejection than other residents and (c) those who display behavioral disturbances

are routinely removed from a familiar care setting and admitted to geriatric assessment wards or transferred to psychiatric facilities.

Of particular interest to the current study is the first of these three routes to social exclusion explored by Bruce (2004). The relationship between cognitive impairment and social exclusion is discussed in terms of an Inverse Care Law which Bruce (2004) describes: "...as dementia becomes more severe, the likelihood of appropriate care for emotional, physical, occupational, spiritual and social needs decreases." (Bruce, 2004, p. 126). One of the fundamental contributing factors to the inverse care law pointed out by the author is that the staff caring for individuals with severe dementia feel ill equipped to meet the social needs of these particular residents. According to Bruce (2004), the observation that staff often fail to meet the socialization needs of this population is due to a lack in specialized communication skills as well as an underlying assumption that these individuals are so cognitively impaired that they are beyond the need for emotional support, stimulation and social contact. Furthermore, Bruce (2004) argued that the staff may feel frustrated with the lack of positive feedback from residents that can no longer verbalize, leaving most of these residents' behaviors open for interpretation and hence, misconception.

The social exclusion of individuals with dementia is emphasized by the work of Bender (2003) and Kitwood (1997) who argue that embedded within our "civilized" society is a subtle but pervasive tendency to demean and discount the interpersonal needs of individuals with cognitive or functional impairments. As such, Kitwood interpreted care staff's tendency to retract from interacting with

individuals with dementia beyond the basic personal care requirements (e.g., bathing, feeding, and toileting) as a lack of awareness of how this practice systematically undermines their inclusion in the social world. An appreciation of social exclusion and inclusion is not unique to the discussion of individuals with dementia. The psycho-social paradigm has long been applied to the education and care of another vulnerable group, those with developmental disabilities. The parallels between these two groups of persons consist of more than their shared cognitive or learning problems, but also within the significance of the interpersonal relationships they enter with individuals who hold a caregiver or educator role. Clegg (1993) argued that moving from an individual to a social focus would allow professionals working with people who have disabilities to broaden the scope of their care. Clegg and others (e.g., DePoy, 2002; Gill, Kewman, & Brannon; Hahn, 1996) have maintained that the emphasis on the development of interpersonal relationships with persons with disabilities should take precedent over a deficit model or even behavioral skill acquisition. As supportive evidence, Clegg argued that the extent to which abilities develop (or deteriorate) do so only in the context of a relationship with another person, embedded within a society of persons. Likewise, the caregiver or professional that engages with the individual with dementia has the opportunity to promote functional abilities, wellbeing, and personhood. Caregivers can also hinder the functional abilities, wellbeing, and personhood of the individual with dementia through their interactions (e.g., Kelly, 2010; Taft, Fazio, Seman, & Stansell, 1997; Teitelman, et al., 2010).

In summary, the social psychological theories of dementia all share one commonality and that is the emphasis on the social relationship between individuals with dementia, their caregivers, and society at large as a means of understanding as well as treating the individual with dementia. The responsibility for a more or less positive interpersonal interaction between the individual with dementia and the caregiver lies with the caregiver (Kitwood, 1997). This is due to the inherent power differential between the caregiver and the individual with dementia; a situation magnified in the context of a care institution where hierarchies of power have traditionally prevailed (Bruce, 2004). As such the following section will discuss the empirical research concerned specifically with social engagement among individuals with dementia who reside within various types of care institutions.

### **Social engagement.**

The term social engagement, as it pertains to the current study, involves actual contact or interaction with others. Several literature and methodological reviews have discussed the social psychological outcomes of individuals with dementia living in institutions. All of these review articles discussed the deterioration in levels of social engagement and increase in social isolation inherent with a loss of communication and language skills secondary to a diagnosis of dementia (Bourgeois et al., 2004; Dupuis et al., 2012; Finnema et al., 2000; Fisher & Swingen, 1997; Forbes, 1998; Kelley, 1997; Sierpina, Sierpina, Loera, & Grumbles, 2005; Werezak & Morgan, 2003). Another common aspect found in the reviews was a discussion of the role of the physical environment and

organizational characteristics that contribute to or ameliorate social isolation among the residents (e.g., Fisher & Swingen, 1997; Hill et al., 2010; Kelley, 1997; van Beek, Frijters, Wagner, Groenewegen, & Ribbe, 2011; Werezak & Morgan, 2003). Other reviews discussed the efficacy of specific social psychological therapies designed to reduce agitation and increase social engagement among residents (Ballard et al., 2011; Finnema et al., 2000; Forbes, 1998; Judge, Camp, & Orsulic-Jeras, 2000; Schneider & Camp, 2002; Sierpina et al., 2005). Overall, the findings suggest that social psychological therapies or activities have a positive effect on social engagement, especially during the period of time when the group or individual activity is being provided and more recent research as suggested that there may be enduring effects that last for up to 12 additional weeks (Roumen, Kellar, McLean, Thompson & Peever, 2008).

***Individual factors related to social engagement and social isolation.***

Degree of cognitive impairment appears to be the single strongest predictor of social engagement among the studies that included this variable in their design (e.g., Chen et al., 2000; Chung, 2004; Kolanowski et al., 2006; Kolanowski, Flick, Campbell, Litaker, & Boustani, 2009; Lemke & Moos, 1989; Potkins et al., 2003; Zimmerman et al., 2003; 2007). When cognitive impairment is controlled for, the other individual factors related to social isolation in the institutional setting include aggression (Chen et al., 2000), being female (Lindesay & Skeat, 1997), having a longer length of stay in the institution (Zeisel et al., 2003), and demonstrating verbally disruptive behavior such as calling out and moaning (Draper et al., 2000). Degree of dependency in activities of daily living (e.g.,

washing, dressing, eating) has also received support as a predictor of social engagement (Castle & Engberg, 2009; Voelkl et al., 1995; Zimmerman et al., 2007). For example, Ballard et al. (2001) found that lower performance on activities of daily living was positively and significantly related to social withdrawal and reduced engagement in activities. Similarly, in a study that evaluated individuals with dementia residing in an Assisted Living facility, engagement in both individual activities and group social activities predicted delays in functional decline (Tighe et al., 2008). Smith and Hirdes (2009) found that activities of daily living remained a significant predictor for social isolation in a multivariate model with a sample of elderly patients being treated in a psychiatry facility. Kolanowski et al. (2006) entered both cognitive impairment and ADL dependency into a multiple logistic regression model and found that neither significantly predicted engagement implying that the two variables may be measuring the same construct given that these two variables tend to be strongly correlated.

Observational studies of resident behavior (e.g., Brooker, Foster, Banner, Payne, & Jackson, 1998; Chung, 2004; Folmar & Wilson, 1989; Kolanowski & Litaker, 2006; Norbergh et al., 2001; Perrin, 1997; VanHaitsma, Lawton, Kleban, Klapper, & Corn, 1997; Zimmerman et al., 2007) found that individuals with a diagnosis of dementia living in institutions for the elderly spend a large portion of their day sitting alone doing nothing. VanHaitsma et al. (1997) reported that the residents in their study spent on average 73% of their day sitting in the same location, and were alone 83% of the day. Social interaction and positive

engagement in activities were witnessed during 13% and 4% of the residents' day respectively. Similarly, Armstrong-Esther et al. (1994) conducted an observational study in a Canadian acute geriatric medical unit and psychiatric unit and concluded that very low levels of staff-patient interactions occurred outside of expected care routines. Furthermore, Armstrong-Esther et al. reported that at no time during the observation periods were the patients engaged by the nursing staff in social activities or prolonged informal conversations. A more recent study conducted by Kolanowski et al. (2009) found that in a sample of 87 nursing home residents observed twice during the day shift over the course of five days, spent approximately 54% of their time engaged in either informal or organized activity. This particular sample spent approximately 45% of their time either "doing nothing" or sleeping. This data provides a positive trend for increased social engagement in nursing home residents when compared to earlier observational studies (Armstrong-Esther et al., 1994; VanHaitsma et al., 1997).

***Organizational factors related to social engagement and social isolation.***

The philosophy or culture of care is an organizational factor hypothesized to have significant effect on resident social interactions (e.g., Hill et al., 2010; Kitwood 1997; McAllister & Silverman, 1999; Moore, 1999; Werezak & Morgan, 2003). The difficulty in assessing philosophy of care is embedded in the discussion of what constitutes quality care for individuals with dementia. Kitwood (1997) provides a list of qualities found in institutions under the auspice of the medical model and psycho-social model but these lists consist primarily of abstract concepts and attitudes which have presented as a significant challenge to measure

(see Hughes, 2003 for a review). Indicators of quality care, according to Kitwood, include determining the facilities general view of dementia, whom provides the ultimate source of knowledge (e.g., physicians and researchers versus care practitioners), the emphasis for research, what caring entails (e.g., solely providing for basic needs versus personhood), the priorities for understanding (e.g., deficits versus abilities), conceptualization of problem behaviors, and how the caregivers process their own feelings.

Philosophy of care has only begun to be successfully operationalized in the literature (e.g., Feil, McLean, & Sultzer, 2007; Lindsay, Briggs, Lawes, MacDonald, & Herzberg, 1991; Taft et al., 1997; Zeisel et al., 2003) and systematically studied (see Hill et al., 2010 for a review). One such study ranked and compared facilities according to “dementia friendliness” (e.g., Zeisel et al., 2003). The construct of “dementia friendliness” in the Zeisel et al. study was measured through an analysis of the facilities mission statement, training protocol, policies and procedures, and activity programming. The dementia friendliness variable in the Zeisel et al. (2003) study was one of the only organizational variables found in the literature that resembled an operationalized “philosophy of care”. However, the dementia friendliness variable may not have reflected a completely accurate picture of the facilities’ philosophy of care given that it was measured only by a facilities statement of what they strove to demonstrate and not what was actually observed to occur. In the case of the Zeisel et al. (2003) study, social isolation of residents, as measured by nursing staff perceptions, was not related to the dementia friendliness organizational variable. Neither was social

isolation related to the other organizational factors such as staff to resident ratio, facility size, or profit versus not for profit facility status (Zeisel et al., 2003). Findings of the Zeisel et al. study were similar to those of Zimmerman et al. (2003), which did not find a relationship between facility size and degree of resident social isolation. On the other hand, Reimer, Slaughter, Donaldson, Currie & Eliasziw (2004), conducted a prospective study that directly compared resident outcomes of individuals randomly assigned to Specialized Care Facilities and traditional institutions in Canada. The researchers found that purposively designed physical and social environments (e.g., small homelike settings with 10 residents per bungalow) had a positive effect on measures of quality of life including engagement in pleasant events and social activities.

Aside from the philosophy of care and facility size, there is also the issue of staffing resources and its impact on the social psychological wellbeing of individuals with dementia. For example, understaffing in nursing homes is a chronic issue cited in the literature as leading to lower levels of care and increased levels of staff burnout (e.g., Kim, Kovner, Harrington, Greene, & Mezey, 2009). Chronic understaffing is also well established as a predictor of recruitment and retention difficulties for nursing staff in dementia care facilities (see Chenoweth, Jeon, Merlyn, & Bodaty, 2010 for a review). Better retention has been linked to higher levels of staff rated social engagement among nursing home residents (Barry, Brannon, & Mor, 2005). Anecdotal reports imply that hospital unit staffing levels change depending on the time of the day as well as day of the week with week days employing the highest amount of staff and evenings and

weekends employing the least amount of staff. Whether social engagement levels differ as an artifact of time of day and week has not been established in the research literature.

There is a growing body of literature to suggest that individuals with dementia residing in institutions spend very little of their day socializing with others or engaged in any socially appropriate tasks (e.g., Armstrong-Esther et al., 1994; Bowie & Mountain, 1993; Chen et al., 2000; Chung, 2004; Kolanowski & Litaker, 2006; Norbergh, et al., 2001, Perrin, 1997; Zimmerman et al., 2007). What has also emerged in the literature is that individuals with a greater degree of cognitive impairment especially as it applies to communication skills, are at a greater risk for social isolation (e.g., Chen et al., 2000; Chung, 2004; Potkins et al., 2003; Zimmerman et al., 2003; 2007). What is less well known are which organization factors such as time of day, type of institution, and day of the week contribute to social engagement among its residents.

### **Physical restraints.**

Physical restraints have been used in the medical field as a means to prevent individuals with cognitive disorders from injuring themselves (Capezuti et al., 2008; Emerson et al., 2000; Fovel, Lash, Barron, & Roberts, 1989; Huizing et al., 2007; Sturmey, 1999), wandering, tampering with medical devices (e.g., intravenous lines), and falling amongst the frail and confused elderly (Bredthauer, Becker, Eichner, Koczy & Nikolaus, 2005; Evans, Wood & Lambert, 2003; Hamers, Gulpers, & Strik, 2004; Karlsson, Nyberg, & Sandman, 1997; Luo et al., 2011). Physical restraint has been identified as any device, material or equipment

attached to or near a person's body and which cannot be controlled or easily removed by the person and which prevents or is intended to prevent a person's free body movement to a position of choice and/or a person's normal access to their body (Retsas, 1998). Examples of physical restraints may include back fastening seatbelts, t-belts, table trays fastened to a chair, one-piece back fastening suits, wrist cuffs, and side rails on beds.

***Prevalence rates.***

In a review of the literature pertaining to physical restraints and the elderly, Hamers and Heizing (2005) suggested that prevalence rates ranged from 15% and 66% in nursing homes and between 8% and 68% in hospital settings. Their review consisted of prevalence studies from several countries including but not limited to, Germany, the United States, Finland, Holland, and Great Britain. Hamers and Heizing concluded that physical restraints are still highly prevalent in health care settings despite efforts by most countries to limit, or prohibit as in the case of Scotland, the use of physical restraints. According to Sullivan-Marx, Strumpf, Evans, Baumgarten, and Maislin (1999), prevalence rates in the United States have decreased nearly 50% since the passage of the Nursing Home Reform Act (NHRA) in 1987. The NHRA mandated that nursing homes reduce their use of physical restraints and that residents have the right to be free from any physical restraint imposed for the purposes of discipline or convenience and not required to treat their medical symptoms (The Nursing Home Reform Act, 1987). Prevalence rates in the United States reported by Sullivan-Marx et al. (1999) and Castle (2002) ranged between 13% and 24.9%. A recent study comparing inter- and

intra-country differences in the prevalence of physical restraints in nursing homes suggested that restraint use varied significantly across countries (Feng, et al., 2009). While there was relatively low prevalence rates reported in countries such as Switzerland (6%) and the United States (9%), data from Hong Kong indicated 20%, Finland 28%, and Canada 31%. Feng et al. (2009) noted that neither facility case mix nor organizational characteristics were particularly predictive of restraint use.

Studies that differ on what devices are considered a physical restraint may systematically alter prevalence rates. For example, Hamers, Gulpers and Strik (2004) chose to include bed side rails as a physical restraint and calculated a restraint prevalence of 49% in Dutch nursing homes which was considerably higher than the restraint prevalence of 14-20% reported by the Phillips et al. (2000), who chose to exclude bed rails as a physical restraint in their study of American nursing homes. It is also likely that prevalence rates for the use of restraints are affected by methodological differences (e.g., observation versus questionnaires) for collecting the data (Hamers & Heizing 2005; Minnick, Mion, Johnson, Catrambone, & Leipzig, 2007).

Unfortunately, there is a paucity of research on the prevalence of physical restraint use in Canada. Peer-reviewed journal articles located using computerized searches of four databases: MEDLINE, PsychINFO, Drugs and Pharmacology EMBASE (Excerpta Medica Database), and CINAHL (Cumulative Index to Nursing and Allied Health Literature) revealed only three studies which described physical restraint prevalence in Canadian institutions for the elderly within the

last twenty years (1991-2011). Lever et al. (1994) found that restraints were used with 21% of patients in an acute-care hospital, 78% of patients in a chronic-care hospital, 12% of patients in a home for the aged, and 35% of patients in psychiatric wards. These prevalence rates were based on a definition of physical restraint that excluded side rails. The authors stated that the data was collected in the province of Ontario where there was widespread use of *least-restraint policies*. A longitudinal evaluation of a restraint reduction program in Edmonton Alberta, presented by Milke, Kendall, Neumann, Wark, and Knapp (2008) reported a 16% prevalence rate at the end of the four year study period in 2006. Milke et al. reported prevalence data from 11 continuing care facilities. However, certain devices were excluded from the list of possible restraints if the resident using them was considered “not mobile in bed”. These devices included specialty chairs with belts, specialty chairs without belts/recliners, or full lap trays. The exclusion rationale was that these devices were used to provide comfort and positioning when the resident was out of bed. A recent study of prevalence rates of restraint use in Canada conducted by Feng et al. (2009) reported an average of 31% in 19 long term care homes and 41 continuing care hospitals. Similarly, few to no prevalence studies were found that were conducted in countries other than the United States, Holland, Sweden, Finland, Norway, Germany, and Switzerland.

***Individual factors related to the use of physical restraints.***

Severity of cognitive impairment and risk of falling were reported as the individual characteristics most often related to physical restraint use (Bourbonniere et al., 2003; Burton, German, Rovner, & Brant, 1992; Castle &

Engberg, 2009; DeSantis, Engberg & Rogers, 1997; Huizing et al., 2007; Karlsson, Bucht, Eriksson & Sandman, 2001; Likkonen & Laitinen, 1994; Luo et al., 2011; Magee et al., 1993; Middleton, Keene, Johnson, Elkins, & Lee, 1999; Minnick et al., 2007; Mitchell-Pedersen, Fingerote, & Edmund; 1989; Ray, Taylor, Lichtenstein, & Meador, 1992; Sullivan-Marx & Strumpf, 1996). Regardless of which country the study was conducted, a diagnosis of dementia seemed to increase one's chance of being physically restrained (Bredthauer et al., 2005; Chien, 2000; Huizing et al., 2007; Robbins, Boyko, Lane, Cooper & Jahnigen, 1987; Sloane et al., 1991; Sullivan-Marx, 2001; Sullivan-Marx, 1995). Individuals with dementia may be restrained more often than individuals without dementia because of an increased propensity for falls due to limited judgment and insight into physical limitations (Karlsson, Bucht, Rasmussen & Sandman, 2000; Luo et al., 2011) and because of behavioral disturbances such as aggression and wandering which are often associated with a diagnosis of dementia (Bourbonniere et al., 2003; Karlsson et al., 2001; Lin, Wu, Kao, Tzeng, Watson, & Tang, 2008; Ryden et al., 1999).

Very few studies have explored the relationship between social engagement and physical restraint use. Folmar and Wilson (1989) compared social behavior in nursing home residents who were restrained versus those who were not and found that restrained individuals spent more time engaged in little to no socialization compared to their unrestrained peers. Although the authors did not control for cognitive impairment or functional dependency, the study marks one of the first to compare observed social engagement with restraint use in a

nursing home setting. Castle (2006) used a retrospective, propensity matching model from the Minimum Data Set with a sample of over 2000 nursing residents to show that restrained nursing home residents are at risk for increased mental health concerns. The Minimum Data Set (MDS) is a summary assessment of nursing home residents completed by Medicare and Medicaid-certified nursing facilities in the United States. Social engagement data was collected based on an index of six MDS items with higher scores indicating less social engagement. The social engagement index from the MDS is completed by nursing staff on behalf of the nursing home resident. The author concluded that restrained residents were more likely to be rated as cognitively impaired, depressed, and socially isolated. It should be noted that both the samples used in Castle (2006) and Folmar and Wilson (1989) consisted of residents from a general nursing home population. Resident diagnosis was not a variable considered in either study.

***Other factors related to the use of physical restraints.***

Considerably fewer studies have looked at nursing staff as opposed to individual patient characteristics and physical restraint use. Education about restraints, years of experience, and occupation (e.g., registered nurse versus personal care attendant) have been correlated with restraint use (e.g., Hantikainen, 1998; Karlsson et al., 2001; Matthiesen, Lamb, McCann, Lollinger-Smith & Walton, 1996; Möhler, Richter, Köpke, & Meyer, 2011). In a study completed with a sample of Canadian nurses, self-reported education of restraints through in-services and workshops was not related to current knowledge of physical restraints, attitudes toward the use of restraints, or self-reported practice of the use

of restraints (Matthiesen et al., 1996). In the same study, years of experience had a weak correlation with attitudes toward restraints but were not correlated with current knowledge of restraints. Matthiesen and colleagues were surprised with their findings as they had originally hypothesized that staff with more professional and personal contact with older adults might have greater knowledge about the appropriate use of and potential consequences of physical restraints. In addition, Matthiesen et al. found that there was a significant difference between knowledge of and attitudes toward restraint use dependent upon setting. The staff from the geriatric units had more knowledge and more positive attitudes toward the proper use of physical restraints than the staff working in the geropsychiatric units. The authors concluded that these differences may have more to do with the philosophy of care and standards of practice (organizational variables) unique to a specific care setting than with individual staff characteristics.

Karlsson et al. (2001) investigated staff characteristics such as staff knowledge of restraint regulation, attitudes toward the use of restraints, profession, gender, age, length of employment in geriatrics, and education in dementia care. The results suggested that the only staff characteristics significantly related to low restraint use wards were negative attitude toward the use of restraints and higher knowledge of restraint use. Interestingly, when staffs from low and high restraint use wards were compared, the staff from the low restraint wards felt more in control of their job. This finding is significant because it might normally be assumed that the use of restraints would predict nurses feelings of being more in control of the patient's behavior (e.g., wandering) and

the consequences of the patient's behavior (e.g., falling). This finding differs somewhat from Huizing, et al., 2007 who found that higher job autonomy experienced by nursing staff and a higher full time equivalency ratio on the wards was associated with increased restraint use.

The relationship between organizational characteristics of dementia care settings and physical restraints has not been consistent in the literature. For example, there remains a discrepancy between the use of physical restraints in Special Care Units (SCUs) versus regular nursing homes. SCU's are intended specifically for residents with dementia while regular nursing homes may consist of a mixed population of residents both with and without a diagnosis of dementia. Initially it was found that when compared to regular nursing homes in the United States, residents of SCU's were physically restrained less (Sloane et al., 1991; Castle et al., 1997). These early findings were challenged by Phillips et al. (2000) who found that when controlling for a diagnosis of dementia, residents in SCUs did not differ from residents with dementia in traditional units in their likelihood of being physically restrained. To its merit, the Phillips et al. (2000) study utilized a very large data base sampling more than 71000 nursing home residents including more than 1100 residents in 48 SCUs. Interestingly, the authors also found that residents in SCUs were more likely to receive psychotropic medication than comparable residents in nursing homes. In a recent review of the studies that have compared SCU's and regular nursing homes in the United States, Lai, Yeung, Mok and Chi, (2009) concluded that the use of physical restraints was less common in SCUs at 6 and 12 months than in regular nursing homes.

Another organizational characteristic that has been mostly overlooked includes the day of the week in which data on restraint use is collected. Most studies that utilized an observational method of data collection, recorded the number of patients in physical restraints during the dayshift on weekdays (e.g., Sloane et al., 1991). However, patients were more likely to be restrained during the weekend than during the weekday in the Bourbonniere et al. (2003) study.

While somewhat counter intuitive, there appears to be very little evidence of a correlation between staff to patient ratio and physical restraint use in a number of studies (e.g., Bourbonniere et al., 2003; Karlsson et al., 2001; Kirkevold, Laake & Engedal, 2003; Yeh, Sehy & Lin, 2002). However, Castle (2000) and Phillips et al. (1996) pointed out that the ratio of staff mix (e.g., registered nurses, personal care attendants or licensed practical nurses) may influence restraint use (e.g., Castle et al., 1997) to a greater extent than total staff to patient ratio.

The use of physical restraints in institutions for the elderly has received a great deal of attention in the research literature over the past two decades. Some studies seem to support the notion that the use of physical restraints is on the decline (e.g., Milke et al., 2008) however, other researchers have pointed out a number of discrepancies in the literature with respect to how restraints are defined (e.g., Hamers et al., 2004) and how data on restraint use is collected (Hamers & Heizing, 2005). Evidence continues to grow with respect to the specific individual, staff, and organization characteristics associated with restraint use. Individual characteristics such as diagnosis of dementia, degree of cognitive

impairment, and behavioral disturbances such as aggression have been established as significant predictors of physical restraint use. Staff variables to date have not been endorsed as strong predictors of physical restraint use (see Möhler et al., 2011 for a review). Preliminary evidence of important organizational variables has begun to emerge such as whether or not the facility is “dementia specific” or consists of a mixed population (e.g., Lai et al., 2009; Phillips et al., 2000) and time of day and day of the week (Bourbonniere et al., 2003) however, replication of these methods are required before firm conclusions regarding these relationships can be made.

### **Summary**

Based on a review of the literature, the individual characteristics common to physical restraint use and social isolation were severity of cognitive impairment and functional dependency and to a lesser degree behavioral disturbances especially aggression, agitation, and wandering (e.g., Bredthauer et al., 2005; Castle & Engberg, 2009; Draper et al., 2000; Karlsson et al., 2001; Robbins et al., 1987; Ryden et al., 1999; Sloane et al., 1991; Sullivan-Marx, 2001). Psychotropic medication use was rarely found to be related to social isolation (Ballard et al., 2001; Kolanowski et al., 2006; 2009) and was related to physical restraint inconsistently (e.g., Castle et al., 1997; Lever et al., 1994).

In the studies pertaining to physical restraint use and social isolation, one organizational characteristic emerged as a common theme among these areas. Matthiesen et al. (1996) used the term “philosophy of care” to describe the specific nursing approaches toward patient care when discussing differences in

restraint use between facilities. Similarly, researchers discussing the social psychological needs of residents stressed the importance of considering philosophy of care in the attempt to reduce social isolation in residents with dementia living in institutional settings (Feil et al., 2007; Hill et al., 2010; Moore, 1999; McAllister & Silverman, 1999; Werezak & Morgan, 2003). Unfortunately, most of the studies that cited philosophy of care as an important contributing factor to resident outcomes did so retrospectively. An exception was Reimer et al. (2004) which demonstrated prospectively that smaller, more homelike settings that offered choice, meaningful activities, and privacy were superior to traditional nursing home settings on measures of quality of life. In general, philosophy of care is a construct that has not been fully operationalized or measured in the research literature to date.

The application of physical restraints is an intervention strictly associated with the medical model of dementia care. The philosophy behind the medical model involves “do no harm” and management of symptoms. One of the means to which this is accomplished is the application of physical restraints to reduce an individual’s risk of falling or harm to others. The use of physical restraints in an institutional setting represents an objective, albeit indirect measure of this type of philosophy of care. The use of physical restraints are in direct opposition to the social psychological theories of dementia care put forth by Kitwood (1997) and Kitwood and Bredin (1992) which emphasize the therapeutic relationship between the individual with dementia and their social environment rather than controlling the behavioral symptoms of dementia through restrictive interventions. Thus, the

reduction or elimination of restrictive procedures and the presence of resident social engagement reflects a philosophy of care more in line with personhood and wellbeing (Castle, 2006).

There have been numerous studies pertaining to physical restraints that have documented the ill effects of their continued use with individuals with dementia (e.g., Capezuti et al., 2008; Castle & Engberg, 2009; Evans & Strumpf, 1989; Evans, Wood, & Lambert, 2003; Miles & Irvine, 1992; Rubin et al., 1993). Furthermore, positive physical or psychological outcomes related to restraint use have not been documented in the literature. Despite these findings, prevalence rates remain high and varied (e.g., Feng et al., 2009; Hamers & Heizing, 2005) and in some countries such as Canada, current prevalence rates have only begun to be reported in the literature (Milke et al., 2008; Feng et al., 2009). While policy amendments such as the Nursing Home Reform Act (1987) and staff education about the appropriate use and consequences of restraint use have been somewhat helpful in reducing restraint use (e.g., Castle et al., 1997; Middleton et al., 1999) large discrepancies between institutions with respect to physical restraint use remains a problem (Castle 2000; 2002; Feng et al., 2009; Lever et al., 1994). Attempts to isolate the specific factors related to high incidence of restraint use and the consequences of restraint use have not been conclusive. However, given the potential for this type of intervention to adversely affect the quality of life of residents through increased risk of falls, confusion, and social isolation, its inclusion in future studies is clearly warranted (Castle & Engberg, 2009).

The few studies that have compared restraint use and social engagement have shown that nursing home residents who are restrained are less likely to be socially engaged (Castle 2006; Folmar & Wilson, 1989). Observed social behavior was compared to restraint use by Folmar and Wilson (1989) but this study did not control for dementia diagnosis, cognitive impairment, functional dependency, or behavioral disturbances. Castle (2006) controlled for functional dependency among other medical and demographic variables but not a diagnosis of dementia. The variable of social engagement was measured using the MDS social engagement index which has only a moderate correlation (.43 to .57) with observed engagement (Castle, 2006).

### **Overview of the Study and Research Questions**

Physical restraint use has yet to be thoroughly studied in relationship to observed social engagement. Given their common correlates (e.g., cognitive impairment, ADL dependency, and behavioral disturbances) the current study seeks to determine if there is a significant relationship between physical restraints and observed social engagement in a sample of individuals with dementia. Furthermore, this study aims to extend the findings of prior research of Bourbonniere et al. (2003) to determine if organizational variables such as shift (day, evening, or weekend) predicts the frequency and quality of social engagement. Finally, the current study strives to determine whether or not physical restraint use predicts social engagement above and beyond cognitive impairment, ADL dependency, and behavioral disturbances. The research questions this study addresses are listed below.

Research question 1: using behavioral observations, how frequently are individuals with dementia actively socially engaged, passively socially engaged, self-engaged, or not socially engaged at all with other individuals in their environment?

Research question 2: Do organizational variables such as time of day affect the frequency and quality of the social engagement? In other words, does social engagement differ across the weekday, evening, or weekend shift?

Research Question 3: Which individual variables (i.e., degree of cognitive impairment, behavioral disturbances, activities of daily living (ADL) dependency, or use of physical restraints) uniquely and jointly predict social engagement?

## Chapter III

### Method

#### Participants.

The sample for the study was drawn from a 125-bed psychiatric treatment hospital located in central Alberta managed by Alberta Health Services. Clinical pharmacists working within the hospital estimated that 80-90% of the patient's served in the program were prescribed psychotropic medications. Therefore, in an effort to control for medication effects, patients who were not prescribed any psychotropic medications were deemed ineligible to participate in the study. Psychotropic medications included minor tranquilizers (i.e., benzodiazepines, anxiolytics, sedatives, or hypnotics), antidepressants, mood stabilizers, and antipsychotic agents. One of the clinical pharmacists working within the program generated a list of potential participants by screening out patients who were not taking any of the psychotropic medications identified above. From that list of patients, only those with a current DSM-IV-TR primary Axis I diagnosis of a probable dementia were identified as potential candidates for the study. The diagnostic type of dementia (e.g., Alzheimer's disease versus Vascular Dementia) was not considered relevant to the selection of participants for this study due to the uncertainty of obtaining an accurate diagnosis unless made post-mortem. From the patients who had a diagnosis of dementia and who were currently taking at least one psychotropic medication, only those who had a legal alternate decision-maker were identified as eligible candidates for participation in the study.

Information regarding the study was provided to the legal alternate decision-makers on two separate occasions. Initially, the legal alternate decision-makers for 86 individuals residing as in-patients in the facility were contacted via telephone or in person during visits to the hospital. Verbal information regarding the study was provided at that time allowing for any questions or concerns about the study or the consent process to be clarified. For legal alternate decision-makers who agreed to have their family member participate, written letters of information along with consent forms were sent out via mail. Reading level for the information and consent forms was set at Grade 8. For individuals who had received written consent from their legal alternate decision-maker, I attempted to obtain their verbal assent for participation. In total, 73 legal alternate decision-makers provided signed consent, however one of the eligible candidates did not provide assent and was omitted from the study.

In total, 35 males and 37 females participated in the study. The mean age of the participants was 78.5 ( $SD = 8.5$ ). The youngest participant was 58 years old and the oldest was 97. Of the 72 participants 3 were missing observational data from one of the shifts (2 evening shifts and 1 weekend shift). Missing data on the observations occurred when one participant passed away and two of the participants were discharged from the hospital before the remainder of their data was collected. Because the amount of missing data was random and was relatively small (2% of the overall evening shift observations and 1% of the weekend shift observations), a group mean was substituted for the missing values (e.g., the evening shift mean value was used for the two participants who had missing data

for the evening shift observations). A total of 7 participants were missing data on the cognitive impairment variable (Mini Mental State Exam; MMSE). Of the 7 participants who did not have MMSE data, one declined to answer any of the questions on the MMSE, three passed away, one was discharged, one suffered from a severe hearing impairment, and one was deemed to be too agitated to attend to the questions.

**Measures: dependent variable.**

*Social engagement.* The dependent variable of social engagement was measured using the Mennorah Park Engagement Scale (MPES; Judge, Camp, & Orsulic-Jeras, 2000). The MPES is an observational tool that was developed specifically for individuals with dementia residing in a care setting. This tool is used to categorize physical and social engagement under 4 subheadings: (a) Constructive or active engagement, (b) passive engagement, (c) self-engagement, and (d) non-engagement. Constructive or active engagement includes any motor or verbal behavior (positive or negative) that a resident exhibits in response to his or her physical and/or social environment (Judge et al., 2000; Schneider & Camp, 2002). According to Schneider and Camp (2002) examples of active engagement include laughing, talking, and reaching for objects. Passive engagement is characterized by passive listening or watching another individual or activity. An example of self-engagement includes talking to self, rubbing hands together, rocking, or responding to unseen stimuli. Non-engagement examples include sleeping or staring into space.

Orsulic-Jeras, Judge and Camp (2000) noted that although large-scale validity studies of the MPES have yet to be conducted, the categories of engagement were chosen based on extensive discussions with nursing staff and long-term care residents. The authors also reported that the scale has achieved inter-rater agreement levels of more than 95%. A conversation with the co-developer of the MPES, C.J. Camp (personal communication, April 5, 2006), enabled a slight modification to the observation method proposed (see Appendix H). Whereas the MPES observation period is normally 10-minutes after which a code of one of the four engagement categories is assigned, the current study coded each participant every 10 seconds during 15 minute periods. The total amount of time spent in each of the four categories during the 15-minute interval served as their scores. To allow the participants time to settle into their new environment and become accustomed to any changes in their medication regimes normally initiated upon admission to the facility, observational data was not collected until the participant had been residing as in-patient for at least 3 weeks.

**Measures: independent variables.**

The independent variables for this study include cognitive impairment, behavioral disturbances, functional disability, and the use of physical restraints.

***Cognitive impairment.***

The Mini-Mental State Exam (MMSE; Folstein & Folstein, 1975) is the most widely used brief standardized screening tool for cognitive impairment (Spreen & Strauss, 1998). The MMSE includes items that measure orientation, registration, memory, attention, concentration, language, and visual-spatial

construction. The maximum score is 30 with lower scores suggestive of cognitive impairment. There has been extensive research conducted with respect to the reliability and validity of this tool as well as the development of norms for various populations. Both age and education based norms are available for the MMSE which have been derived from various studies (Bravo & Herbert, 1997; Iverson, 1998; Crum, Anthony, Bassett, & Folstein, 1993; Marcopulos & McLain, 2003; Tombaugh, McDowell, Kristjansson, & Hubley, 1996). Cut-off scores indicating cognitive impairment range between 24 for those aged 60-64 to 19 for those over the age of 85 (Crum et al., 1993). The approximate administration time is 10-15 minutes by a trained examiner.

Internal consistencies of .31 for community-based samples to .96 for a mixed group of medical patients have been reported (e.g., Espino, Lichtenstein, Palmer, & Hazuda, 2004; Foreman, 1987; Hopp, Dixon, Backman, & Gut, 1997; Jorm, Scott, Henderson, & Kay, 1988; Lopez, Charter, Mostafavi, Nibut, & Smith, 2005; Tombaugh, et al., 1996). It has been suggested that the lower reliability in some samples likely represents the reduced variability inherent in the healthy and more highly educated samples (Strauss, Sherman, & Spreen, 2006). A study conducted by Clark et al. (1999) indicated that the MMSE demonstrates adequate test-retest reliability estimates given a two month interval between administrations (.80 to .95). Individuals with dementia or mild cognitive impairment tend not to benefit from prior exposure the MMSE following a three month interval or more (Helkala et al., 2002). On the other hand, interrater reliability has been shown to be marginal (.65) especially for certain items such as

on the overlapping pentagons (Folstein et al., 1975). Some researchers suggest that interrater reliability can be increased with more precise administration and scoring criteria (e.g., Molloy, Alemayehu, & Roberts, 1991). Because the MMSE scores for the current study were taken from the participant's health record, only the total score was available. Therefore it was not possible to assess internal consistency.

Correlational studies have demonstrated that the MMSE has moderate to high correlations with other cognitive screening tools (e.g., Adunsky, Fleissig, Levenkrohn, Arad, & Noy, 2002) as well as neuropsychological tests, especially those that measure verbal learning (Mitrushina & Salz, 1991). On the other hand, concordance rates between the individual MMSE tasks and neuropsychological tests concerned with specific cognitive domain is low (Jefferson et al., 2002). Therefore the current study only utilized the total score on the MMSE as opposed to breaking down the scores into the smaller cognitive domains (e.g., memory, language, and construction).

Despite the limitations of the MMSE that are well documented in the literature, the use of the MMSE in the current study was warranted for two important reasons. First, the MMSE is used as a clinical indicator of cognitive impairment in the facility in which the study took place. By using the MMSE scores found on the participant's charts, many participants did not have to endure additional assessments of their cognitive abilities. Using existing MMSE scores minimized the potential distress participants may have endured had they been subjected to a formal assessment of their cognition. Secondly, because the MMSE

is the most widely used measure of cognitive impairment in research with geriatric populations (Spreeen & Strauss, 1998; Stewart, O'Riley, Edelstein, & Gould, 2012) its use in the current study will allow for a comparison between the demographics of the individuals in this and other comparable studies.

With respect to the current study, the patients admitted to the hospital are normally administered the MMSE within 4 weeks of admission. The MMSE on the participants chart was obtained for the study if it had been administered within the previous 3 months of the study. If, for whatever reason an MMSE score on the chart was not available or deemed to be older than 3 months (Helkala et al., 2002) the participant was administered the MMSE by either the primary investigator or one of the research assistants during times that were convenient for the participant.

***Behavioral disturbance.***

The Cohen-Mansfield Agitation Inventory long form (CMAI) measures the frequency of specific behaviors often observed in a clinical dementia population. Higher scores on the CMAI represent more frequent occurrences of the behaviors. Regular full or part time staff members who are employed on the unit the participant currently resides were asked to complete this questionnaire (Appendix I) as long as they had worked with the participant in the last 7 days and the participant had been a resident in the facility for a minimum of 5 five weeks. The CMAI is a caregiver rated questionnaire that consists of 29 agitated behaviors that are rated on a 7-point scale of frequency. The rater indicates which of the 29 dementia behaviors occurred in the past week, and a sum score is obtained.

Interrater reliabilities for the CMAI have ranged from 0.92 to 0.95 and has reported convergent validity with the Ward Behavior Inventory (Cohen-Mansfield & Billig, 1986). Factor analyses of the CMAI have indicated that for nursing home residents there are four apparent factors which include Aggressive Behavior, Physically Non-aggressive Behavior, Verbally Agitated Behavior, and Hiding and Hoarding (Cohen-Mansfield, Marx, & Rosenthal, 1989; Rabinowitz, Davidson, De Deyn, Dratz, Brodaty, & Cohen-Mansfield, 2005; Schreiner, Yamamoto, & Shiotani, 2000). However Weiner et al., (2002) found that the CMAI was best suited to describe only overall levels of behavioral disturbance rather than subtypes. Because the current study aimed to explore the contribution of overall behavioral disturbances in predicting social engagement, the total score on the CMAI was used as the index of behavioral disturbances. Consistent with the results of previous studies using the CMAI (e.g., Finkel, Lyons, & Anderson 1992; Miller, Snowdon, & Vaughan, 2011), in the current study there was a moderately high Cronbach's alpha coefficient for the CMAI items ( $r = .75$ ).

In addition to the CMAI data, physical and verbal aggression observed during the direct observation periods was documented for descriptive purposes only. Physical aggression was defined as acts of physical violence such as slapping, punching, biting, shoving, pushing, scratching, or sexual abuse. It included high-risk activities that have the potential to harm one's self or others (e.g., self mutilation or throwing objects). Verbal aggression included angry outbursts, screaming, foul or abusive language including verbal threats that were made but not acted upon.

*Functional dependence for activities of daily living (ADL).*

The Bristol Activities of Daily Living Scale (BADLS) was designed specifically for the use with individuals diagnosed with a dementia and consists of twenty daily living activities. A higher total score on the BADLS represents increased functional dependency. Face validity was established through identifying commonly used items located on a variety of widely used ADL assessment scales available as well as through means of a questionnaire where the developers sought the feedback from actual caregivers on the items chosen to be included (Bucks, Ashworth, Wilcock & Siegfried, 1996). Construct validity was established using principal components analysis (Bucks, et al., 1996). The developers also claim that the BADLS has adequate concurrent validity by demonstrating that it correlates well with observed ADL task performance. The BADLS has also been shown to be sensitive to change in activities of daily living over time and shows the expected relationship with measures of cognition (Byrne, Wilson, Bucks, Hughes, & Wilcock, 1999). With respect to the current study, the BADLS was used to assess degree of dependence ranging from total dependence to total independence on a variety of ADLs (e.g., dressing, bathing, eating, and walking). Internal consistency was assessed using Cronbach's alpha which resulted in a high reliability coefficient of .96. Staff who had provided assistance or had observed the participant during the various listed activities of daily living in the previous two weeks completed the tool (Appendix J) so long as the participant had been a resident in the facility for a minimum of 5 five weeks.

***Physical restraints.***

Data on the type and duration of the physical restraints used during the time the behavioral observations occur was obtained. Physical restraints were defined as any mechanical device attached to the body that restricts mobility or use of a limb. Examples included Broda chairs with t-belts or back fastening seat belts, shoulder restraints, wrist restraints, mittens or gloves, one-piece back fastening suits, side rails on the bed, segufix belts, table trays attached to wheelchairs, and wheelchair brakes or front-fastening seat belts that have been engaged and could not be disengaged by the participant due to a cognitive impairment. Both the type and number of physical restraints were calculated during each observation.

**General procedures.**

The Health Research Ethics Board of the University of Alberta approved all procedures prior to participant recruitment. As the consent forms to participate in the study were obtained, the participant names were entered into a database and randomly assigned to the observers (research assistants) each day. Prior to beginning data collection, training on the observational measure (MPES) was provided by the primary investigator until inter-observer reliabilities (percent agreement) between the research assistants and primary investigator exceeded 85% on average. Twenty 15-minute training sessions were conducted with each research assistant before the inter-observer reliabilities were consistently above 85%. The three female research assistants consisted of two Psychometrists and a University of Alberta undergraduate psychology internship student all of whom

were employed by Alberta Health Services. A minimum of 85% inter-observer reliability prior to using the tool for research or therapeutic purposes is recommended by the authors of the MPES (Judge et al., 2000).

Once formal data collection had begun, inter-observer reliabilities were obtained on the first 10% of the observations used in the data analysis. Twenty three participants were observed at the same time by the primary investigator and the research assistants. The mean inter-observer reliability percent agreement was 91.95% ( $SD = 8.10$ ) and ranged from 75.56% to 100%.

The observers completed all the observations assigned to them each day unless one of the following conditions were present: (a) The participant was away from the hospital, (b) the participant had been transferred to one of the hospitals infirmity beds due to acute medical illness, or (c) the participant had family who were visiting who made it known to the observer that they were not comfortable having an observer present. Any incomplete observations at the end of the day were returned to the pool of participants and were randomly assigned the following day.

The observations for each participant occurred during three separate shifts for staff including (a) a weekday shift, (b) an evening shift, and (c) a weekend day shift. The participants were observed during times that did not include personal care routines (e.g., getting dressed or bathed in the morning or evening) or during the regularly scheduled meal times. Therefore, the approximate times when observations occurred during the day (weekday and weekend day shifts) included: 9:30-11:30 and 12:30-3:30. During the evening shift, observations occurred either

between 3:30-4:30 or 5:30-8:00. Participants were observed approximately in the order informed consent was obtained. Observations on week day shifts occurred during the day and evening since day shifts have notably more staff from disciplines other than nursing (including management) compared to the evening shifts. Weekend shifts were assumed to be similar on both the day and evening because the staffing levels are the same, hence observations on weekends only occurred during the day. In summary, each participant was observed three times throughout the study. The participants were observed for 15 minutes on each of the three shifts (e.g., day, evening, weekend). A total of 45 minutes of observation data was therefore collected for each participant.

The collection of the BADLS and CMAI data occurred at times that were convenient for the hospital staff who had agreed to participate in completing these rating tools (e.g., nursing, occupational therapy, psychology). Prior to participating, each of these hospital staff members were provided with an information sheet that described the study (Appendix F) and asked to sign a Staff Participation Agreement Form (Appendix G). Both the CMAI and BADLS data sheets were accompanied by a cover letter (Appendix A and B respectively), which provided the necessary information regarding the purpose of these tools. Each measure took less than 20 minutes each to complete.

### **Statistical analysis.**

The first research question is addressed by examining the percentage of time the participants were actively socially engaged, passively socially engaged, self-engaged, or not socially engaged at all (see Tables 2 and 3). Using a repeated

measures multivariate analysis of covariance, the shift (i.e., day, evening, or weekend) during which the observation of social engagement occurred was compared in order to answer the second research question. The variable of activities of daily living (ADL) dependency as measured by the BADLS was set as the covariate. Finally, the third research question is addressed by examining the correlations between the variables and four separate hierarchical linear regression analyses to determine which individual variables (i.e., ADL dependency, behavioral disturbances, or use of physical restraints) uniquely and jointly predict the different types of social engagement. Data were analyzed using SPSS version 14.0. and for all analyses the alpha level was set at .05.

## Chapter IV

### Results

To begin this chapter, the descriptive statistics and distributional properties of all variables are addressed (Table 1). Distributional properties of the data and violations to normality were evaluated using skewness and kurtosis statistics. A commonly used test of normality was employed, whereby the skewness and kurtosis statistics are divided by their standard errors. Any values falling within a -2 to 2 range were considered normally distributed. In an effort to achieve a more normal distribution, variables with scores falling outside of this range were subjected to square root, logarithmic, or inverse transformations depending on the severity of the skewness (Tabachnick & Fidell, 2007). Outliers were identified using box plots and scatter plots before and after the variables were transformed. The transformed variables were used for all subsequent analyses with the exception of descriptive statistics. Because of significant multicollinearity between the cognitive impairment (MMSE) and ADL dependency (BADLS) variable ( $r = 0.82$ ,  $p < 0.01$ ), only the BADLS score was used in the remainder of the analyses outside of descriptive data (Tabachnick & Fidell, 2007). The BADLS was chosen over the MMSE for two reasons: 1) because analysis of the BADLS revealed normally distributed data, and 2) because the MMSE scores suggested a significant floor effect for this particular sample of participants (Barbarotto, Cerri, Acerbi, Molinari & Capitani, 2000; de Jonghe, Wetzels, Mulders, Zuidema, & Koopmans, 2009; Franco-Marina et al., 2010). Several ( $n = 22$ ) participants received scores of a zero on the MMSE.

Because of this floor effect, the MMSE artificially restricted how low scores may have been in this sample. Ten percent of the MMSE data was missing from the analysis, however there was no missing data from the BADLS sample. The results show that the BADLS did not have the same floor effect as the MMSE data and as such, appears to provide a better representation of this sample with respect to the construct of function dependency.

### **Descriptive statistics.**

Table 1 reports the means and standard deviations for all measures. All of the variables with the exception of the BADLS and restraint use were positively skewed. Because most of the variables had a minimum score of 0, a constant of 1 was added during all transformations. The exception to adding a constant during transformations was in the case of the CMAI because it had a minimum raw score above zero. The transformations reduced the impact of all outliers with the exception of one within the CMAI data.

### ***MMSE.***

No outliers were identified within the MMSE distribution of scores; however the kurtosis statistic was outside the -2 to +2 range when it was divided by its standard error (Garson, 2006) suggesting a slightly flat kurtosis. This non-normal kurtosis suggests that the MMSE data's variance may be underestimated in this sample. Transformations were not performed since this variable was not used in subsequent analyses. Compared to normal samples (Crum et al., 1993), the present sample appears to have significant cognitive impairment represented by the mean MMSE score of 9.25 and a standard deviation of 8.64. This average

MMSE score is well below the expected mean of 26 and standard deviation of 2.1 for individuals aged 75-79 (Spreen & Strauss, 1998).

### ***CMAI.***

An evaluation of the skewness and kurtosis of the CMAI revealed a violation of normality. Logarithmic transformation corrected the substantial positive skewness. Following logarithmic transformation of the CMAI variable one outlier remained and was assigned a raw score that was one unit of measurement larger than the next most extreme score on the CMAI (Tabachnick and Fidell, 2001). The CMAI total score variable was then transformed once again without any resulting outliers. According to Zuidema, Derksen, Verhey, and Koopmans (2007), agitation measured with the CMAI is commonly defined as behavior occurring at least once a week or more (frequency score greater than or equal to a rating of 3). Eighty one percent of the current sample had at least one behavior rated at a 3 or more on the CMAI. This percentage is similar to other samples of individuals with dementia being cared for in institutions; 82% (Schreiner, Shiotain, & Yamamoto, 2000), 83% (Suh, 2004; Zuidema, van der Meer, Pennings, & Koopmans, 2006) and 85% (Zuidema et al., 2007). The CMAI mean of 43.5 and standard deviation of 12.31 is similar to those reported in larger samples of community based individuals with probable dementia (Ferris, Mackell, Mohs, Schneider, Galasko, Whitehouse, et al., 1997; Teri, Logsdon, Peskind, Raskind, Weiner, Tractenberg, et al., 2000).

***BADLS.***

There were no outliers identified within the BADLS distribution, nor were the skewness and kurtosis scores found to fall outside of the -2 to +2 range of acceptability when each statistic was divided by its standard error. The current sample had a mean BADLS score of 37.75 ( $SD = 14.15$ ). These results suggest that the ADL dependency of individuals in the current sample is quite a bit higher than that found in the Bucks et al. (1996) study. The original sample introduced by Bucks et al., (1996) had a mean of 19.2 and a standard deviation of 11.2 on the BADLS.

***Restraint use.***

The use of restraints was fairly constant across the three different shifts. A one-way analysis of variance, ANOVA, indicated no significant difference between the shifts with respect to restraint use  $F(2,213) = 0.06, p = .95$ . During the day shift observations, 30 participants were physically restrained. Of these 30 participants, 21 had one restraint and 9 had two restraints. The most common restraint was the front fastening lap belt on a wheelchair that the participant could not disengage due to their degree of cognitive impairment. Whether or not the participant could undo the front fastening lap belt was ascertained by asking the participant to undo the belt themselves. In addition, data collectors asked the nurse in charge of the shift to verify whether the individual could remove the belt independently. If neither of these two conditions were met, the participant's front fastening lap belt was considered a physical restraint. The second most common restraint was the Broda Chair which holds the individual into the chair with a t-

belt that runs between the legs and over the thighs and is then fastened at the back of the chair. A Broda Chair has a tilt mechanism that allows an attending staff to tilt the chair back in space so the patient's back is nearly parallel to the ground. The purpose of this mechanism is to relieve pressure from sitting in one position for a length of time.

During the evening shift observation, 29 participants were physically restrained (22 had one restraint, 2 had a combination of 2 restraints, and 1 participant had 3 physical restraints). Thirty-one participants were observed to be physically restrained on the weekend shift observation. Of the 31 participants in a physical restraint on the weekend shift, 26 had one restraint and only 5 participants had 2 restraints. During all three shifts, the most common restraint combination was a table tray with a back fastening seatbelt or a front fastening lap belt the participant could not disengage because the table tray restricted access to the lower part of the body.

***Behavioral disturbance during observations.***

During the day shift, there was only one participant who displayed verbal aggression (yelling) during the observation period. There were two participants who displayed verbal aggression (yelling) during the evening shift and one participant who was observed pushing another individual during the evening shift. The weekend observations had slightly more witnessed aggression. There were three participants who were verbally aggressive (2 cursing; 1 yelling) during the observations and one participant who was witnessed during several intervals engaging in self abusive behavior (hitting self).

Table 1  
*Descriptive Statistics*

	<i>M</i>	<i>SD</i>	<i>Range</i>	<i>Skewness</i>	<i>Kurtosis</i>
<b>Demographic</b>					
Age	78.47	8.53	58 - 97	-0.29	0.35
MMSE	9.25	8.64	0 - 25	0.29	-1.36
<b>Observations of Social Engagement using Mennorah Park Engagement Scale</b>					
Day CON	10.85	17.92	0 - 73	2.16	4.08
Day PAS	4.96	11.71	0 - 57	3.19	10.49
Day SELF	32.11	31.14	0 - 90	0.54	-1.12
Day NON	41.81	34.40	0 - 90	0.20	-1.56
Evening CON	8.58	12.42	0 - 57	1.99	4.44
Evening PAS	4.86	13.87	0 - 86	4.28	20.03
Evening SELF	43.96	32.12	0 - 125	0.36	-0.70
Evening NON	37.61	33.30	0 - 107	0.49	-1.20
Weekend CON	13.32	24.53	0 - 90	2.33	4.49
Weekend PAS	3.49	11.20	0 - 75	5.28	29.80
Weekend SELF	28.46	32.42	0 - 90	0.75	-1.09
Weekend NON	47.32	38.86	0 - 138	0.04	-1.51
Total CON	32.75	40.90	0 - 188	1.99	3.76
Total PAS	13.30	20.20	0 - 86	1.91	3.08
Total SELF	104.53	70.11	0 - 256	0.38	-0.72
Total NON	126.73	76.36	0 - 287	0.08	-0.86
<b>Functional Dependency and Behavioral Disturbance</b>					
BADLS	37.75	14.15	5 - 60	-0.55	-0.74
CMAI	43.50	12.31	29 - 77	1.03	0.29
<i>Sum</i>					
<b>Restraint Use</b>					
Day	30				
Evening	29				
Weekend	31				

*Note.* MMSE = Mini Mental State Exam; CON = Constructive Engagement; PAS = Passive Engagement; SELF = Self-Engagement; NON = Non-Engagement; BADLS = Bristol Activity of Daily Living Scale; CMAI = Cohen Mansfield Agitation Inventory  
*n* = 72

**Research question 1: using behavioral observations, how frequently are individuals with dementia actively socially engaged, passively socially engaged, self-engaged, or not socially engaged at all with other individuals in their environment?**

*Social Engagement.*

In order to answer the first research question, social engagement was measured during each shift (day, evening, and weekend) using the proportion of time out of 15 minutes (90 intervals of 10 seconds) each participant engaged in one of the four possible actions; constructive, passive, self, or non-engagement. Each combination of four actions across three shifts was evaluated for outliers and for non-normality on the basis of skewness and kurtosis values.

*Constructive engagement – day shift.*

During the day shift, the participants spent on average 12.06% of their time constructively engaged. In one 15 minute interval, 12% would equal approximately 1 minute and 50 seconds. Analysis of the day shift constructive engagement variable distribution revealed a number of outliers, substantial positive skewness, and highly peaked kurtosis. Logarithmic transformation of the day shift constructive engagement variable eliminated the outliers, and abnormal skewness but was only able to produce a kurtosis statistic that remained slightly outside the acceptable range (-2.5). A square root transformation and inverse transformation only served to substantially increase the skewness of the variable. Therefore the logarithmic transformation for the day shift constructive engagement was used for the remaining analyses.

*Constructive engagement – evening shift.*

The results gathered during the 15 minute observations on the evening shift suggest that the participants were spending on average 9.53% of their time constructively engaged. In other words, during one 15 minute interval, they were spending approximately 1 minute and 35 seconds constructively engaged with other individuals in the environment. Similar to the day shift constructive engagement variable, logarithmic transformations were successful in eliminating outliers, and correcting skewness but was only able to produce a kurtosis statistic that was slightly outside the acceptable range of +2 through -2, when divided by its standard error (-2.5). Neither the square root transformation nor inverse transformation improved the normality as much as the logarithmic transformation. Therefore the logarithmic transformation for the evening shift constructive engagement was used for the remaining analyses.

*Constructive engagement – weekend shift.*

The participants spent 14.80% of their time constructively engaged. This percentage of time equals approximately 2 minutes and 10 seconds of a 15 minute interval. Logarithmic transformation was successful in eliminating the outliers and correcting the skewness and kurtosis to within an acceptable range.

*Total constructive engagement.*

Overall, the participants were spending 12.13% of their time constructively engaged when all three shifts were combined. This equals

approximately 5 minutes and 30 seconds for each 45 minute interval. The total constructive engagement variable was tested for outliers and violations of normality by dividing the skewness and kurtosis statistics by their respective standard errors. The results showed substantial positive skewness and peaked kurtosis, hence a logarithmic transformation was applied to successfully eliminate the outliers. Since both skewness and kurtosis were corrected using the logarithmic transformation the logarithmic transformation scores for total constructive engagement were used for subsequent analyses.

*Passive engagement – day shift.*

During the day shift, the participants spent on average 5.51% of their time passively engaged. Given a 15 minute interval, the participants were spending approximately 50 to 60 seconds passively engaged. Analysis of the day shift passive engagement variable distribution revealed a number of outliers, severe skewness, and severely peaked kurtosis. Inverse transformations were the only transformations of the day shift passive engagement variable that was successful in eliminating the outliers and improving both the skewness and kurtosis. However, even following the inverse transformation, the skewness and kurtosis statistics suggested the data was non-normal albeit to a much more reasonable degree than they had been prior the transformation. Hence, the inverse transformation scores for day shift passive engagement was used for the remaining analyses.

*Passive engagement – evening shift.*

The results gathered during the 15 minute observations on the evening shift suggest that the participants were spending on average 5.40% of their time passively engaged. Similar to the day shift, participants were spending approximately 50 to 60 seconds passively engaged with other individuals during the evening observations. The passive engagement data gathered during the evening shift resulted in numerous outliers and non-normal data. An inverse transformation was used to reduce the severity of skewness and kurtosis as well as eliminate outliers.

*Passive engagement – weekend shift.*

The participants spent only 3.88% of their time passively engaged on the weekend shift. This percentage of time equates to approximately 30 to 40 seconds during a 15 minute interval. Once again inverse transformation was required, due to the severity of the positive skewness and a highly peaked kurtosis. The inverse transformation was also successful in reducing the influence of outliers.

*Total passive engagement.*

When day, evening, and weekend data for passive engagement were combined, the results showed that the participants were spending 4.91% of their time passively engaged. This means that they were spending only about 2 minutes and 10 seconds out of each 45 minute interval watching and/or listening attentively during social activities going on around them. Inverse transformation was successful in eliminating outliers, and correcting the severity of the skewness but was only able to produce a kurtosis statistic that was slightly outside the

acceptable range of +2 through -2, when divided by its standard error (-2.6).

Neither the square root transformation nor logarithmic transformation improved the normality as much as the inverse transformation. Therefore the inverse transformation was used for the remaining analyses.

*Self-engagement – day shift.*

Participants spent on average 35.68% of their time self-engaged on the day shift. In each 15 minute interval, participants would spend approximately 5 minutes and 20 seconds self-engaged. Analysis of the day shift self-engagement variable distribution revealed an absence of outliers and a normal distribution; however, because the weekend shift self-engagement data required square root transformation to improve both kurtosis and skewness, both the day shift and evening shift data were subjected to square root transformation in order to maintain a common unit of comparison between the three shifts.

*Self-engagement – evening shift.*

During the evening shift, the participants were spending nearly half of their time self-engaged (48.84%). In other words, during a 15 minute interval, they were spending approximately 7 minutes and 20 seconds self-engaged. Although transformation of the data was not required because of the normal distribution of data and the absence of outliers, square root transformation of the self-engagement evening data was performed to ensure a common unit of comparison with the weekend and day shift self-engagement data.

*Self-engagement – weekend shift.*

The participants spent 31.62% of their time self-engaged during the weekend shift. This percentage of time equates to approximately 4 minutes and 40 seconds for each 15 minute interval. Square root transformation was successful in eliminating the outliers and correcting the skewness to within an acceptable range. Unfortunately, following transformation of this variable the kurtosis statistic remained slightly outside the acceptable range of +2 through -2 (-2.6), when divided by its standard error. Neither the logarithmic transformation nor inverse transformation improved the normality as much as the square root transformation. Therefore the square root transformation was used for the remaining analyses.

*Total self-engagement.*

Overall, the participants were spending 38.72% of their time self-engaged when all three shifts were combined. This equates to approximately 17 minutes and 20 seconds in each 45 minute interval. The Total Self-engagement variable did not have any outliers or violations of normality.

*Non-engagement – day shift.*

During the day shift, the participants spent on average 46.46% of their time not engaged at all. Given a 15 minute interval on the day shift, the participants were spending approximately 7 minutes not socially or self-engaged. Analysis of the day shift non-engagement variable distribution revealed a number of outliers, moderate positive skewness, and a moderately peaked kurtosis. Square root transformation was the most successful in improving the data's normality and eliminating outliers when compared to logarithmic and inverse transformations.

Following square root transformation, the skewness was within the acceptable range when divided by its standard error and the kurtosis was just outside the acceptable range (-2.2) when divided by its standard error.

*Non-engagement – evening shift.*

Non-engagement was observed 41.79% of the time on the evening shift. On average, the participants were spending approximately 6 minutes and 20 seconds out of a 15 minute interval not engaged with other individuals or involved in any type of activities. Similar to the day shift, the non-engagement data gathered during the evening shift resulted in outliers and non-normal data. Square root transformation proved to be the most successful transformation of the data to correct for problems with skewness and kurtosis when compared to the other types of transformations.

*Non-engagement – weekend shift.*

Non-engagement data collected on the weekend shift suggests that the participants were spending 52.58% of their time not engaged at all. This percentage of time equates to approximately 7 minutes and 50 seconds during a 15 minute interval. Once again square root transformation helped correct the moderate positive skewness and flat kurtosis as well as reduce the influence of outliers.

*Total non-engagement.*

When day, evening, and weekend data for non-engagement was combined, the results demonstrated that the participants were spending 46.94% of their time not engaged at all. This means that they were spending only about 21 minutes and

10 seconds out of 45 minutes doing nothing at all. The total non-engagement variable did not have any outliers or violations of normality.

Table 2  
*Time Spent in each Engagement Level during the Three Shifts*

		Time spent per 15 minute interval		
		min	sec	%
Day Shift				
	CON	1	50	12.06
	PAS	0	50-60	5.51
	SELF	5	20	35.68
	NON	7	0	46.46
Evening Shift				
	CON	1	35	9.53
	PAS	0	50-60	5.40
	SELF	7	20	48.84
	NON	6	20	41.79
Weekend Shift				
	CON	2	10	14.80
	PAS	0	30-40	3.88
	SELF	4	10	31.62
	NON	7	50	52.58

*Note.* CON = Constructive Engagement; PAS = Passive Engagement; SELF = Self-engagement; NON = Non-engagement.

Table 3  
*Total Amount of Time Spent in each Engagement Level*

	Time spent per 45 minute interval		
	min	sec	%
Total CON	5	30	12.13
Total PAS	2	10	4.91
Total SELF	17	20	38.72
Total NON	21	10	46.94

*Note:* CON = Constructive Engagement; PAS = Passive Engagement; SELF = Self-engagement; NON = Non-engagement.

**Research question 2: Do organizational variables such as time of day affect the frequency and quality of the social engagement? In other words, does social engagement differ across the weekday, evening, or weekend shift?**

A repeated measures multivariate analysis of covariance was performed using the four engagement codes. The grouping variable was the shift on which the observation occurred (day, evening, or weekend). Activity of daily living dependency as measured by the BADLS was set as the time-invariant covariate. SPSS GLM was used for the major analysis. Wilks' Lambda was significant,  $F(8, 274) = 2.64, p = .008$  indicating that there was a significant difference within the model. Mauchly's test of sphericity suggested that the variances of the differences between the shifts were not significantly different for any of the four social engagement codes. Because compound symmetry was achieved, a univariate repeated measures was employed to analyze the difference between the dependent variables across shifts. The univariate approach to repeated measures provides a more powerful design and allows for an easier interpretation of the findings (Glass & Hopkins, 1996). Post hoc tests were not possible because they are not designed for analyses that include covariates. Table 4 provides the results of the repeated measures ANCOVA and effect size for all four of the engagement variables.

***Constructive engagement.***

Constructive engagement is the highest quality of social engagement represented in this study. Participants who were constructively engaged during the direct observations were communicating either verbally or non-verbally with

other individuals. Alternatively, participants who were activity engaged in an organized activity (e.g., exercise group, baking, or discussing current events in a group lead by a staff member) were also considered to be constructively engaged (Schneider & Camp, 2002) Each participant's total score of constructive engagement served as a measure of frequency. The effect of shift (day, evening, or weekend) on amount of constructive engagement observed was examined after adjusting for the covariate of ADL dependency (BADLS). Univariate  $F(2, 140) = 2.94, p = .056$  suggested that constructive engagement did not differ across the three shifts. However, a marginally significant interaction was observed between the covariate and the shift  $F(2, 140) = 3.10, p = .048$ . This interaction suggests that depending on the participants' level of dependency in ADLs, there was a small but significant difference observed in constructive engagement across the shifts.

***Passive engagement.***

Participants' passive engagement differed across the three shifts  $F(2, 140) = 4.967, p = .008$ , however a highly significant interaction effect was also noted between the covariate and the independent variable of shift  $F(2, 140) = 4.90, p = .009$  thereby complicating the interpretation of the main effect of shift. A significant interaction denotes heterogeneity of regression slopes across the independent variable (shift). By examining the correlations between the covariate and the dependent variable (passive engagement) the strength and the direction of the relationship could be determined thereby providing insight into the reason for an interaction effect. The correlation between day shift passive engagement and

the BADLS total score was  $r = .40, p < .01$  suggesting a moderate positive correlation. On the other hand, the correlation between evening shift passive engagement and the BADLS total score was only  $r = .14, p > .05$ . The correlation between weekend shift passive engagement and the BADLS total score was negative and also very small  $r = -.06, p > .05$ . Without a significant relationship between the covariate and the dependent variable, its usefulness as a covariate and its ability to reduce within-group error variance is questionable. One possible explanation for this is that the range for the passive engagement variable in the sample was attenuated, in that nearly all the participants in the sample had very small overall passive engagement scores. When passive engagement across the three shifts was compared using a one-way repeated measures but the covariate of ADL dependency was left out of the analysis, passive engagement no longer significantly differed between the shifts  $F(2,142) = .18, p = .83$ .

***Self-engagement.***

When the variable of self-engagement was entered into the repeated measures ANCOVA as the dependent variable and the BADLS total score as the covariate, there was no difference between the participants self-engagement scores when compared across the day, evening, and weekend shift  $F(2,140) = .61, p = .54$ . An interaction effect between the covariate and the dependent variable was not evident either  $F(2, 140) = .53, p = .59$ .

***Non-engagement.***

When non-engagement was the dependent variable of interest and compared across the three separate shifts with the BADLS total score was once

again set as the covariate, there were neither significant main nor significant interaction effects evident  $F(2,140) = 1.30, p = .28$  and  $F(2,140) = 1.93, p = .15$  respectively.

Table 4  
*Repeated Measures ANCOVA and Effect Size for Social Engagement Across Shifts*

Measure	Mean(SD)			Source	$F(2,140)$	$p$	Effect size	Power
	Day	Evening	Wkend					
Log	0.64	0.62	0.62	Shift	2.94	.06	.04	.57
CON	(.62)	(.58)	(.68)	Shift*BADLS	3.10	.05	.04	.59
Inv	0.69	0.71	0.73	Shift	4.97	.01	.07	.80
PAS	(.40)	(.39)	(.38)	Shift*BADLS	4.90	.01	.07	.80
Sqrt	4.57	6.00	4.04	Shift	0.61	.54	.01	.15
SELF	(3.37)	(2.85)	(3.51)	Shift*BADLS	0.53	.59	.01	.14
Sqrt	5.52	5.45	5.80	Shift	1.30	.28	.02	.28
NON	(3.38)	(2.30)	(3.72)	Shift*BADLS	1.93	.15	.03	.40

*Note.* Log CON = Logarithmic transformation of Constructive Engagement; Inv PAS = Inverse transformation of Passive Engagement; Sqrt SELF = Square root transformation of Self-engagement; Sqrt NON = Square root transformation of Non-engagement.

**Research Question 3: Which individual variables (i.e., degree of cognitive impairment, behavioral disturbances, activities of daily living (ADL) dependency, or use of physical restraints) uniquely and jointly predict social engagement?**

*Correlations between the variables.*

Table 5 presents the correlations between the predictor variables and the dependent variables. Dependent variables consisted of the social engagement variables collapsed across the three shifts therefore yielding a total constructive

engagement, a total passive engagement, a total self-engagement, and a total non-engagement variable. The functional dependency variable (BADLS) was correlated with two of the dependent variables. There was a strong correlation between the functional dependency and constructive engagement ( $r = -.50, p < .001$ ) and a moderate correlation with self-engagement variables ( $r = .33, p < .001$ ). These results were expected on the basis of existing studies (e.g., Ballard et al. 2001; Smith & Hirdes, 2009; Voelkl et al., 1995). Behavioral disturbance measured by the CMAI correlated moderately with the dependent variable of self-engagement and weakly with non-engagement. There was a small but significant correlation between restraint use and constructive engagement and a moderate correlation between restraint use and self-engagement. None of the predictor variables were correlated with passive engagement.

Constructive engagement was negatively correlated with non-engagement which is not surprising given their opposing nature. It was also negatively correlated with passive engagement which was unexpected. Theoretically, individual's engaged in passive social engagement (e.g., listening to and/or watching a social interaction) would also be expected to demonstrate the tendency to actively engage in a social exchange either verbally or non-verbally (Schneider & Camp, 2002). However, in this sample, participants who had a tendency to be passively engaged displayed very little constructive engagement. There was a strong negative correlation between non-engagement and self-engagement. This was also an unexpected finding suggesting that the participants in this sample who were self-engaged the majority of the time (e.g., behaviors such as pacing,

wandering, fidgeting with their clothing, and rubbing their hands together were coded as self-engagement) rarely were observed to be still, not engaged in any activity, social or otherwise. Interestingly, the participants with elevated self-engagement also had elevated CMAI scores ( $r = .35, p = .003$ ). Apparently, the participants who were observed during this study to be restless were also rated by staff as having increased agitation. As mentioned earlier, restraint use was moderately correlated with self-engagement but was not correlated with CMAI scores. The participants who were restrained had a tendency to display more self-engaged behaviors but did not have elevated scores on the measure of behavioral disturbance.

Table 5  
*Intercorrelations Between Dependent and Independent Variables*

Variable	1	2	3	4	5	6	7
1. Restraint	—						
2. Total CON	-.29*	—					
3. Total PAS	.13	-0.46**	—				
4. Total SELF	.38**	-.04	.09	—			
5. Total NON	-.07	-.40**	.20	-.67**	—		
6. BADLS	.73**	-.50**	.23	.33**	.15	—	
7. CMAI	.13	-.03	.19	.35**	-.28*	.29*	—

*Note:* Total CON = Total Constructive Engagement; Total PAS = Total Passive Engagement; Total SELF = Total Self-engagement; Total NON = Total Non-engagement; BADLS = Bristol Activity of Daily Living Scale; CMAI = Cohen Mansfield Agitation Inventory.

\* $p < .05$  \*\* $p < .01$

### ***Regression analyses.***

Regression analyses were used next to examine the unique contributions of predictor variables to the dependent variables. There were four dependent variables consisting of total constructive engagement, passive engagement, self-

engagement, and non-engagement therefore four separate regression models were constructed. Each of the independent variables were entered into the regression equation in the same order for all four models. In the first step for each of the models, the control variable of functional dependency (BADLS) was entered, followed by the behavioral disturbance variable (CMAI), and finally restraint use. Hierarchical regression was employed to determine if additional information regarding behavioral disturbances and then restraint use improved prediction of social engagement beyond that afforded by differences in functional dependency. Tables 6 through 9 display the unstandardized regression coefficients ( $b$ ), the standard error ( $SE$ ), the standardized regression coefficients ( $\beta$ ), and the  $R^2$  change ( $R^2 \Delta$ ) at each step for each of the four models.

*Predicting constructive engagement.*

The dependent variable for Model 1 was constructive engagement. The overall model that included the BADLS, the CMAI, and restraint use was significant,  $F(3,68) = 2.41, p < 0.001 (R^2=.28)$ . After controlling for functional dependency, neither the  $R^2 \Delta (.01)$  for behavioral disturbances nor the  $R^2 \Delta (.02)$  for restraint use was significant. The  $R^2$  value of .25 after the BADLS was entered indicates that a quarter of the variability in constructive engagement is predicted from the participant's functional dependency in activities of daily living. Adding behavioral disturbance and restraint use to the model did not significantly improve the predictability of constructive engagement.

Table 6  
*Model 1 Hierarchical Multiple Regression Analysis Predicting Constructive Engagement*

Predictor	Constructive Engagement			
	<i>b</i>	<i>SE</i>	<i>B</i>	<i>R</i> <sup>2</sup> $\Delta$
<i>Step 1</i>				.25**
BADLS	-.02	.00	-.50**	
<i>Step 2</i>				.01
BADLS	-.02	.01	-.54**	
CMAI	.65	.57	.12	
<i>Step 3</i>				.02
BADLS	-.03	.01	-.68**	
CMAI	.74	.57	.14	
Restraint	.23	.18	.19	

*Note.* *N* = 72

\**p* < .05; \*\**p* < .01.

*Predicting passive engagement.*

The dependent variable for Model 2 was Passive engagement. The overall model that included the BADLS, the CMAI, and restraint use was not significant,  $F(3,68) = 0.28, p = 0.17 (R^2=.07)$ . After controlling for functional dependency, neither the  $R^2 \Delta$  (.02) for behavioral disturbances nor the  $R^2 \Delta$  (.00) for restraint use was significant. The  $R^2$  value of .05 after the BADLS was entered indicates that only 5% of the variability in passive engagement is predicted from the participant's functional dependency in activities of daily living.

Table 7  
 Model 2 Hierarchical Multiple Regression Analysis Predicting Passive Engagement

Predictor	Passive Engagement			
	<i>b</i>	<i>SE</i>	$\beta$	$R^2 \Delta$
<i>Step 1</i>				.05
BADLS	.01	.00	.23	
<i>Step 2</i>				.02
BADLS	.01	.00	.19	
CMAI	.50	.44	.14	
<i>Step 3</i>				.00
BADLS	.01	.01	.23	
CMAI	.48	.44	.13	
Restraint	-.05	.14	-.06	

Note.  $N = 72$

\* $p < .05$ ; \*\* $p < .01$ .

*Predicting self-engagement.*

The dependent variable for Model 3 was self-engagement. The overall model that included the BADLS, the CMAI, and restraint use was significant,  $F(3,68) = 7.08, p < 0.001 (R^2=.24)$ . After controlling for functional dependency, the  $R^2 \Delta (.07)$  for behavioral disturbances was significant as was the  $R^2 \Delta (.06)$  for restraint use. The  $R^2$  value of .24 indicates that approximately one quarter of the variability in self-engagement is predicted by functional dependency, behavioral disturbances, and restraint use. All three of these independent variables added to the predictability of self-engagement in this particular model.

Table 8  
 Model 3 Hierarchical Multiple Regression Analysis Predicting Self-engagement

Predictor	Self-engagement			$R^2 \Delta$
	$b$	$SE$	$\beta$	
<i>Step 1</i>				.11**
BADLS	1.64	.56	.33**	
<i>Step 2</i>				.07**
BADLS	1.25	.56	.25*	
CMAI	171.43	69.87	.28*	
<i>Step 3</i>				.06*
BADLS	-.08	.80	-.02	
CMAI	190.33	68.41	.31**	
Restraint	49.19	21.82	.35*	

Note. \* $p < .05$ ; \*\* $p < .01$ .

#### *Predicting non-engagement.*

The dependent variable for Model 4 was non-engagement. The overall model that included the BADLS, the CMAI, and restraint use was significant,  $F(3,68) = 6.88, p < 0.001 (R^2 = .23)$ . After controlling for functional dependency  $R$  square was not significant ( $R^2 = .02, p = .21$ ) but the  $R^2 \Delta (.11), p = .003$  for behavioral disturbances was significant as was the  $R^2 \Delta (.06), p = .005$  for restraint use. Overall the  $R^2$  value of .23 indicates that 21% of the variability in self-engagement is predicted by behavioral disturbances and restraint use. While the control variable did not add to the prediction of non-engagement, both behavioral disturbances and restraint use remained significant predictors of non-engagement in this model. With the dependent variable set as non-engagement, there appears to be a case of classical suppression. For example, the BADLS correlated very weakly with non-engagement and restraint use did not correlate at all with non-engagement. However when entered into the model together, restraint use's ability to predict non-engagement improved substantially. The

BADLS variable serves as a suppressor variable because it suppresses variance that is irrelevant to the prediction of non-engagement.

Table 9  
*Model 4 Hierarchical Multiple Regression Analysis Predicting Non-engagement*

Predictor	Non-engagement			$R^2 \Delta$
	<i>b</i>	<i>SE</i>	$\beta$	
<i>Step 1</i>				.02
BADLS	.82	.64	.15	
<i>Step 2</i>				.11**
BADLS	1.36	.63	.25*	
CMAI	-236.24	78.11	-.35**	
<i>Step 3</i>				.10**
BADLS	3.22	.88	.60	
CMAI	-262.92	74.76	-.39**	
Restraint	-69.44	23.85	-.46**	

Note. \* $p < .05$ ; \*\* $p < .01$ .

## **Chapter V**

### **Discussion**

The goal of this final dissertation chapter is to restate the study purpose and research questions as well as review the major methods used in the study. In addition, this chapter provides a summary of the results and discusses their limitations and implications for clinical practice and future research.

### **Purpose**

The general purpose of this study was to explore social engagement in a sample of hospitalized individuals diagnosed with dementia. More specifically, this research sought to determine if the type and frequency of social engagement observed in this sample differed depending upon which hospital shift (i.e., day, evening, or weekend) it was measured. By developing a more comprehensive understanding of social engagement in this population some practical and theoretical outcomes are realized. First, knowing if social engagement patterns change depending on shift can provide insight into when the most ideal time would be to implement certain treatments or interventions. Second, information about the relationship between social engagement and hospital shifts has theoretical implications by contributing to the understanding of how organizational factors can impact social interactions. This study also aimed to determine if physical restraint use was a significant predictor of social engagement after the variance of well known predictors of social engagement such as behavioral disturbance and ADL dependency have been statistically controlled for. With this knowledge, clinicians and caregivers can target specific

interventions or policies that have the potential to reduce the negative impact physical restraint use has on social psychological well being. In terms of theory, it is important to know which factors influence social engagement outside those already well established in the research literature (e.g., cognitive impairment, behavioral disturbance, and functional dependency) in order to develop the most accurate model to predict social psychological wellbeing in this vulnerable population.

### **Research questions.**

Well established in the extant literature is a strong association between dementia and social engagement (Chen et al., 2000; Chung, 2004; Fritsch et al., 2009; Kolanowski et al., 2006; 2009; Lemke & Moos, 1989; Potkins et al., 2003; Zimmerman et al., 2003). As cognition deteriorates and the ability to complete daily living decreases, individuals with dementia become less likely to engage with others (Kolanowski et al., 2006; Tighe et al., 2008). Other factors that impact social engagement include organizational factors. Lower levels of constructive social engagement are prominent in large traditional nursing home institutions (Reimer et al., 2004) as well as hospital settings including both psychiatric and acute medical facilities (Armstrong-Ester et al., 1994). Staffing resources change depending on the time of day as well as day of the week; lower levels of staffing are often observed on the evening and weekend shifts compared to day shifts. Based on a review of the literature, no studies could be located that compared social engagement on different shifts; however, there has been a trend in the study of physical restraint use to incorporate shift differential (Bourbonniere et al.,

2003; Fogel et al., 2009; Meyer et al., 2008). Existing research provides support for a strong association between dementia and the use of physical restraints (Evans & Strumpf, 1989; Evans, et al., 2003; Huizing et al, 2007; Miles & Irvine, 1992; Mion et al., 2010; Phillips et al., 2003; Rubin et al., 1993). Although they commonly occur in institutions for the elderly, these two variables; restraint use and observed social engagement, have only been minimally addressed in the research literature (e.g., Castle, 2006; Folmar & Wilson, 1989). The research questions in this study included: (a) how frequently are individuals with dementia actively socially engaged, passively socially engaged, self-engaged, or not socially engaged at all with other individuals in their environment; (b) do organizational variables such as time of day affect the frequency and quality of the social engagement? In other words does social engagement differ across the weekday, evening, or weekend shift; and (c) which individual variables (i.e., degree of cognitive impairment, behavioral disturbances, activities of daily living (ADL) dependency, or use of physical restraints) uniquely and jointly predict social engagement?

#### **Method and summary of findings.**

The first research question was addressed by examining the percentage of time participants were constructively engaged, passively engaged, self-engaged, or not socially engaged at all. In order to answer the second research question, a univariate repeated measures analysis of covariance was employed. The shift (i.e., day, evening, or weekend) during which the observation of social engagement occurred served as the grouping variable. The variable for activities of daily living

(ADL) dependency as measured by the BADLS was set as the covariate. Finally, the third research question was addressed by examining the correlations between the variables in addition to running four separate hierarchical linear regression analyses to determine which individual variables (i.e., ADL dependency, behavioral disturbances, or use of physical restraints) uniquely and jointly predicted the different types of social engagement.

***Question 1: How frequently are individuals with dementia actively socially engaged, passively socially engaged, self-engaged, or not socially engaged at all with other individuals in their environment?***

During 15 minute observation periods, participants' social behavior was assessed using the Mennorah Park Engagement Scale (MPES; Judge et al., 2000). Constructive engagement included any verbal or nonverbal interactions with others in the environment in addition to active engagement in organized (staff initiated) activities. Overall, the participants were spending 12% of their time constructively engaged when the observational data from all three shifts were combined. The constructive engagement data reported in this study is similar to what was reported by VanHaitsma et al. (1997) whereby social engagement was observed 13% of the time and activity engagement was observed 4% of the time. Armstrong-Esther et al. (1994) also reported similar results suggesting low levels of social interaction with staff but no engagement in social activities or prolonged informal conversations. Active social interaction was reported 7.1% of the time in an observational study by McKee et al., (2002), however the authors also reported the participants were involved in "recreation" 19% of the time. In an

observational study conducted in hospital wards for patients with dementia, Bowie and Mountain (1993) reported that constructive social engagement occurred on average only 5.5% of the time. Constructive engagement in the current study differed significantly from a more recent study completed by Kolanowski et al. (2009) that revealed “active” engagement in 54% of their sample of nursing home residents with dementia. The definition of active engagement in the Kolanowski et al. (2009) study included informal activity and organized activity. Possible reasons for the discrepancy between these two studies might include the manner in which the engagement was coded during observations. In the current study, behavior was coded once every 10 seconds while in the Kolanowski et al. (2009) study, social engagement behavior was coded only once in the 20 minute interval (e.g., which behavior the observer determined to be occurring for more than 50% of the time). Furthermore, it was difficult to determine from the article, what the definitions of informal activity and organized activity were as the authors did not provide examples. It is possible that the definition of informal and organized activities might have encompassed the behaviors that were defined in the current study under passive engagement and self-engagement.

A high degree of constructive social engagement was observed in an intervention study by Fritsch and colleagues (2009). The researchers reported the participants were engaged with others in their environment 85% of the time (intervention group) and 81% of the time (control group). These results differ a great deal from the results of the current study. One possible reason may be that

the observers in the Fritsch et al. study were directed to observe staff-resident interactions specifically. They were instructed to begin recording observational data only once a staff-resident interaction began.

In the current study, passive engagement was defined as listening or watching a social interaction or organized activity. Passive engagement was observed infrequently in most of the sample but a closer examination of the data revealed several outliers as a few participants spent the entire 15 minute time period passively engaged. Overall, the participants were observed spending approximately 4% of their time passively engaged. Interestingly, participants who were watching television were coded as passively engaged, but despite the television being on continuously; very few participants were observed actually attending to the television. This phenomenon occurred even though the majority of the participants were observed in the common area of the unit where the television is located. McKee et al. (2002) also found relatively low levels of passive social engagement (17%) in their sample of nursing home residents although not as low as the passive engagement observed in the current sample. The finding that there were very low levels of passive engagement overall, possibly contradicts those reported by VanHaitsma et al. whom reported high levels of “gazing with interest” (40%). However, the term “gazing with interest” was also defined as “inactive gaze” in the same article which made it difficult to compare to the terminology used in the current study. A passive engagement code in the current study was assigned only if the observer could determine that the participant was watching or listening to a specific social interaction or organized

activity, otherwise the behavior was coded as non-engagement. Passive engagement would seem to better fit VanHaitsma et al.'s definition of "gazing with interest", while "inactive gaze" would be more comparable to the definition of non-engagement in the current study.

Self-engagement was observed 38% of the time which was not a surprising finding. Self-engagement was coded when the participant was observed spending the majority of the 10 second interval wandering, moving about in their chair, wringing their hands, picking at their clothing, etc. High levels of restlessness were expected given that the majority of admissions to this in-patient program facility are for the treatment of behavioral disturbances related to a moderate to severe dementia diagnosis. Bowie and Mountain (1993) also reported similar levels of self-engagement, indicating that participants in their study were observed spending approximately 30% of their time "engaged in useless activities". Several informant-based inventories such as the CMAI and Neuropsychiatric Inventory (Cummings et al., 1994) describe self-engagement behaviors as agitation (wandering, restlessness, picking at clothing, moving furniture, etc.). This study demonstrated that self-engagement and CMAI scores were indeed correlated. Application of the social psychological framework to self-engagement or agitated behavior suggests their expression represents unmet needs (e.g., social, psychological, or physical) that could be amplified for two reasons. The first reason being the individual's diminished cognitive capacity whereby there is a failure to create the initiatives that would normally lead to needs being met (Dupuis et al., 2012; Fisher & Swingen, 1997; Kitwood, 1997). The second

reason is the physical and social environment which often fails to support or validate the individual with dementia in their quest to meet their needs (Bruce, 2004; Kitwood, 1997; Teitelman et al., 2010).

Although it could be conceptualized as non-engagement, self-engagement was included in this study to highlight two things. While the results suggest these individuals are spending much of their time without social stimulation, the results also suggest they are spending a great deal of time attempting to meet an unmet social, psychological, or physical need. By exploring self-engagement, it is my hope clinicians and researchers will become more sensitized to this phenomenon as an indicator of an unmet need. While the idea that unmet need is reflected through “agitated behaviors” is not new (Algase, Beck, Kolanowski, Whall & Berent, 1996; Bruce, 2004; Penrod, Yu, Kolanowski, Fick, Loeb, & Hupcey, 2007; Teitelman et al., 2010), by labeling this behavior as a disturbance, nuisance, or symptom we run the risk of undermining its communicative value. When strictly labeled as a behavioral or psychiatric disturbance, the agitation or self-engagement becomes a medical symptom to manage or treat rather than a starting point from which to explore and inform psycho-social intervention.

The non-engagement code was the most commonly assigned social engagement code during the observations. The participants spent approximately 46% of their time not engaged at all. This often included sleeping or looking around, but not at anything or anyone in particular. Very similar results were reported by Bowie and Mountain (1993) who stated “well over 50%” of the participant’s time was spent “doing nothing at all”. This was iterated in the

Kolanowski et al., (2009) study whereby the nursing home residents in their sample spent 45% of their total time either “doing nothing” or sleeping. VanHaitisma et al., (1997) reported lower levels of non-engagement (24%) which they coined “totally passive behaviors” but defined as sleeping and null behavior. Similarly, McKee et al., (2002) reported observations of “sleeping or dozing” behaviors only 25.7% of the time and Fitsch et al., (2009) reported “disengagement” only 11% of the time. Daytime sleeping or resting does not in and of itself signal unmet social needs in this population, however it does beg the question as to how well the individual is sleeping at night, the possibility of medication side effects, and concurrent physical health problems. This study and others demonstrating similar findings, provide the basis for further inquiry into caring for individuals with dementia. Questions that remain to be answered include: Why are individuals with dementia who are being cared for in institutions spending so much of their day doing nothing at all? How much daytime rest or sleep is optimal for an individual with dementia? How does their non-engagement patterns compare with their community dwelling peers (both with and without dementia)?

***Question 2: Do organizational variables such as time of day affect the frequency and quality of the social engagement? In other words, does social engagement differ across the weekday, evening, or weekend shift?***

The current study attempted to extend existing research by determining if social engagement changed depending upon when it was observed. Although McKee et al. (2002) and Bowie and Mountain (1993) reported observations

throughout the day and evening; neither of these studies compared social engagement levels between the two time periods. Bowie and Mountain noted that most social engagement was observed in the afternoon between 1:00 and 4:00 but did not provide a statistical analysis of the data. Overall, the findings from the current study suggested that each of the four levels of social engagement were consistent across the day, evening, and weekend shifts. The exception was passive engagement which initially appeared to be significantly different across the shifts. However, further analysis of the data revealed a significant interaction effect between the covariate (BADLS) and the independent variable (shift). In an effort to determine why the interaction was significant, the correlations between the covariate and independent variable were examined. What became apparent was the lack of relationship between the covariate and the dependent variable, rendering the BADLS inoperable as a covariate and its ability to reduce within-group error variance controvertible. When passive engagement was compared across the three shifts without using the covariate in the analysis, the significant difference between the shifts no longer existed. Although there was typically more staff employed during the day shift than on the evening and weekend shifts, no significant differences in social engagement were observed. This finding is somewhat surprising considering there are activity programs available Monday through Friday on the day shift throughout the hospital that are not offered during evenings and weekends. One possible reason weekend constructive engagement was similar to day shift constructive engagement might be that family visits are generally more common on weekends than during the week days. Because the

psychiatric hospital serves a large catchment area, many families must travel a long distance to visit. Visitation is therefore more feasible on the weekends.

***Question 3: Which individual variables (i.e., degree of cognitive impairment, behavioral disturbances, activities of daily living (ADL) dependency, or use of physical restraints) uniquely and jointly predict social engagement?***

The strongest predictors of social engagement in this population are degree of cognitive impairment (Castle & Engberg, 2009; Chen et al., 2000; Chung, 2004; Kolanowski et al., 2006; 2009; Lemke & Moos, 1989; Potkins et al., 2003; Zimmerman et al., 2003) and dependency with activities of daily living (Ballard et al., 2001; Smith and Hirdes 2009; Tighe et al., 2008). Similarly, the current study demonstrated that these two variables are highly correlated (i.e., the MMSE and the BADLS exhibited a correlation coefficient of  $r = .82$ ). With such high degree of intercorrelation it is reasonable to infer that ADL dependency and cognitive functioning represent a similar construct, especially in moderate to severe cases of dementia (Boller, Verny, Hugonot-Diener, & Saxton, 2002; Doble, 2009; Marra, Pereira, Faria, Tirado, & Pereira, 2011). On the other hand, Kolanowski et al., 2006 stressed the need to include both cognitive and functional abilities separately and argued that they represent distinct aspects of dementia. In the data analysis for the current study, only the BADLS was used as a predictor of social engagement in order to eliminate the possible confounding effects of multicollinearity. The rationale for using the BADLS instead of MMSE data was

based on the superior distributional properties, reduced attenuation, and absence of floor effects yielded from the BADLS data.

Correlational analysis revealed that the BADLS was strongly correlated with constructive engagement and moderately correlated with self-engagement. The correlation between constructive engagement and BADLS was expected based on a review of the literature suggesting that as functional dependency for activities of daily living increases, constructive engagement decreases (e.g., Ballard et al. 2001; Kolanowski et al., 2009; Smith & Hirdes, 2009; Voelkl et al., 1995). Alternately, the BADLS was not significantly correlated with either passive or non-engagement, which is inconsistent with the findings of Ballard et al., 2000 who demonstrated that lower performance on activities of daily living was correlated with social withdrawal and “passive activities”.

The CMAI correlated with self-engagement indicating that participants who were rated by staff members as agitated were also observed by the research team as spending a lot of time engaged in self stimulating behaviors (e.g., wandering around the unit, vocalizing but to no one discernable, manipulating their hair, clothes, furniture, etc.). There is mixed support in the literature for the consistency between observational and informant based information for agitation. While Kolanowski and Litakor (2006) found a weak relationship between informant CMAI data and observational agitation data in a sample of nursing home residents with advanced dementia, other research has demonstrated good concordance between observational measures of agitation and the CMAI (Cohen-Mansfield & Libin, 2004). Some research has suggested that decreased social

engagement is observed in those individuals who are rated as aggressive by their caregivers (Chen et al., 2000). However, in the current study the CMAI was not a strong predictor of any of the other levels of social engagement (constructive, passive, or non-engagement). Similarly, there has been mixed results in the literature to support behavioral disturbances (e.g., agitation) as a significant predictor of social engagement within institutional settings (e.g., Ballard et al., 2000).

In the current study restraint use was correlated negatively with constructive engagement and positively with self-engagement. Restraint use also had a very high correlation with the BADLS suggesting that the participants with greater dependency in their activities of daily living were more likely to be using a physical restraint. The connection between restraint use and dependency has been established in the literature (Bredthauer, et al., 2005; Castle & Engberg, 2009; Evans et al., 2003; Hamers et al., 2004; Karlsson et al., 1997). Interestingly, the CMAI was not highly correlated with restraint use in this study. This finding was somewhat surprising given that the majority of the individuals in this study had been admitted to the facility because of behavioral disturbances related to a diagnosis of dementia. It would appear that, at least in this study, restraints were not applied to control agitated or aggressive behavior but to compensate for functional deficits such as reduced mobility and to prevent falls.

Physical restraint use in this sample was high (42%) considering recent reports of prevalence rates in Canada (e.g., 31% in Feng et al., 2009 and 16% in Milke et al., 2008). In the current sample, restraint use was only noted if the

restraint was applied during the 15 minute observation of social engagement. It was not taken into consideration if a restraint had been applied during any other time throughout the entire data collection period (e.g., at night) so it is possible that restraint use reported in the current study represents an underestimate.

Restraint use was also consistent across the three shifts unlike what has been reported in earlier findings (e.g., Bourbonniere et al., 2003) where restraint use was more common on the weekends when staffing levels were lower. When the restraint data from all three shifts was combined, the most commonly used restraint was the Broda Chair (38%) which has a belt that holds the individual in the chair. The belt runs between the legs and over the thighs and is then fastened at the back of the chair. The second most frequently used physical restraint was a front fastening lap belt on a wheelchair (32%) which the participant could not disengage due to their degree of cognitive impairment.

The reason why a participant was in a physical restraint was not measured. The reason this variable was not included in the current study was because a review of the participants health record indicated that this information was often not available, outdated, or ambiguous and difficult to interpret (i.e., “to reduce injury to self or others” could mean the individual was at risk to fall or aggressive towards others, or both). Instead, the focus was the relationship between restraint use and social engagement. In other words, what are the social consequences of being physically restrained? How does the physical restraint influence one’s ability or opportunity to socialize? For obvious reasons, individuals in a physical restraint may have reduced mobility. They are less able to physically move about

the space thereby decreasing their opportunity to seek out others in their environment. In addition, it is plausible that when an individual is physically restrained they may be intentionally avoided by co-residents and staff because they are perceived as less able to engage in a meaningful interaction. Therefore the current study attempted to determine if physical restraint use contributed to the prediction of social engagement after controlling for ADL dependency and behavioral disturbance.

*Predicting constructive engagement.*

After controlling for functional dependency (i.e., BADLS), neither behavioral disturbances nor restraint use was a significant predictor of constructive engagement. On its own, functional dependency accounted for 25% of the variability in constructive engagement. This finding is in keeping with Kitwood's theory of personhood and related research literature suggesting that individuals with dementia who exhibit the mildest functional deficits engage in the most constructive social interactions (Chen et al., 2000; Chung, 2004; Kolanowski et al., 2006; Kolanowski et al., 2009; Lemke & Moos, 1989; Potkins et al., 2003; Zimmerman et al., 2003.) The BADLS taps into several domains associated with activities of daily living including personal hygiene, mobility, communication, orientation, and recreational activities. From a practical perspective, the BADLS may serve as a reasonable measure of an individual's potential to benefit from certain types of psycho-social interventions. For example, a low score on the BADLS would indicate the individual is more independent in their ADL functioning. As such, a psycho-social interventions and

activities that challenge and maintain those existing abilities would be appropriate. Examples of these interventions may include multi step activities or projects that encourage constructive social engagement between members of a group. For individuals with higher scores on the BADLS appropriate interventions might include social or functional activities introduced at a slower rate, one step at a time, with few cognitive demands.

*Predicting passive engagement.*

As stated earlier, passive engagement was observed rarely in this sample. And the difference between the amount of passive engagement observed in this sample and others cited in the literature may have been a consequence of how passive engagement was defined. Scores on this variable were so attenuated it was not surprising that it did not correlate well with the independent variables. As such, when entered into the regression analysis, the overall model was not significant.

*Predicting self-engagement.*

The data from the current study suggest participants spent a great deal of their time self-engaged. Functional dependency, behavioral disturbance and restraint use uniquely and jointly predicted self-engagement in this sample. Using a hierarchical regression model where the BADLS was entered first, followed by the CMAI data, and finally restraint use, each contributed a small but significant amount to the model. Overall, the model accounted for 24% of the variability in self-engagement. This finding suggests that each of these variables (functional dependency, overall frequency of behavioral disturbance, and restraint use) are

important factors related to self-engagement. In other words, individuals who spend most of their time self-engaged (e.g., wandering, rocking, or fidgeting) are also the individuals who are most likely physically restrained, displaying frequent behavioral disturbances, and requiring the most assistance with their activities of daily living. While it has been well established that individual variables such as cognitive impairment and functional dependency are related to a reduction in meaningful social engagement, this study adds to the existing research by highlighting the role of physical restraints.

#### *Predicting non-engagement*

As stated earlier, functional dependency was not correlated with non-engagement. Not surprisingly then, when non-engagement was entered into the regression model with behavioral disturbances and restraint use, the BADLS failed to add to the prediction of non-engagement. However, the overall model was significant suggesting functional dependency, behavioral disturbances, and restraint use jointly predicted non-engagement. This was an unexpected finding because on its own, restraint use, like functional dependency, was not significantly related to non-engagement. It appears that the relationship between the functional dependency variable and the restraint use variable influenced the relation between the restraint variable and non-engagement. In effect, the functional dependency variable suppressed the error variance in the restraint variable and thus acted to enhance the relation between the restraint use variable and non-engagement. This finding builds on the work of previous studies (e.g., Castle 2006 and Folmar & Wilson, 1989) and suggests that restraint use is a

salient predictor of non-engagement only when functional dependency is included in the model.

### **Limitations.**

Some limitations of the study should be noted. Although there was an attempt to control for psychotropic medication use by screening out any potential participants who were not receiving psychotropic medications, the type of psychotropic and dosage was not controlled for in the study design. The inclusion of these variables may have highlighted a potential relationship between medication use and social engagement. Although previous studies have not successfully demonstrated a significant relationship between psychotropic medication use and social engagement in nursing home residents (e.g., Kolanowski et al., 2009), given the demographic specifics of the current sample (i.e., psychiatric inpatients), the specific type and dosage of psychotropic medications may have an important impact on social engagement.

The use of direct behavioral observations was considered a key process in obtaining a valid description of social engagement in this sample. However, the use of direct observations as a method of data collection has drawbacks. The length of each observation, 15 minutes, captured a relatively short period of time in an 8 hour shift. Thus, the extent to which these 15 minute observation periods were able to measure social engagement in this sample might be questionable. Longer observations have been employed in similar studies (e.g., Bowie & Mountain, 1993; Van Haitsma et al., 1997) which yielded similar results as the current study. Using direct behavioral observations is time intensive and

expensive. The amount of resources required to conduct a study using direct observations can impact the study's potential for replication. Questionnaires that are designed to assess the same construct but completed by caregivers is an attractive alternative to behavioral observations (e.g., Castle 2006). However, observations provide rich data on patterns of behavior that might not be caught using proxy assessments (Kolanowski & Litaker, 2006; McKee et al., 2002; Vanhaisma et al., 1997).

The assessment of cognitive impairment in the current sample proved to be problematic. Cognitive impairment is the cardinal symptom that determines dementia severity. However, the Mini Mental State Exam (MMSE) proved to be too difficult for several of the participants to complete. The floor effects of the MMSE likely contributed to the poor distributional properties of the data. Perhaps the use of a different assessment tool that was designed specifically for use in individuals with severe cognitive impairments such as the Severe Impairment Battery (SIB; Saxton, McGonigle-Gibson, Swihart, Miller & Boller, 1990) would have better represented the cognitive impairment variable. The use of cognitive impairment in the analyses of the current study would have allowed for more meaningful interpretation of the results when comparing it to similar studies.

Generalizability of the results is limited because the sample represents a specific population; individuals with dementia being treated in an in-patient psychiatric facility. Studies exploring social engagement in individuals with dementia most commonly use samples drawn from nursing homes. This makes sense since nursing homes (or their equivalent) are where the vast majority of

individuals with moderate to severe dementia are cared for outside of their own home. Individuals with dementia who are being cared for in nursing homes versus psychiatric facilities may differ for a number of reasons (e.g., severity or frequency of behavioral disturbances and psychotropic medications use). Also, psychiatric in-patient facilities may have different organizational factors that contribute to resident outcomes. For example staffing levels, staffing mix, philosophy of care including policies and procedures regarding restraint use, all could potentially contribute to differences between samples drawn from nursing homes and psychiatric facilities. Although social engagement levels were similar in the current sample to those reported in some nursing home samples, (e.g., Armstrong-Esther et al., 1994; Mountain & Bowie, 1993; VanHaitsma et al., 1997) there were a few studies had very different findings with respect to social engagement levels (e.g., Kolanowski et al., 2009; Fritsch et al., 2009). Also, restraint use was high in the current study compared to the prevalence rates reported nationally and internationally (Feng et al., 2009; Milke et al., 2008).

### **Conclusion.**

In summary, the data indicate that the participants in this study spent most of the time doing nothing at all or engaged in self stimulating behavior. The participants were observed to be spending only 12% of their time constructively engaged (e.g., socializing with others or engaged in staff initiated activities). Although much of the self-engagement behavior may be classified as agitation, very little overt aggression was observed. Verbal aggression was documented only 6 times over the course of 213 fifteen minute observation periods and

physical aggression was documented only twice. None of the four types of engagement differed when compared across the three nursing shifts (i.e., day, evening, and weekend). This was an unexpected finding since staffing mix and staff to patient ratios vary across the shifts in most hospital settings (Bourbonniere et al., 2003). Physical restraints were used during 42% of the observations. Physical restraint use uniquely predicted self-engagement. Physical restraint use also predicted self-engagement jointly with ADL dependency and behavioral disturbances. Although not uniquely related to non-engagement, restraint use predicted non-engagement when combined with functional dependency. The use of physical restraints was not a significant predictor of constructive or passive engagement. The only significant predictor of constructive engagement was functional dependency whereby participants who were rated by staff as being the most independent were also observed by the research team to be spending the most time constructively engaged.

On a microcosmic level, these findings are in keeping with Kitwood's theory of personhood in dementia. Kitwood argued that social exclusion or depersonalization can occur at multiple levels for individuals with dementia. Social exclusion can start the moment the symptoms begin to emerge and continue throughout the course of the illness into the late stages when the individual is institutionalized. Kitwood pointed out that use of the medical model would only amplify the depersonalization because of the medical model's reliance on certain methods (i.e., chemical and physical restraint use) to treat individuals with dementia. Physical restraint use in the current study serves as an example of

yet another route in which social exclusion can occur in dementia. Finally, the results from the current study support Kitwood's and others (i.e., Bruce, 2004) suggestion that individuals with the greatest care needs will receive the least amount of positive social interactions in an institutional environment.

#### **Implications for clinical practice and future research.**

The results of this study only begin to describe the relationship between social engagement and physical restraint use. While restraints have been linked with a number of negative physical health outcomes (see Capezuti et al., 2008; Castle & Engberg, 2009; Evans et al., 2003; Luo et al., 2011) the relationship between restraint use and social or psychological outcomes in this population has not been well established. The results of the current study suggest that restraints contribute to self-engagement and non-engagement in individuals with dementia. This study did not explore if the reason why a restraint was used was related to social engagement. It is possible the relationship between restraint use and social engagement is partially dependent on why the restraint was applied in the first place. This constitutes an area for further research.

The examination of the social engagement in samples of age matched individuals both with and without a diagnosis of dementia warrants further investigation. Although it has been established that very little constructive social engagement occurs among individuals with dementia who reside in nursing homes or psychiatric facilities, little is known about how much social engagement occurs in healthy community dwelling seniors. Furthermore, little is known about

how much social engagement occurs in individuals with dementia who continue to live in their own homes.

There is a growing body of research that has been working toward determining which types of psycho-social interventions improve the well being of individuals with dementia (e.g., Finnema et al., 2000; Fritsch et al., 2009; Forbes, 1998; Kolanowski et al., 2005; Lai et al., 2003; O'Connor, et al. 2009; Richeson, 2003). To extend the work that has been done in this area, researchers and clinicians must take into account that individuals who are in physical restraints are at increased risk of being socially isolated.

## References

- AD2000 Collaborative Group. (2004). Long-term donepezil treatment in 565 patients with Alzheimer's disease (AD2000): Randomized double-blind trial. *The Lancet*, *363*, 2105-2115.
- Adunsky, A., Fleissig, Y., Levenkrohn, S., Arad, M., & Noy, S. (2002). Clock drawing task, Mini-Mental State Examination and cognitive-functional independence measure: Relation to functional outcome of stroke patients. *Archives of Gerontology and Geriatrics*, *35*, 153-160.
- Agüero-Torres, H., Strauss, E., Viitanen, M., Winblad, B., & Fratiglioni, L. (2001). Institutionalization in the elderly: The role of chronic diseases and dementia. Cross-sectional and longitudinal data from a population-based study. *Journal of Clinical Epidemiology*, *54*, 795-801.
- Albert, M. S. (2011). Changes in cognition. *Neurobiology of Aging*, *32*, S58-S63.
- Algase, D., Beck, C., Kolanowski, A., Whall, A., & Berent, S. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease*, *11*(6), 10-19.
- Alzheimer Society of Canada. (2010). *Rising tide: the impact of dementia on Canadian Society*. Retrieved from [http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/~/\\_media/Files/national/Advocacy/ASC\\_Rising%20Tide\\_Full%20Report\\_Eng.ashx](http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/~/_media/Files/national/Advocacy/ASC_Rising%20Tide_Full%20Report_Eng.ashx)
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4<sup>th</sup> ed., text revised)*. Washington, DC.

- Armstrong-Esther, C. A., Browne, K. D., & McAfee, J. G. (1994). Elderly patients: Still clean and sitting quietly. *Journal of Advanced Nursing, 19*, 264-271.
- Ballard C., Khan Z., Clack H., & Corbett A. (2011). Nonpharmacological treatment of Alzheimer disease. *Canadian Journal of Psychiatry, 56(10)*, 589-595.
- Ballard C., Khan Z., & Corbett A. (2011). Treatment of Dementia with Lewy Bodies and Parkinson's Disease dementia. *Drugs and Aging, 28(10)*, 769-777.
- Ballard, C., & O'Brien, J. (1999). Treating behavioral and psychological signs in Alzheimer's disease: The evidence for current pharmacological treatments is not strong. *British Medical Journal, 319*, 138-139.
- Ballard, C., O'Brien, J., James, I., Mynt, P., Lana, M., Potkins, D., et al. (2001). Quality of life for people with dementia living in residential and nursing home care: The impact of performance on activities of daily living, behavioral and psychological symptoms, language skills, and psychotropic drugs. *International Psychogeriatric Association, 13(1)*, 93-106.
- Ballard, C., O'Brien, J., James, L., & Swan, A. (2001). *Dementia: Management of behavioural and psychological symptoms*. New York: Oxford University Press.

- Barbarotto, R., Cerri, M., Acerbi, C., Molinari, S., & Capitani, E. (2000). Is SIB or BNP better than MMSE in discriminating the cognitive performance of severely impaired elderly patients? *Archives of Clinical Neuropsychology*, *15(1)*, 21-29.
- Barry, T. T., Brannon, D., & Mor, V. (2005). Nurse aide empowerment strategies and staff stability: effects on nursing home resident outcomes. *Gerontologist*, *45(3)*, 309-317.
- Beck, C., Rossby, L., & Baldwin, B. (1991). Correlates of disruptive behavior in cognitively impaired elderly nursing home residents. *Archives of Psychiatric Nursing*, *5(5)*, 281-291.
- Bekris, L. M., Yu, C., Bird, T. D., & Tsuang, D. W. (2010). Genetics of Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology*, *23(4)* 213-227.
- Bender, M. (2003). Explorations in dementia: Theoretical and research studies into the experience of remediable and enduring cognitive losses. London: Jessica Kingsley Publishers.
- Bennett, K. M. (2002). Low level social engagement as a precursor of mortality among people in later life. *Age and Ageing*, *31*, 165-168.
- Bianchetti, A., & Trabucchi, M. (2001). Clinical aspects of Alzheimer's disease *Aging-Clinical & Experimental Research*, *13(3)*, 221-30.
- Black, W., & Almeida, O. P. (2004). A systematic review of the association between the behavioral and psychological symptoms of dementia and burden of care. *International Psychogeriatrics*, *16(3)*, 295-315.

- Bloom, B., Pouvourvill, N., & Straus, W. L. (2003). Cost of illness of Alzheimer's disease: How useful are current estimates? *Gerontologist, 43*, 158-163.
- Bondi, M. W., Salmon, D. P., & Kaszniak, A. W. (2009). The neuropsychology of dementia. In Grant, I., & Adams, K. M. (Eds.), *Neuropsychological assessment of neuropsychiatric and neuromedical disorders, third edition*. New York: Oxford University Press.
- Bourgeois, M. S., Kijkstra, K., Burgio, L. D., & Allen, R. S. (2004). Communication skills training for nursing aides of residents with dementia: The impact of measuring performance. *Clinical Gerontologist, Vol. 27(1/2)*, 119-138.
- Bourbonniere, M., Strumpf, N. E., Evans, L. K., & Maislin, G. (2003). Organizational characteristics and restraint use for hospitalized nursing home residents. *Journal of the American Geriatrics Society, 51*, 1079-1084.
- Bowie, P., & Mountain, G. (1993). Using direct observation to record the behavior of long-stay patients with dementia. *International Journal of Geriatric Psychiatry, 8*, 857-864.
- Brack, H., & Brack, E. (1991). Neuropathological staging of Alzheimer-related changes. *Acta Neuropathologica, 82*, 239-259.
- Brandt, J. (2009). Huntington's Disease. In Grant, I., & Adams, K. M. (Eds.), *Neuropsychological assessment of neuropsychiatric and neuromedical disorders, third edition*. New York: Oxford University Press.

- Bravo, G., & Herbert, R. (1997). Age- and education-specific reference values for the Mini-Mental and Modified Mini-Mental State Examinations derived from a non-demented elderly population. *International Journal of Geriatric Psychiatry, 12*, 1008-1018.
- Bredthauer, D., Becker, C., Eichner, B., Koczy, P., & Nikolaus, T. H. (2005). Factors relating to the use of physical restraints in psychogeriatric care: A paradigm for elder abuse. *Zeitschrift für Gerontologie und Geriatrie, 38(1)*, 10-18.
- Breitner, J. C. S., Wys, B., Anthony, J., Welsh-Bohmer, K., Stefens, D., Norton, M., et al. (1999). APOE E4 count predicts age when prevalence of AD increases, then declines. The Cache County Study. *Neurology, 53*, 321-331.
- Brooker, D., Foster, N., Banner, A., Payne, M. & Jackson, L. (1998). The efficacy of dementia care mapping as an audit tool: Report of a 3-year British MHS evaluation. *Ageing and Mental Health 2*, 60-70.
- Bruce, E. (2004). Social exclusion (and inclusion) in care homes. In A. Innes, C. Archibald & C. Murphy (Eds.), *Dementia and social inclusion* (pp. 123-136). London, UK: Jessica Kingsley Publishers.
- Brun, A., Englund, B., Gustafson, L., Passant, U., Mann, D., Neary, D., & Snowden, J. (1994). Clinical and neuropathological criteria for frontotemporal dementia. *Journal of Neurology, Neurosurgery, and Psychiatry, 57*, 416-418.

- Buber, M. (1937). *I and Thou [Ich und Du]* (trans. R. G. Smith, 2004). London: Continuum.
- Bucks, R. S., Ashworth, D. L., Wilcock, G. K. & Siegried, K. (1996). Assessment of activities of daily living in dementia: Development of the Bristol Activities of Daily Living Scale. *Age and Ageing*, 25, 113-120.
- Burgio, L. D. (1996). Interventions for the behavioral complications of Alzheimer's disease: Behavioral approaches. *International Psychogeriatrics*, 8(Suppl. 1), 45-52.
- Burton, L. C., German, P. S., Rovner, B. W., & Brant L. J. (1992). Physical restraint use and cognitive decline among nursing home residents. *Journal of the American Geriatrics Society*, 40(8), 811-816.
- Byrne, L. M., Wilson, P. M., Bucks, R. S., Hughes, A. O., & Wilcock, G. K. (1999). The sensitivity to change over time of the Bristol Activities of Daily Living Scale in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 15, 656-661.
- Capezuti, E., Brush, B. L., Won, R. M., Wagner, L. M., & Lawson, W. T. (2008). Least restrictive or least understood? Waist restraints, provider practices, and risk of harm. *Journal of Aging & Social Policy*, 20(3), 305-322.
- Caselli, R. J., & Tariot, P. N. (2010). *Alzheimer's disease and its variants: A diagnostic and therapeutic guide*. Oxford: Oxford University Press.
- Castle, N. G. (2000). Differences in nursing homes with increasing and decreasing use of physical restraints. *Medical Care*, 12, 1154-1163.

- Castle, N. G. (2002). Nursing homes with persistent deficiency citations for physical restraint use. *Medical Care, 49(10)*, 868-878.
- Castle, N. G. (2006). Mental health outcomes and physical restraint use in nursing homes. *Administration and Policy in Mental Health, 33*, 696-704.
- Castle, N. G., & Engberg, J. (2009). The health consequences of using physical restraints in nursing homes. *Medical Care, 47(11)*, 1164-1173.
- Castle, N. G., Fogel, B., & Mor, V. (1997). Risk factors for physical restraint use in nursing homes: Pre- and post-implementation of the Nursing Home Reform Act. *The Gerontologist, 37(6)*, 737-747.
- Chang-Quan, H., Hui, W., Chao-Min, W., Zheng-Rong, W., Jun-Wen, G., Yong-Hong, L., ... Qing-Xiu, L. (2011). The association of antihypertensive medication use with risk of cognitive decline and dementia: A meta-analysis of longitudinal studies. *International Journal of Clinical Practice, 65(12)*, 1295-305.
- Chen, Y., Ryden, M. B., Feldt, K., & Savik, K. (2000). The relationship between social interaction and characteristics of aggressive, cognitively impaired nursing home residents. *American Journal of Alzheimer's Disease, 15(1)*, 10-17.
- Chenoweth, L., Jeon, Y., Merlyn, T., & Brodaty, H. (2010). A systematic review of what factors attract and retain nurses in aged and dementia care. *Journal of Clinical Nursing, 19(1-2)*, 156-67.

- Cheung, G., & Stapelberg, J. (2011). Quetiapine for the treatment of behavioural and psychological symptoms of dementia (BPSD): a meta-analysis of randomised placebo-controlled trials. *New Zealand Medical Journal*, *124(1336)*, 39-50.
- Chien, W. (2000). Use of physical restraints on hospitalized psychogeriatric patients. *Journal of Psychosocial Nursing*, *38(2)*, 13-20.
- Chou, K. R., LaMontagne, L. L., & Hepworth, J. T. (1999). Burden experienced by caregivers of relatives with dementia in Taiwan. *Nursing Research*, *48(4)*, 206-14.
- Chui, H. C. (2007). Subcortical ischemic vascular dementia. *Neurologic Clinics*, *25*, 717-740.
- Chung, J. C. C. (2004). Activity participation and well-being of people with dementia in long-term care settings. *Occupational Therapy Journal of Research*, *24(1)*, 22-31.
- Clark, C. M., Sheppard, L., Fillenbaum, G. G., Glasako, D., Morris, J. C., Koss, E., Mohs, R., Heymann, A., & the Cerad Investigators. (1999). Variability in annual Mini-Mental State Examination score in patients with probable Alzheimer disease. *Archives of Neurology*, *56*, 857-862.
- Clegg, J. A. (1993). Putting people first: A social constructionist approach to learning disability. *British Journal of Clinical Psychology*, *32*, 389-406.
- Cohen-Mansfield, J., & Billig, N. (1986). Agitated behaviors in the elderly: A conceptual review. *Journal of the American Geriatric Society*, *34*, 711-721.

- Cohen-Mansfield, J., & Libin, A. (2004). Assessment of agitation in elderly patients with dementia: Correlations between informant rating and direct observation. *International Journal of Geriatric Psychiatry, 19*(9), 881-891.
- Cohen-Mansfield, J., Marx, M. S., & Rosenthal, A. S. (1989). A description of agitation in a nursing home. *Journal of Gerontology: Medical Sciences, 44*(3), M77-M84.
- Cohen-Mansfield, J., & Mintzer, J. E. (2005). Time for change: The role of nonpharmacological interventions in treating behavior problems in nursing home residents with dementia. *Alzheimer Disease and Associated Disorders, 19*(1), 37-40.
- Conn, D. & Thorpe, L. (2007). Assessment of behavioural and psychological symptoms associated with dementia. *Canadian Journal of Neurological Sciences, 34 Suppl 1*, S67-71.
- Connell, C. M., Janevic, M. R., & Gallant, M. P. (2001). The costs of caring: Impact of dementia on family caregivers. *Journal of Geriatric Psychiatry & Neurology, 14*(4), 179-87.
- Cooper, C., Balamurali, T., & Livingston, G. (2007). A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. *International Psychogeriatrics, 19*(2), 175-95.

- Croezen, S., Haveman-Nies, A., Alvarado, v. J., Van't Veer & De Groot, C. (2009). Characterization of different groups of elderly according to social engagement activity patterns. *The Journal of Nutrition, Health & Aging*, 13(9), 776-781.
- Crum, R.M., Anthony, J.C., Bassett, S.S., & Folstein, M.F. (1993). Population-based norms for the Mini-Mental State Examination by age and education level. *Journal of the American Medical Association*, 269, 2386-2391.
- Cummings, J. L. (1990). Introduction. In J. L. Cummings (Ed.), *Subcortical dementia* (pp.87-107). New York: Oxford University Press.
- Cummings, J. L. (2003). *The neuropsychiatry of Alzheimer's Disease and related dementias* London: Muartin Dunitz Ltd, Taylor and Francis Group.
- Cummings, J. L., & Benson, D. F. (1992). *Dementia: A clinical approach*. Boston: Butterworth-Heinemann.
- Cummings J. L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D. A., Gornbein, J. (1994). The Neuropsychiatric Inventory: Comprehensive assessment of psychopathology in dementia. *Neurology* 44, 2308–2314.
- Cummings, J. L., & Mega, M. S. (2003). *Neuropsychiatry & behavioral neuroscience*. New York: Oxford University Press.
- Darvesh, S., & Freedman, M. (1996). Subcortical dementia: A neurobehavioral approach. *Brain and Cognition*, 31, 230-249.
- De Jonghe, J., Wetzels, R., Mulders, A., Zuidema, S., & Koopmans, R. (2009). Validity of the Severe Impairment Battery Short Version. *Journal of Neurological Neurosurgery Psychiatry*, 80, 954-959.

- DePoy, E. (2002). Will the real definition of disability please stand up. *Psychological Process, 15*, 50-53.
- DeSantis, J., Engberg, S., & Rogers, J. (1997). Geropsychiatric restraint use. *Journal of the American Geriatrics Society, 45*, 1515-1518.
- Draper, B., et al. (2000). Case-controlled study of nursing home residents referred for treatment of vocally disruptive behavior. *International Psychogeriatrics, 12*(3), 333-344.
- Dupuis, S. L., Wiersma, E., & Loiselle, L. (2012). Pathologizing behavior: Meanings of behaviors in dementia care. *Journal of Aging Studies, 26*, 163-172. doi: 10.1016/j.jaging.2011.12.001
- Edvardsson, D., Sandman, P., & Rasmussen, B. (2010). Forecasting the ward climate: A study from a dementia care unit. *Journal of Clinical Nursing, 21*, 1136-1144. doi: 10.1111/j.1365-2702.2011.03720.x
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., et al. (2000). Treatment and management of challenging behaviours in residential setting. *Journal of Applied Research in Intellectual Disabilities, 13*, 197-215.
- Espino, D.V., Lichtenstein, M. J., Palmer, R. F., & Hazuda, H. P. (2004). Evaluation of the Mini-Mental State Examination's internal consistence in a community-based sample of Mexian-American and European-American elders: Results from the San Antonio longitudinal study of aging. *Journal of the American Geriatrics Society, 52*, 822-827.

- Evans, L. K., & Strumpf, N. E. (1989). Tying down the elderly: A review of the literature on physical restraint. *Journal of the American Geriatrics Society*, 37, 65-74.
- Evans, L. K., Wood, J., & Lambert, L. (2003). Patient injury and physical restraint devices: A systematic review. *Journal of Advanced Nursing*, 41(3), 274-282.
- Exum, M. E., Phelps, B. J., Nabers K. E., & Osborne, J. G. (1993). Sundown syndrome: Is it reflected in the use of PRN medications for nursing home residents? *The Gerontologist*, 33(6), 756-761.
- Feng, Z., Hirdes, J. P., Smith, T. F., Finne-Soveri, H., Chi, I., Du Pasquier, J-N., et al., (2009). Use of physical restraints and antipsychotic medications in nursing homes: A cross-national study. *International Journal of Geriatric Psychiatry*. 24, 1110-1118.
- Ferris, S. H., Mackell, J. A., Mohs, R., Schneider, L. S., Galasko, D., Whitehouse P. J., et al. (1997). A multicenter evaluation of new treatment efficacy instruments for Alzheimer's disease clinical trials: Overview and general results. *Alzheimer's Disease and Associated Disorders*, 11(2), 1-12.
- Finkel S. I., Lyons J. S., Anderson R. L. (1992). Reliability and validity of the Cohen-Mansfield Agitation Inventory in institutionalised elderly. *International Journal of Geriatric Psychiatry*, 7, 487-490.

- Finnema, E., Dröes, R., Ribbe, M., & Van Tilburg, W. (2000). The effects of emotion oriented approaches in the care for persons suffering from dementia: A review of the literature. *International Journal of Geriatric Psychiatry, 15*, 141-161.
- Fisher, J. E., & Swingen, D. N. (1997). Contextual factors in the assessment and management of aggression in dementia patients. *Behavior Therapy, 171-183*.
- Folmer, S., & Wilson, H. (1989). Social behavior and physical restraints. *The Gerontologist, 29*, 650-653.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-Mental State." A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198.
- Forbes, D. (1998). Strategies for managing behavioral symptomatology associated with dementia of the Alzheimer Type: A systematic overview. *Canadian Journal of Nursing Research, 30(2)*, 67-86.
- Forman, M. D. (1987). Reliability and validity of mental status questionnaires in elderly hospitalized patients. *Nursing Research, 36*, 216-220.
- Fortinsky, R. H., Kercher, K. & Burant, C. J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging & Mental Health, 6(2)*, 153-160.

- Foster, J. R., Selan, S., Welkowitz, J., Boksay, I., & Seeland, I. (1988).  
Psychiatric assessment in medical long-term care facilities: Reliability of  
commonly used rating scales. *International Journal of Geriatric  
Psychiatry*, 3, 229-233.
- Fovel, J. T., Lash, P. S., Barron, D. A., & Roberts, M. S. (1989). A survey of self-  
restraint, self-injury, and other maladaptive behaviors in an  
institutionalized retarded population. *Research in Developmental  
Disabilities*. 10(4), 377-82.
- Franco, K. N., & Messinger-Rapport, B. (2006). Pharmacological Treatment of  
Neuropsychiatric Symptoms of Dementia: A Review of the Evidence.  
*Journal of the American Medical Directors Association*, 7(3), 201-202.
- Franco-Marina F., García-González J., Wagner-Echeagaray F., Gallo J., Ugalde  
O., Sánchez-García S., et al. (2010). The Mini-mental State Examination  
revisited: Ceiling and floor effects after score adjustment for educational  
level in an aging Mexican population. *International Psychogeriatrics*,  
22(1), 72-81.
- Fritsch , T., Kwak , J., Grant , S., Lang , J., Montgomery , R. R., & Basting, A. D.  
(2009). Impact of TimeSlips, a creative expression intervention program,  
on nursing home residents with dementia and their caregivers. *The  
Gerontologist*, 49(1), 117-127.
- Gauthier, S., Cummings, Ballard, C., Brodaty, H., Grossberg, G., Robert, P., &  
Lyketsos, C. (2010). Management of behavioral problems in Alzheimer's  
Disease. *International Psychogeriatrics*, 22(3), 346-372.

- Gearing, M., Mirra, S., Sumi, S., Hansen, L., Hedreen, J., & Heyman, A. (1995). The Consortium to Establish a Registry for Alzheimer's Disease (CERAD) Part X: Neuropathology confirmation of the clinical diagnosis of Alzheimer's disease. *Neurology*, *45*, 461-446.
- Gill, C. J., Kewman, D. G., & Brannon, R. W. (2003). Transforming psychological practice and society: Policies that reflect the new paradigm. *American Psychologist*, *58*(4), 305-312.
- Glass, G. V., & Hopkins, K. D. (1996). *Statistical methods in education and psychology third edition*. Needham Heights, MA: Allyn & Bacon.
- Goetz, C. G., Emre, M., & Dubois, B. (2008). Parkinson's disease dementia: Definitions, guidelines, and research perspectives in diagnosis. *Annals of Neurology*. *64*(2), 81-92.
- Green, J. (2000). *Neuropsychological evaluation of the older adult: A clinician's guidebook*. San Diego: Academic Press.
- Gustafson, L. (1993). Clinical picture of frontal lobe degeneration of non-Alzheimer type. *Dementia*, *4*, 143-148.
- Hahn, H. (1996). Antidiscrimination laws and social research on disability: The minority group perspective. *Behavioural Sciences and the Law*, *14*, 41-59.
- Hamers, J.P.H., Gulpers, M. J. M. & Strik, W. (2004). Use of physical restraints with cognitively impaired nursing home residents. *Journal of Advanced Nursing*, *45*(3), 246-251.
- Hamers, J.P.H., & Huizing, A. R. (2005). Why do we use physical restraints in the elderly? *Zeitschrift fur Gerontologie und Geriatrie*, *38*(1), 19-25.

- Hantikainen, V. (1998). Physical restraint: A descriptive study in Swiss nursing homes. *Nursing Ethics*, *5*(4), 330-346.
- Heindel, W. C., Salmon, D. P., Shults, C. W., Walicke, P. A., & Butters, N. (1989). Neuropsychological evidence for multiple implicit memory systems: A comparison of Alzheimer's, Huntington's, and Parkinson's disease patients. *Journal of Neuroscience*, *9*(2), 582-587.
- Helkala E. L., Kivipelto, M., Hallikainen, M., Alhainen, K., Heinonen, H., Tuomilehto, J., Soininen, H., & Nissinen, A. (2002). Usefulness of repeated presentation of Mini-Mental State Examinations as a diagnostic procedure – a population-based study. *Acta Neurologica Scandinavica*, *106*, 341-346.
- Hill, N. L., Kolanowski, A., Kürüm, E. (2010). Agreeableness and activity engagement in nursing home residents with dementia. *Journal of Gerontological Nursing*, *36*(9), 45-52.
- Hjaltadottir, I., Hallberg, I. R., Ekwall, A. K., & Nyberg, P. (2011). Predicting mortality of residents at admission to nursing home: A longitudinal cohort study. *BMC Health Services Research*, *11*, 86-86.
- Hodges, J. R. (Ed.). (2007). *Frontotemporal dementia syndromes*. Cambridge: Cambridge University Press.
- Hopp, G. A., Dixon, R. A., Backman, I., & Gut, M. (1997). Stability of two measures of cognitive functioning in nondemented old-old adults. *Journal of Clinical Psychology*, *53*, 673-686.

- Howard, R., Ballard, C., O'Brien, J., & Burns, A. (2001). Guidelines for the management of agitation in dementia. *International Journal of Geriatric Psychiatry, 16*(7), 714-717.
- Hubbard, G., Cook, A., Tester, S., & Downs, M. (2002). Beyond words: Older people with dementia using and interpreting nonverbal behavior. *Journal of Aging Studies, 16*, 155-167.
- Huber, S., Shuttleworth, E., Paulson, G., Bellchambers, M., & Clapp, L. (1986). Cortical vs subcortical dementia: Neuropsychological differences. *Archives of Neurology, 43*, 392-394.
- Hughes, J. C. (2003). Quality of life in dementia: An ethical and philosophical perspective. *Expert Review on Pharmacoeconomics Outcomes Research, 3*(5), 525-534.
- Hughes, J. C., Louw, S. J., & Sabat, S. R. (2006). Seeing whole. In Hughes, J. C., Louw, S. J., & Sabat, S. R. (Eds.), *Dementia: Mind, meaning, and the person* (pp. 1-39). New York: Oxford University Press.
- Huizing, A., Hatners, J., Jonge, J., Candel, M., & Berger, M. (2007). Organizational determinants of the use of physical restraints: A multilevel approach. *Social Science & Medicine, 65*, 924-933.
- Iverson, G. L. (1998). Interpretation of Mini-Mental State Examination scores in community-dwelling elderly and geriatric neuropsychiatry patients. *International Journal of Geriatric Psychiatry, 12*, 661-666.

- Jefferson, A. L., Consentino, S. A., Ball, S. K., Bogdanoff, B., Kaplan, E., & Libon, D. J. (2002). Errors produced on the Mini-Mental State Examination and neuropsychological test performance in Alzheimer's disease, ischemic vascular dementia, and Parkinson's disease. *Journal of Neuropsychiatry and Clinical Neurosciences, 14*, 311-320.
- Jorm, A. F., Scott, R., Henderson, A. S., & Kay, D. W. (1988). Educational level differences on the Mini-Mental State. *Psychological Medicine, 18*, 727-788.
- Johansen, K. K., White, L. R., Sando, S. B., & Aasly, J. O. (2010). Biomarkers: Parkinson disease with dementia and dementia with Lewy bodies. *Parkinsonism and Related Disorders, 16(5)*, 307-315.
- Judge, K. S., Camp, C. J., & Orsulic-Jeras, S. (2000). Use of Montessori-based activities for clients with dementia in adult day care: Effects on engagement. *American Journal of Alzheimer's Disease, 15(1)*, 42-46.
- Keith A. Josephs, K. A., Hodges, J. R., Snowden, J. S., Mackenzie, I. R., Neumann, M., Mann, D. M., & Dickson, D. W. (2011). Neuropathological background of phenotypical variability in frontotemporal dementia. *Acta Neuropathologica, 122*, 137–153 DOI 10.1007/s00401-011-0839-6
- Kang, I. O., Lee, S., Kim, S. Y., & Park, C. Y. (2007). Economic cost of dementia patients according to the limitation of the activities of daily living in Korea. *International Journal of Geriatric Psychiatry, 22*, 675-681.

- Karlsson, S., Bucht, G., Eriksson, S., & Sandman, P. (1996). Physical restraints in geriatric care in Sweden: Prevalence and patient characteristics. *Journal of the American Geriatrics Society, 44(11)*, 1348-1354.
- Karlsson, S., Bucht, G., Eriksson, S., & Sandman, P. (2001). Factors relating to the use of physical restraints in geriatric care settings. *Journal of the American Geriatrics Society, 49*, 1722-1728.
- Karlsson, S., Bucht, G., Rasmussen, B. H., & Sandman, P. O. (2000). Restraint use in elder care: decision making among registered nurses. *Journal of Clinical Nursing, 9(6)*, 842-850.
- Karlsson, S., Nybert, L., & Sandman, P. O. (1997). The use of physical restraints in elder care in relation to fall risk. *Scandinavian Journal of Caring Science, 11*, 238-242.
- Kelley, M. F. (1997). Social interaction among people with dementia. *Journal of Gerontological Nursing, 23(4)*, 16-20.
- Kelly, F. (2010). Recognizing and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care. *Ageing and Society, 30*, 103-124.
- Kempler, D. (2005). *Neurocognitive Disorders in Aging*. Thousand Oaks, CA: Sage Publications Ltd.
- Kiely, D. K., Simon, S. E., Jones, R. N., & Morris, J. N. (2000). The protective effect of social engagement on mortality in long-term care. *Journal of the American Geriatrics Society, 48(11)*, 1367-1372.

- Kim, H., Kovner, C., Harrington, C., Greene, W., & Mezey, M. (2009). A panel data analysis of the relationships of nursing home staffing levels and standards to regulatory deficiencies. *Journals of Gerontology Series B: Psychological Sciences & Social Sciences, 64B(2)*, 269-78.
- Kinosian, B P., Stallard, E., Lee, J H., Woodbury, M A., Zbrozek, A S., & Glick, H A. (2000). Predicting 10-year care requirements for older people with suspected Alzheimer's disease. *Journal of the American Geriatrics Society, 48(6)*, 631-8.
- Kirkevold, Ø., & Engedal, K. (2004). A study into the use of restraints in nursing homes in Norway. *British Journal of Nursing, 13(15)*
- Kirkevold, Ø., & Engedal, K. (2004). Prevalence of patients subjected to constraint in Norwegian nursing homes. *Scandinavian Journal of Caring Science, 18*, 281-286.
- Kirkevold, Ø, Laake, K., & Engedal, K. (2003). Use of constraints and surveillance in Norwegian wards for the elderly. *International Journal of Geriatric Psychiatry, 18*, 491-497.
- Kitwood, T. (1996). The experience of dementia. *Aging and Mental Health, 1*, 13-22.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, England: Open University Press.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and wellbeing. *Ageing and Society, 12*, 269-287.

- Kolanowski, A., & Litaker, M. (2006). Social interaction, premorbid personality, and agitation in nursing home residents with dementia. *Archives of Psychiatric Nursing, 20*, 12-20.
- Kolanowski, A. M., Litaker, M., & Buettner, L. (2005). Efficacy of theory-based activities for behavioral symptoms of dementia. *Nursing Research, 54*(4), 219-228.
- Kolanowski, A. M., Litaker, M., Buettner, L., Moeller, J., & Costa, P. T. (2011). A randomized clinical trial of theory-based activities for the behavioral symptoms of dementia in nursing home residents. *Journal of the American Geriatric Society, 59*, 1032-1041. doi: 10.1111/j.1532-5415.2011.03449.x
- Kolanowski, A. M., Litaker, M., Buettner, L., & Yu, F. (2006). Factors that relate to activity engagement in nursing home residents. *American Journal of Alzheimer's disease and Other Dementias, 21*(1), 15-22.
- Kolanowski, A. Fick, D., Campbell, J., Litaker, M., & Boustani, M. (2009). A preliminary study of anticholinergic burden and relationship to a quality of life indicator, engagement in activities, in nursing home residents with dementia. *Journal of the American Medical Directors Association, 10*, 252-257.
- Kwasky, A., N., Harrison, B. E., & Wall, A. L. (2010). Quality of life and dementia: An integrated review of literature. *Alzheimer's Care Today, 11*(3), 186-195.

- Lai, C. K., Chi, I., & Kayser-Jones, J. (2004). A randomized controlled trial of a specific reminiscence approach to promote the well-being of nursing home residents with dementia. *International Psychogeriatrics*, *16*(1), 33-49.
- Lai C., Yeung J., Mok V., & Chi, I. (2009). Special care units for dementia individuals with behavioural problems. *Cochrane Database of Systematic Reviews* , *4*, 1-50. doi: 0.1002/14651858.CD006470
- Langa, K. M., Foster, N. L., & Larson, E. B. (2004). Mixed dementia: Emerging concepts and therapeutic implications. *Journal of the American Medical Association*, *292*, 2901-2908.
- Larner, A. J. (2012). *Dementia in clinical practice: A neurological perspective*. London: Springer-Verlag.
- Lawton, M. P., Van Haitsma, K., & Kapper, J. (1996). Observed affect in nursing home residents with Alzheimer's Disease. *Journal of Gerontology*, *51B*(1), P3-14.
- Lemke, S., & Moos, R. H. (1989). Personal and environmental determinants of activity involvement among elderly residents of congregate facilities. *Journal of Gerontology: Social Sciences*, *44*(4), S139-148.
- Lever, J. A., et al.(1994). Use of physical restraints and their relationship to medication use in patients in four different institutional settings. *Humane Medicine*, *10*(1), 17-26.
- Lin, L., Wu, S., Kao, C., Tzeng, Y., Watson, R., & Tang, S. (2008). Single ability among activities of daily living as a predictor of agitation. *Journal of Clinical Nursing*, *18*, 117-123.

- Lindesay, J. & Skeat, D. (1997). Gender and interactions between care staff and elderly nursing home residents with dementia. *International Journal of Geriatric Psychiatry, 12*, 344-348.
- Lindesay, J., Briggs, K., Lawes, M., MacDonald, A., & Herzberg, J. (1991). The Domus philosophy: A comparative evaluation of a new approach to residential care for the demented elderly. *International Journal of Geriatric Psychiatry, 6*, 727-736.
- Liukkonen, A., & Laitinen, P. (1994). Reasons for uses of physical restraint and alternatives to them in geriatric nursing: A questionnaire study among nursing staff. *Journal of Advanced Nursing, 19*, 1082-1087.
- Lopez, M. N., Charter, R. A., Mostafavi, B., Nibut, L. P., & Smith, W. E. (2005). Psychometric properties of the Folstein Min-Mental State Examination. *Assessment, 12*, 137-144.
- Luo, H., Lin, M., & Castle, N. (2011). Physical restraint use and falls in nursing homes: A comparison between residents with and without dementia. *American Journal of Alzheimer's Disease & Other Dementias, 26(1)*, 44-50.
- Luttenberger, K., Donath, C., Uter, W., & Graessel, E. (2012). Effects of multimodal nondrug therapy on dementia symptoms and need for care in nursing home residents with degenerative dementia: A randomized-controlled study with 6-month follow-up. *Journal of American Geriatric Society, 60*, 830-840. doi: 10.1111/j.1532-5415.2012.03938.x

- Magee, R., Hyatt, E. C., Hardin, S. B., Stramann, D., et al. (1994). Institutional policy: Use of restraints in extended care and nursing homes. *Journal of Gerontological Nursing, 19*(4), 31-39.
- Marcopulos, B. A., & McLain, C. A. (2003). Are our norms normal? A 4-year follow-up study of biracial sample of rural elders with low education. *The Clinical Neuropsychologist, 11*, 111-131.
- Marra, T. A., Pereira, D. S., Faria, C. D., Tirado, M. G., & Pereira, L. S. (2011). Influence of socio-demographic, clinical and functional factors on the severity of dementia. *Archives of Gerontology & Geriatrics, 53*(2), 210-215.
- Martinon-Torres, G., Fioravanti, M., & Grimley, E. J. (2004). Trazodone for agitation in dementia. *Cochrane Database of Systematic Reviews, (4)*: CD004990.
- Mathias, J. L., & Burke, J. (2009). Cognitive functioning in Alzheimer's and vascular dementia: A meta-analysis. *Neuropsychology, 23*(4), 411-423.
- Matthiesen, V., Lamb, K. V., McCann, J., Hollinger-Smith, L., & Walton, J. C. (1996). Hospital nurses' views about physical restraint use with older patients. *Journal of Gerontological Nursing, 22*, 8-16.
- Mauskopf, J., Racketta, J., & Sherrill, E. (2010). Alzheimer's disease: the strength of association of costs with different measures of disease severity. *Journal of Nutrition, Health & Aging, 14*(8), 655-663.

- Mayeux, R., Reitz, C., Brickman, A. M., Haan, M. N., Manly, J. J., Glymour, M. M. et al., (2011). Operationalizing diagnostic criteria for Alzheimer's disease and other age related cognitive impairment – Part 1. *Alzheimer's & Dementia* 7, 15–34.
- McAllister, C. L., & Silverman, M. A. (1999). Community formation and community roles among persons with Alzheimer's disease: A comparative study of experiences in a residential Alzheimer's facility and a traditional nursing home. *Qualitative Health Research*, 9(1), 65-85.
- McKee, K. J., Houston, D. M., & Barnes, S. (2002). Methods for assessing quality of life and well-being in frail older people. *Psychology and Health*, 17(6), 737-751.
- McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman B. T., Jack, C. R., Kawash, C. H.,... Phelps, C. H. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, 7, 263–269.
- McKeith, I., Galasko, D., Kosak, K., Perry, E., Dickson, D., Hansen, L., et al. (1996). Consensus guidelines for the clinical and pathologic diagnosis of dementia with Lewy bodies (DLB): Report of the consortium on DLB international workshop. *Neurology*, 47, 1113-1124.

- McPherson, S. & Cummings, J. L. (2009). Neuropsychological aspects of Parkinson's Disease and Parkinsonism. In Grant, I., & Adams, K. M. (Eds.), *Neuropsychological assessment of neuropsychiatric and neuromedical disorders, third edition*. New York: Oxford University Press.
- Merdes, A. R., Hansen, L. A., Jeste, D. V., Galasko, D., Hofstetter, C. R., et al. (2003). Influence of Alzheimer pathology on clinical diagnostic accuracy in dementia with Lewy bodies. *Neurology*, *30*, 1586-1590.
- Middleton, H., Keene, R. G., Johnson, C., Elkins, A. D., & Lee, A. E. (1999). Physical and pharmacological restraints in long-term care facilities. *Journal of Gerontological Nursing*, *25(7)*, 26-33.
- Miles, S. H., & Irvine, P. (1992). Deaths caused by physical restraints. *The Gerontologist*. *32(6)*, 762-766.
- Miller, R. J., Snowdon, J., & Vaughan, R. (2011). The use of the Cohen-Mansfield Agitation Inventory in the assessment of behavioral disorders in nursing homes. *Journal of the American Geriatrics Society*, *43(5)*, 546-549.
- Minnick, A. F., Mion, L. C., Johnson, M. E., Catrambone, C., & Leipzig, R. (2007). Prevalence and variation of physical restraint use in acute care settings in the US. *Journal of Nursing Scholarship*, *39(1)*, 30-37.

- Mion, L. C., Sandhu, S. K., Halim Khan, R., Ludwick, R., Claridge, J. A., Pile, J., et al. (2010). Effect of situational and clinical variables on the likelihood of physicians ordering physical restraints. *Journal of the American Geriatrics Society, 58*, 1279-1288.
- Mitrushina, M., & Salz, P. (1991). Utility of Mini-Mental State Examination in assessing cognition in the elderly. Paper presented to the International Neuropsychological Society, Cincinnati, OH.
- Möhler, R., Richter, T., Köpke, S., & Meyer, G. (2011). Interventions for preventing and reducing the use of physical restraints in long-term geriatric care. *Cochrane Database of Systematic Reviews, 2*, 1-32. doi: 10.1002/14651858.CD007546.pub2
- Molloy, D. W., Alemayehu, E., & Roberts, R. (1991). Reliability of a standardized Mini-Mental State Examination compared with the traditional Mini-Mental State Examination. *American Journal of Psychiatry, 148*, 102-105.
- Moore, K. D. (1999). Dissonance in the dining room: A study of social interaction in a special care unit. *Qualitative Health Research, 9(1)*, 133-155.
- Mor, V., Branco, K., Fleishman, J., Hawes, C., Phillips, C., Morris, J., & Fries, B. (1995). The structure of social engagement among nursing home residents. *Journal of Gerontology: Psychological Sciences, 50B(1)*, P1-8.
- Nagata, K., Saito, H., Ueno, T., Sato, M., Nakase, T., Maeda, T. et al., (2007). Clinical diagnosis of vascular dementia. *Journal of the Neurological Sciences 257*, 44-48.

- Neary, D., & Snowden. (1996). Fronto-temporal dementia: Nosology, neuropsychology, and neuropathology. *Brain and Cognition*, 31, 176-187.
- Nejtek, V. A., Hardy, S., Hall, J. R., & Winter, A. S. (2011). Characteristics and psychosocial predictors of psychiatric emergency center transport and length of stay in patients with dementia and Alzheimer's Disease: A preliminary report. *Journal of Psychiatric Practice*, 17(4), 251-257.
- Norbergh, K., Asplund, K., Rasmussen, B. H., Nordahl, G., & Sandman, P. O. (2001). How patients with dementia spend their time in a psycho-geriatric unit. *Scandinavian Journal of Caring Sciences*, 15, 215-221.
- Nursing Home Reform Act (1987). In the Omnibus Budget Reconciliation Act of 1987. P. L. 100-203. Subtitle C. 42 U.S.C. 1395i-39a)-(h)(Medicare); 139r (a) (h)(Medicaid).
- O'Connor, D. W., Ames, D., Gardner, B., & King., M. (2009). Psychosocial treatments of psychological symptoms in dementia: A systematic review of reports meeting quality standards. *International Psychogeriatrics*. 21(2), 241-51.
- Oremus, M., & Aguilar, S. C. (2011). A systematic review to assess the policy-making relevance of dementia cost-of-illness studies in US and Canada. *Pharmacoeconomics*, 29(2), 141-156.
- Orsulic-Jeras, S., Judge, K. S., & Camp, C. J. (2000). Montessori-based activities for long-term care residents with advanced dementia: Effects on engagement and affect. *The Gerontologist*, 40, 107-111.

- Penrod, J., Yu, F., Kolanowski, A., Fick, D. M., Loeb, S. J., & Hupcey, J. E. (2007). Reframing person-centered nursing care for persons with dementia. *Research and Theory for Nursing Practice: An International Journal, 21(1)*, 57-72.
- Perrin, T. (1997). Occupational need in severe dementia: A descriptive study. *Journal of Advanced Nursing, 25*, 934-941.
- Phillips, C. D., Spry, K. M., Sloane, P. D., & Hawes, C. (2000). Use of physical restraints and psychotropic medications in Alzheimer special care units in nursing homes. *American Journal of Public Health, 90(1)*, 92-96.
- Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18(2)*, 250-267.
- Post, S. (2006). Respectare: Moral respect for the lives of the deeply forgetful. In Hughes, J. C., Louw, S. J., & Sabat, S. R. (Eds.), *Dementia: Mind, meaning, and the person* (pp. 223-234). New York: Oxford University Press.
- Potkins, D., et al. (2003). Language impairment in dementia: Impact on symptoms and care needs in residential homes. *International Journal of Geriatric Psychiatry, 18*, 1002-1006.
- Powell, C., Mitchell-Pedersen, L., Fingerote, E., & Edmund, L. (1989). Freedom from restraint: Consequences of reducing physical restraints in the management of the elderly. *Canadian Medical Association Journal, 141*, 561-564.

- Rabinowitz, J., Davidson, M., De Deyn, P. P., Katz, I., Brodaty, H., & Cohen-Mansfield, J. (2005). Factor analysis of the Cohen-Mansfield Agitation Inventory in three large samples of nursing home patients with dementia and behavioral disturbance. *American Journal of Geriatric Psychiatry, 13(11)*, 991-998.
- Rascovsky, K., Salmon, D. P., Ho, G. J., Galasko, D., Peavy, G. M., Hansen, L. A., et al. (2002). Cognitive profiles differ in autopsy-confirmed fronto-temporal dementia and Alzheimer's disease. *Neurology, 58*, 1801-1808.
- Ray, W. A., Taylor, J. A., Lichtenstein, M. J., & Meador, K. G. (1992). The nursing home behavior problem scale. *Journal of Gerontology, 47(1)*, 6-16.
- Resnick, H. E., Fries, B. E., & Verbrugge, L. M. (1997). Windows to their world: The effect of sensory impairments on social engagement and activity time in nursing home residents. *Journals of Gerontology Series B-Psychological Sciences & Social Sciences, 52(3)*: S135-44.
- Retsas, A. P. (1998). Survey findings describing the use of physical restraints in nursing homes in Victoria, Australia. *International Journal of Nursing Studies, 35(3)*, 184-91.
- Richeson, N. E. (2003). Effects of animal-assisted therapy on agitated behaviors and social interactions of older adults with dementia. *American Journal of Alzheimer's Disease and Other Dementias, 18(6)*, 352-358.

- Robbins, L. J., Boyko, E., Lane, J., Cooper, D., & Jahnigen, D. W. (1987). Binding the elderly: A prospective study of the use of mechanical restraints in an acute care hospital. *Journal of the American Geriatrics Society, 35*, 290-296.
- Roberts, M. S., et al. (1998). Medication prescribing and administration in nursing homes. *Age & Ageing, 27(3)*, 385-392.
- Roberts, M. S., et al. (2001). Outcomes of a randomized controlled trial of clinical pharmacy intervention in 52 nursing homes. *Journal of Clinical Pharmacy, 51*, 257-265.
- Robinson, L., Hutchings, D., Dickinson, H.O., Corner, L., Beyer, F., Finch, T., et al. (2007). Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: a systematic review. *International Journal of Geriatric Psychiatry, 22*, 9-22.
- Rogers, C. R. (1961). *On becoming a person*. Boston, MA: Houghton Mifflin.
- Røsvik, J., Kirkevold, M., Engedal, K., Brooker, D., & Kirkevold, Ø. (2011). A model for using the VIPS framework for person-centred care for persons with dementia in nursing homes: A qualitative evaluative study. *International Journal of Older People Nursing, 6*, 227-236.
- Roumen, M. V., Kellar, T., McLean, M., Thompson S., & Peever, L. (2008). Multisensory stimulation for elderly with dementia: A 24-week single-blind randomized controlled pilot study. *American Journal of Alzheimer's Disease & Other Dementias, 23(4)*, 372-376.).

- Rubin, B. S., Dube, A. H., & Mitchell, E. K. (1993). Asphyxial deaths due to physical restraint. *Archives of Family Medicine, 2*, 405-408.
- Ryden, M. B. et al. (1999). Relationships between aggressive behavior in cognitively impaired nursing home residents and use of restraints, psychoactive drugs, and secured units. *Archives of Psychiatric Nursing, 8*(4), 170-178.
- Saddichha, S. & Pandey, V. (2008). Alzheimer's and non-Alzheimer's dementia: A critical review of pharmacological and nonpharmacological strategies. *American Journal of Alzheimer's Disease & Other Dementias, 23*(2), 150-161.
- Saxton, J., McGonigle-Gibson, K., Swihart, A., Miller, M. & Boller, F. (1990). Assessment of the severely impaired patient: Description and validation of a new neuropsychological test battery. *Psychological Assessment: Journal of Consulting and Clinical Psychology, 2*, 298-303.
- Scherder, E. J., Bogen, T., Eggermont, L. H., Hamers, J. P., & Swaab, D. F. (2010). The more physical inactivity, the more agitation in dementia. *International Psychogeriatrics, 22*(8), 1203-1208.
- Schneider, L. S., Dagerman, K. S., Higgins, J. P., McShane, R. (2011). Lack of evidence for the efficacy of memantine in mild Alzheimer disease. *Archives of Neurology, 68*(8), 991-998.
- Schneider, N. M. & Camp, C. J. (2002) Use of Montessori-based activities by visitors of nursing home residents with dementia. *Clinical Gerontologist, 26*, 71-84.

- Schreiner, A. S., Yamamoto, E., & Shiotani, H. (2000). Agitated behavior in elderly nursing home residents with dementia in Japan. *Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, 55, P180–P186.
- Shadish, W. R., Cook, T. D., & Campbell, D. T. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. Boston, MA: Houghton Mifflin Company.
- Sierpina, V. S., Sierpina, M., Loera, J. A., & Grumbles, L. (2005). Complementary and integrative approaches to dementia. *Southern Medical Journal*, 98(6), 636-645.
- Sink, K. M., Holden, K. F., & Yaffe, K. (2005). Pharmacological treatment of neuropsychiatric symptoms of dementia: A review of the evidence. *Journal of the American Medical Association*, 293(5), 596-608.
- Sloane, P. D., et al. (1991). Physical and pharmacologic restraint of nursing home patients with dementia: Impact of specialized units. *Journal of the American Medical Association*, 265(10), 1278-1283.
- Smith, T. F. & Hirdes, J. P. (2009). Predicting social isolation among geriatric psychiatry patients. *International Psychogeriatrics*. 21(1), 50-59.
- Snowden, M., Sato, K., & Roy-Byrne, P. (2003). Assessment and treatment of nursing home residents with depression or behavioral symptoms associated with dementia: A review of the literature. *Journal of the American Geriatrics Society*, 51, 1305-1317.

- Spore, D., Mor, V., Hiris, J., Larrat, E. P., & Hawes, C. (1995). Psychotropic use among older residents of board and care facilities. *Journal of the American Geriatrics Society, 43*(12), 1403-1409.
- Spreeen, O., & Strauss, E. (1998). *A compendium of neuropsychological tests: Administration, norms, and commentary*. (2<sup>nd</sup> ed.). New York: Oxford University Press.
- Stevens, M., Van Duijn, C., Kamphorst, W., de Knijff, P., Heutink, P., vanGool, W., Scheltens, P., ... vanSwieten, J. (1998). Familial aggregation in frontotemporal dementia. *Neurology, 50*, 1541-1545.
- Stewart, S., O'Riley, A., Edelstein, B., & Gould, C. (2012). A preliminary comparison of three cognitive screening instruments in long term care: The MMSE, SLUMS, and MoCA. *Clinical Gerontologist, 35*(1), 57-75.
- Stokes, J. A., Purdie, D. M., & Roberts, M. S. (2004). Factors influencing PRN medication use in nursing homes. *Pharmacy World Science, 26*, 148-154.
- Strauss, E., Sherman, E.M.S., & Spreeen, O. (2006). *A compendium of neuropsychological tests*. (3<sup>rd</sup> ed.). New York: Oxford University Press.
- Sturmey, P. (1999). Correlates of restraint use in an institutional population. *Research in Developmental Disabilities, 20*(5), 339-346.
- Suh, G. H. (2004). Agitated behaviours among institutionalized elderly with dementia: Validation of the Korean version of the Cohen-Mansfield Agitation Inventory. *International Journal of Geriatric Psychiatry, 19*, 378-385.

- Sullivan-Marx, E. M. (1995). Delirium and physical restraint in the hospitalized elderly. *Journal of Nursing Scholarship, 26*(4), 295-300.
- Sullivan-Marx, E. M. (2001). Achieving restraint-free care of acutely confused older adults. *Journal of Gerontological Nursing, 27*(4), 56-61.
- Sullivan-Marx, E. M., Strumpf, N. E., Evans, L. K., Baumgarten, M., & Maislin, G. (1999). Initiation of physical restraint in nursing home residents following a restraint reduction efforts. *Research in Nursing & Health, 22*, 369-379.
- Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics (5<sup>th</sup> ed.)*. Boston, MA: Pearson Education Inc.
- Taft, L. B., Fazio, S., Seman, D., & Stansell, J. (1997). A psychosocial model of dementia care: Theoretical and empirical support. *Archives of Psychiatric Nursing, 11*(1), 13-20.
- Talerico, K. A., Evans, L. K., & Strumpf, N. E. (2002). Mental health correlates of aggression in nursing home residents with dementia. *The Gerontologist, 42*(2), 169-177.
- Taylor, D. H., & Sloan, F. A. (2000). How much do persons with Alzheimer's disease cost Medicare? *Journal of American Geriatrics Society, 48*, 639-646.
- Teitelman, J., Raber, C., & Watts, J. (2010). The power of the social environment in motivating persons with dementia to engage in occupation: *Qualitative findings. Physical & Occupational Therapy in Geriatrics, 28*(4), 321-333. doi: 10.3109/02703181.2010.532582

- Teri, L., Logsdon, R. G., & McCurry, S. M. (2002). Nonpharmacologic treatment of behavioral disturbance in dementia. *The Medical Clinics of North America*, *86*, 641-656.
- Teri, L., Logsdon, R. G., Peskind, E., Raskind, M., Weiner, M. F., Tractenberg, R. E., et al. (2000). Treatment of agitation in AD: A randomized, placebo-controlled clinical trial. *Neurology*, *55*, 1271-1278.
- Tighe, S. K., Leoutsakos, J. S., Carlson, M. C., Onyike, C. U., Samus, Q., ... Baker, A. (2008). The association between activity participation and time to discharge in the assisted living setting. *International Journal of Geriatric Psychiatry*, *23*, 586-591.
- Tombaugh, T. N., McDowell, I., Kristjansson, B., & Hubble, A. M. (1996). Mini-Mental State Examination (MMSE) and the modified MMSE (3MS): A psychometric comparison and normative data. *Psychological Assessment*, *8*, 48-59.
- Torti, F. M., Gwyther, L. P., Reed, S. D., Friedman, J. Y., & Schulman, K. A. (2004). A multinational review of recent trends and reports in dementia caregiver burden. *Alzheimer Disease & Associated Disorders*, *18*(2), 99-109.
- Trinh, N., Hoblyn, J., Mohanty, S., & Yaffe, K. (2003). Efficacy of cholinesterase inhibitors in the treatment of neuropsychiatric symptoms and functional impairment in Alzheimer Disease: A meta-analysis. *Journal of the American Medical Association*, *289*(2), 210-216.

- Tröster, A. I., & Arnett, P. A. (2006). Movement and demyelinating disorders. In P. J. Snyder, P. D. Nussbaum, & D. L. Robins (Eds.), *Clinical neuropsychology: A handbook for assessment (2<sup>nd</sup> ed.)*. Washington, DC: American Psychological Association.
- van Beek, A. P., Frijters, D. H., Wagner, C., Groenewegen, P. P., Ribbe, M. W. (2011). Social engagement and depressive symptoms of elderly residents with dementia: a cross-sectional study of 37 long-term care units. *International Psychogeriatrics*, *23*(4), 625-633.
- VanHaitma, K., Lawton, M. P., Kleban, M. H., Kapper, J., & Corn, J. (1997). Methodological aspects of the study of streams of behavior in elders with dementia illness. *Alzheimer Disease and Associated Disorders*, *11*(4), 228-238.
- Verhey, F. (2006). Recommendations concerning neuropsychiatric symptoms assessment. *Journal of Nutrition, Health & Aging*, *10*(2), 134-135.
- Voelkl, J. E., Fries, B. E., & Galecki, A. T. (1995). Predictors of nursing home residents' participation in activity programs. *The Gerontologist*, *35*(1), 44-51.
- Wayne, S. J., Rhyne, R. L., & Stratton, M. (1992). Longitudinal prescribing patterns in a nursing home population. *Journal of the American Geriatrics Society*, *40*(1), 53-56.
- Weiner, C., Tabak, N., & Bergman, R. (2003). The use of physical restraints for patients suffering from dementia. *Nursing Ethics*, *10*(5), 512-524.

- Weiner, M. F., Tractenberg, R. E., Jin, S., Gamst, A., Thomas, R. G., Koss, E., et al. (2002). Assessing Alzheimer's disease patients with the Cohen-Mansfield Agitation Inventory: Scoring and clinical implications. *Journal of Psychiatric Research, 36*, 19-25.
- Welsh-Bohmer, K. A., & Warren, L. H. (2006). Neurodegenerative dementias. In D. K. Attix & K. A. Welsh-Bohmer (Eds.), *Geriatric neuropsychology: Assessment and intervention*. (pp.56-88). New York, NY: The Guilford Press.
- Werezak, L. J., & Morgan, D. G. (2003). Creating a therapeutic psychosocial environment in dementia care: A preliminary framework. *Journal of Gerontological Nursing, 29(12)*, 18-25.
- Wilkie, J., McCaffrey, D., Jones, M. & Comeau, J. (2007, November). *Facilitating social engagement: An intervention for hospitalized individuals with dementia*. Paper presented at the annual education and scientific meeting of the Canadian Association on Gerontology, Calgary, Alberta.
- Yeh, S. H., Sehy, Y. A., & Lin, L. W. (2002). The quality of nursing home care in Taiwan. *Journal of Gerontological Nursing, 28(8)*, 13-21.
- Zekry, D. & Gold, G. (2010). Management of mixed dementia. *Drugs Aging, 27(9)*, 715-728.
- Zeisel, J., Sliverstein, N. M., Hyde, J., Levkoff, S., Lawton, M. P., & Holmes, W. (2003). Environmental correlates to behavioral health outcomes in Alzheimer's special care units. *The Gerontologist, 43(5)*, 697-711.

- Zimmerman, S., Scott, A.C., Park, N.S., Hall, S.A., Wetherby, M.M., Gruber-Baldini, A.L., et al. (2003). Social engagement and its relationship to service provision in residential care and assisted living. *Social Work Research, 27*(1), 6-18.
- Zimmerman, S., Mitchell, C. M., Chen, C. K., Morgan, L. A., Gruber-Baldini, A. L., Sloane, P. et al. (2007). An observation of assisted living environments: Space use and behavior. *Housing Outcomes, 49*(3), 185-203.
- Zuidema, S. U., Derksen, E., Verhey, F., & Koopmans, R. (2007). Prevalence of neuropsychiatric symptoms in a large sample of Dutch nursing home patients with dementia. *International Journal of Geriatric Psychiatry, 22*, 632–638.
- Zuidema, S. U., van der Meer, M. M., Pennings, G., & Koopmans, R. (2006). Prevalence of behavioural problems in a group of demented nursing home patients. *Tijdschrift voor Gerontologie en Geriatrie, 37*(1), 19-24.

## Appendix A

**Cover letter for the staff completing Cohen-Mansfield Agitation Inventory**

Dear (insert name of individual and their respective discipline),

I am currently a Ph.D. student in the Educational Psychology Department at the University of Alberta. The present study will be used to fulfill the dissertation requirements for my Doctorate of Philosophy (Ph.D.) and will be conducted under the supervision of Professor Dick (Richard J.) Sobsey.

The enclosed package contains one of the measures that will be used to assess the relationship between social engagement behaviors, physical restraints, behavioral disturbance, cognitive impairment, and functional dependency in individuals diagnosed with a dementia residing within an in-patient facility. Given your familiarity with the listed participants and expertise in the area of behavioral assessment, I am asking you to complete the Cohen-Mansfield Agitation Inventory in order to help me better understand the impact behavioral disturbances have on the social engagement levels for this particular population. The authors of the scale suggest that it takes approximately 15-20 minutes to complete for each resident. I know your time is valuable and I would greatly appreciate your participation in this study. For each individual named, I have obtained informed consent from their respective legal alternate decision-makers to participate in the study.

Participation on your part is voluntary. If you agree to support this study, I am asking that you first read the enclosed "Information Sheet" and complete the attached form. Please return the signed agreement to me at the address provided. To ensure the confidentiality of the participants, please limit the discussion of those participating in the study with any research assistants or myself. If questions arise during the course of the study from other staff members, family members, or management please direct these questions to me.

Sincerely,

Jocelyn Wilkie, M.Ed.  
Registered Psychologist

## Appendix B

**Cover letter for the staff completing Bristol Activities of Daily Living Scale**

Dear (insert name of individual and their respective discipline),

I am currently a Ph.D. student in the Educational Psychology Department at the University of Alberta. The present study will be used to fulfill the dissertation requirements for my Doctorate of Philosophy (Ph.D.) and will be conducted under the supervision of Professor Dick (Richard J.) Sobsey.

The enclosed package contains one of the measures that will be used to assess the relationship between social engagement behaviors, physical restraints, behavioral disturbance, cognitive impairment, and functional dependency in individuals diagnosed with a dementia residing within an in-patient facility. Given your familiarity with the listed participants and expertise in the area of functional assessment, I am asking you to complete the Bristol Activities of Daily Living Scale in order to help me better understand the impact functional dependency has on the social engagement levels for this particular population. The authors of the scale suggest that it takes approximately 10 minutes to complete for each resident. I know your time is valuable and I would greatly appreciate your participation in this study. For each individual named I have obtained informed consent from their respective legal alternate decision-makers to participate in the study.

Participation on your part is voluntary. If you agree to support this study, I am asking that you first read the enclosed "Information Sheet" and complete the attached form. Please return the signed agreement to me at the address provided. To ensure the confidentiality of the participants, please limit the discussion of those participating in the study with any research assistants or myself. If questions arise during the course of the study from other staff members, family members, or management please direct these questions to me.

Sincerely,

Jocelyn Wilkie, M.Ed.  
Registered Psychologist

## Appendix C

**Information Sheet for Legally Accepted Representative (Guardian or Agent)**

**Study Title:** Exploration of Institutional Dementia Care: Social Engagement and the Use of Physical Restraints

**Co-Investigator:** Jocelyn Wilkie, M.Ed.

**Principal Investigator:** Dick (Richard J.) Sobsey, PhD.

**Introduction:**

My name is Jocelyn Wilkie. I am a Psychologist at the Centennial Centre for Mental Health and Brain Injury (CCMHBI). I am also a student at the University of Alberta. This study will be used to complete my Doctorate of Philosophy (Ph.D.). This study will be carried out under the direction of Professor Dick (Richard J.) Sobsey. I am contacting you because you have a family member in the Centennial Centre who has dementia. We would like to invite you and <Patient Name> to participate in this research. The research study is about caring for people with dementia.

The following information will help you decide if you and <Patient Name> want to be part of this study. This information will explain why we are doing the study and how <Patient Name> will be involved. After you have read it, please contact myself about anything that is not clear. Whether or not you choose to have <Patient Name> take part in this study is for you to decide. However, if you agree to have <Patient Name> participate, I will also talk to <Patient Name> about this study. I will try to explain it to them so they can understand what they are being asked to participate in. If they are able to, I will have them sign a “Verbal Assent” form.

**Purpose:**

This study will mainly be looking at the social interactions between patients with dementia and others in their environment. I would like to find out what type of the social interactions is most common. Then I will compare these interactions with any behavioral problems they might have. Social interactions will also be compared to problems with thinking and memory. The amount of help they need from the staff for their care will also be measured. Any use of seatbelts on chairs or wheelchairs will also be compared to social interactions. I will also try to understand if some of these characteristics differ depending on when they are measured (i.e., during the day, evening, or on the weekend). **This is an important thing to study because social interactions are linked to quality of life. We hope that the findings of this study will be used to improve programs for seniors with dementia. It is also our hope that these programs will focus on improving social well-being and quality of life.**

**Procedures:**

If you agree to having <Patient Name> be in the study, you will sign the consent form. I will send you a copy for your records. Only after I receive the signed consent will we begin collecting information. Someone from our research team

will watch participants' social behaviors. This will be 15 minutes at a time and will happen at three separate times for each person. The observations will occur only when the patient's are NOT receiving direct care from nursing staff. Direct care includes dressing, bathing, or toileting. Staff that interact with the participants will be asked to complete short questionnaires. These questionnaires will be about each patient's routine and behaviors. I will also be gathering information from tests of their thinking and memory. These tests were given by a hospital psychology staff. Some participants may be given the Mini Mental State Exam. This exam is a 10-15 minute measure of thinking and memory abilities. It will only be given if there is no record of having had this test within the past three months.

### **Possible Benefits:**

Even though there may be no direct benefits of being in this study, there may be some important indirect benefits. In the long-term, this study may influence what type of programs and resources are offered to treat seniors with dementia. The results of this study will provide information about how people with dementia experience living in a facility not just during the day but also in the evening and on the weekend. The evening and weekend are often when staffing levels are lower. Very little is known about how much social interaction happens during these times.

### **Possible Risks:**

As this is a study where we are just observing, we do not expect there to be any significant risks. If a Mini Mental State Exam is given there is a small possibility that the questions might upset the participant. If this happens we will stop immediately. Reassurance and support will be provided until the individual has settled.

### **Voluntary Participation:**

This is a voluntary study. You have the right to refuse to participate. You can choose to withdraw from the study at any time without providing a reason. Declining to participate will by no means affect the care this individual receives.

### **Confidentiality:**

Names of the participants will never be used in any presentations or publications of the study results. All information will remain private unless professional ethics or the law requires reporting. The names of participants will be removed from any information collected. The names will be replaced with an ID number. Only I will have access to the ID numbers and names. A summary of the outcome of the study can be obtained from myself when the study is complete. By signing this consent form you are saying it is ok for the researchers to collect, use, and disclose specific information about <Patient's Name> from their personal health record. This information will include basic demographic information, diagnosis, and the results on their last Mini Mental State Exam.

For questions regarding participants' rights and ethical conduct of research, contact the administrative office of the Health Research Ethics Board at (780) 492-2615. This office has no affiliation with the study investigator.

Please keep this information sheet for your own records. If you are interested in participating, please read and complete the consent form and return it in the self-addressed stamped envelope provided. Thank you for considering this request. Feel free to contact me if you have any questions.

Sincerely yours,

Jocelyn Wilkie, M.Ed.  
Registered Psychologist  
(403) 783-7750, ext 7586.  
(587) 877-3940

## Appendix D

**Consent Form for Legally Accepted Representative (Guardian or Agent)**

**Project Title:** Exploration of Institutional Dementia Care: Social Engagement and the Use of Physical Restraints

<b>Part 1: Contact Information</b>		
<b>Name of Co Investigator:</b> Jocelyn Wilkie, M.Ed. <b>Contact Information:</b> (403) 783-7750, ext.586, (780) 668-3940 <a href="mailto:jwilkie@ualberta.ca">jwilkie@ualberta.ca</a>		
<b>Name of Principal Investigator:</b> Dick (Richard J.) Sobsey, PhD <b>Contact Information:</b> (780) 492-5245, <a href="mailto:dick.sobsey@ualberta.ca">dick.sobsey@ualberta.ca</a>		

<b>Part 2: (To be completed by the legally accepted representative: Guardian or Agent)</b>	<b>Yes</b>	<b>No</b>
Do you understand that the person under your guardianship/agency has been asked to be in a research study?		
Have you received and read a copy of the attached Information Sheet?		
Do you understand the benefits and risks involved for the person under your guardianship/agency to take part in this research study?		
Do you understand that you or the person under your guardianship/agency is free to refuse to participate or withdraw from the study at any time and that you do not have to give a reason and it will not affect the care received by the person under your guardianship/agency?		
Has the issue of confidentiality been explained to you?		
Do you understand who will have access to the data collected?		

<b>Part 3: Signatures</b>	
I agree to have _____ take part in this study.  (name of participant)	
_____ Signature of Guardian or Agent	_____ Date
_____ Printed name of Guardian or Agent	
_____ Signature of witness	_____ Date
_____ Printed name of witness	

Appendix E  
**Verbal Assent Form**

**Title of Research Study:** Exploration of Institutional Dementia Care: Social Engagement and the Use of Physical Restraints

\*Information under the following headings will be described verbally to potential participants.

**What will you have to do?** If you and your family member/guardian/agent agree to be in this study, I am going to ask you a few questions about your thinking and memory. I will also be observing you and some of the other residents socializing throughout the day. You will probably notice me standing with a clip board but you don't have to do anything out of the ordinary while I'm around. It's actually best if you just ignore the fact that I'm here.

**Why should you participate?** The reason I'm doing this study is to try to better understand social engagement in a hospital like this.

**Can you quit?** You don't have to take part in the study, and you can quit if you want. No one will be mad at you if you decide you don't want to do this, or if you decide to stop part way through. If you decide that you want to do this and you start to get tired or frustrated once I start asking you questions, just let me know and we can stop and start a bit later.

**Your signature:** We would like you to sign this form to show that you agree to take part. Your family member/guardian/agent has already been asked to sign another form agreeing for you to take part in the study.

**Do you have more questions?** If you have any more questions, you can ask me or your family member/guardian/agent about anything you don't understand.

I agree to take part in the study.

Signature of research participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of researcher: \_\_\_\_\_ Date: \_\_\_\_\_

\*For participants who are unable or too cognitively impaired to sign their names, verbal assent will be documented by the researcher.

## Appendix F

**Information Sheet for Participating Staff**

**Project Title:** Exploration of Institutional Dementia Care: Social Engagement and the Use of Physical Restraints  
**Co Investigator:** Jocelyn Wilkie, M.Ed., Registered Psychologist  
 Alberta Health Services, Centennial Centre for Mental Health and Brain Injury (CCMHBI)

**Background:**

My name is Jocelyn Wilkie and I am a Registered Psychologist at the CCMHBI. I am also a Ph.D. student in the Educational Psychology Department at the University of Alberta. The present study will be used to fulfill the dissertation requirements for my Doctorate of Philosophy (PhD.) and will be conducted under the supervision of Professor Dick (Richard J.) Sobsey. Only patients in the Seniors Mental Health Program at the Centennial Centre for Mental Health and Brain Injury whom have a diagnosis of dementia will be offered an opportunity to participate. This study will be measuring the relationship between social behavior, behavioral problems, cognitive functioning, reliance on others for activities of daily living, and the use of physical restraints (e.g., seatbelts on wheelchairs) in persons with dementia residing within a care facility. I also would like to know if some of these characteristics differ depending on what shift they are measured on (i.e., day, evening, or weekend shifts).

**Purpose:**

Unfortunately, this is a topic and population that has received very little attention in research. **The results of this study will assist us in understanding what personal characteristics (e.g., cognitive impairment or physical restraint use) are related to the amount and type of social behavior the individual with dementia engages in (e.g., conversations with staff and other residents). This information is important because social contact with other people is considered to be a strong indicator of quality of life in persons with dementia.**

**Procedure:**

The participants' social behavior will be observed by the study investigator and a trained research assistant. Observations will be 15 minutes long and will occur at three separate times for a total of 45 minutes. The observations will occur during the day and evening at times when the participants are NOT receiving direct care from nursing staff (dressing, bathing, or toileting). Staff familiar with the participants will be asked to complete short questionnaires about each participant's activities of daily living and behaviors. A review of each participant's health record chart will be performed by one of the facilities pharmacist to obtain information about medication and the study investigator will

review the health record to obtain information regarding age, diagnosis, and level of education. Some participants may be administered the Mini Mental State Exam, a 10-15 minute assessment tool.

**Confidentiality:**

I am asking you to carefully read through enclosed information and provide your signature if you agree to support this important study. I do not expect any risks to the patients or staff that take part in this study. This is a voluntary project and you have the right to refuse to participate or withdraw from the study at any time without providing a reason. Declining to participate will by no means incur a penalty. Furthermore, neither yours nor any research participant names will be used in any presentations or publications of the study results. All information gathered in this study will remain confidential unless professional codes of ethics, legislation, or the law require reporting. A summary of the main research findings can be obtained from the study investigator after the study has been completed. The study has been reviewed and approved by the Health Research Ethics Board at the University of Alberta. For questions regarding participants' rights and ethical conduct of research, contact the Chair of the Research Ethics Board at (780) 492-0459.

Please keep this information sheet for your own records. If you are interested in supporting this research, please read and complete the agreement form and return it in the self-addressed envelope provided. Feel free to contact me if you have any questions.

Sincerely,

Jocelyn Wilkie, M.Ed.  
Registered Psychologist  
(403) 783-7750, ext 7586.  
(587) 877-3940

## Appendix G

**Staff Participation Agreement Form**

**Project Title:** Exploration of Institutional Dementia Care: Social Engagement and the Use of Physical Restraints

<b>Part 1: Contact Information</b>
<b>Name of Co Investigator:</b> Jocelyn Wilkie, M.Ed. <b>Contact Information:</b> (403) 783-7750, ext.586, (780) 668-3940 <a href="mailto:jwilkie@ualberta.ca">jwilkie@ualberta.ca</a>
<b>Name of Principal Investigator:</b> Dick (Richard J.) Sobsey, PhD <b>Contact Information:</b> (780) 492-5245, <a href="mailto:dick.sobsey@ualberta.ca">dick.sobsey@ualberta.ca</a>

<b>Part 2: (To be completed by the participant)</b>	<b>Yes</b>	<b>No</b>
Do you understand that you have been asked to support a research study?		
Have you received and read a copy of the attached Information Sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss this study?		
Do you understand that you are free to refuse to participate/?		
Has the issue of confidentiality been explained to you?		
Do you understand who will have access to the data collected?		

<b>Part 3: Signatures</b>	
<b>I, _____ agree to support this study.</b> <b>(name of participant)</b>	
_____ <b>Signature of staff</b>	_____ <b>Date</b>
_____ <b>Printed name of staff</b>	
_____ <b>Signature of witness</b>	_____ <b>Date</b>
_____ <b>Printed name of witness</b>	

## Appendix H

**Mennorah Park Engagement Scale  
Aggression and Physical Restraint Use**

**Page 1**

Date: \_\_\_\_\_ Participant ID: \_\_\_\_\_

Shift: Day ( )                  Evening ( )                  Weekend ( )

Engagement Codes:    Constructive     Passive +    Self -    Non O

Aggression Codes with 1-2 word description:

Physical : **P** (pushing, throwing, hitting, etc.)

Verbal : **V** (cursing, yelling, screaming, etc)

None : **0**

Interval	Time	Engage e	Aggressio n	Interva l	Time	Engage	Aggression
0-1	.10			31	5:10		
2	.20			32	5:20		
3	.30			33	5:30		
4	.40			34	5:40		
5	.50			35	5:50		
6	1:00			35	6:00		
7	1:10			37	6:10		
8	1:20			38	6:20		
9	1:30			39	6:30		
10	1:40			40	6:40		
11	1:50			41	6:50		
12	2:00			42	7:00		
13	2:10			43	7:10		
14	2:20			44	7:20		
15	2:30			45	7:30		
16	2:40			46	7:40		
17	2:50			47	7:50		
18	3:00			48	8:00		
19	3:10			49	8:10		
20	3:20			50	8:20		
21	3:30			51	8:30		
22	3:40			52	8:40		
23	3:50			53	8:50		
24	4:00			54	9:00		
25	4:10			55	9:10		
26	4:20			56	9:20		
27	4:30			57	9:30		
28	4:40			58	9:40		
29	4:50			59	9:50		
30	5:00			60	10:00		

**Menorah Park Engagement Scale**  
**Aggression and Physical Restraint Use**  
**Page 2**

Date: \_\_\_\_\_ Participant ID: \_\_\_\_\_

Shift: Day ( )          Evening ( )          Weekend ( )

Engagement Codes:    Constructive  $\surd$     Passive +    Self -    Non O

Aggression Codes with 1-2 word description:

Physical : **P** (pushing, throwing, hitting, etc.)

Verbal : **V** (cursing, yelling, screaming, etc)

None : **0**

Interval	Time	Engagement	Aggression	<b>Restraint use (circle one):</b>
61	10:10			None
62	10:20			
63	10:30			Broda chair with t-belt or back fastening belt/Segufix
64	10:40			
65	10:50			Front fastening seatbelt (participant can not disengage)
66	11:00			
67	11:10			
68	11:20			Back fastening seatbelt or Segufix
69	11:30			
70	11:40			Full side rails on bed
71	11:50			
72	12:00			One piece suit
73	12:10			
74	12:20			Mitts/gloves
75	12:30			
76	12:40			Wrist/arm restraint
77	12:50			
78	13:00			Shoulder restraint
79	13:10			
80	13:20			Table tray
81	13:30			
82	13:40			Wheelchair brakes (participant can not disengage)
83	13:50			
84	14:00			Other (describe):
85	14:10			
86	14:20			
87	14:30			
88	14:40			
89	14:50			
90	15:00			

## Appendix I

**The Cohen-Mansfield Agitation Inventory – Long Form  
With expanded descriptions of behaviors**

Rate behaviors as they occur on your shift (during past two weeks).

Rating Scale for Agitated Behaviors

Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour
1	2	3	4	5	6	7

8 – Would be occurring if not prevented (e.g., would pace if not restrained)

9 – Not applicable (e.g., cannot pace because cannot walk or move wheelchair)

*☞ If prevented part of the time, estimate how frequently it would happen if not prevented.*

*☞ Do not include rare behaviors that are clearly explained by situational factors.*

1. Pacing and aimless wandering – constantly walking back and forth, does not indicate normal purposeful walk, include wandering when done in a wheelchair \_\_\_\_\_
2. Inappropriate dressing or disrobing – putting on too many clothes, putting on clothing in a strange manner (e.g., putting pants on head), taking off clothing in public or when it is inappropriate (if only genitals are exposed, do not rate; see item #28.) Do not rate person's ability to dress/undress as in ADL's \_\_\_\_\_
3. Spitting (including while feeding) – spitting onto floor, other people, etc.; do not include salivating of which personal has no control, or spitting into tissue, toilet, or onto ground outside \_\_\_\_\_
4. Cursing or verbal aggression – only when using words; swearing, use of obscenity, profanity, unkind speech or criticism, verbal anger, verbal combativeness. Nonverbal will be marked under screaming \_\_\_\_\_

Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour
1	2	3	4	5	6	7

8 – Would be occurring if not prevented (e.g., would pace if not restrained)

9 – Not applicable (e.g., cannot pace because cannot walk or move wheelchair)

*☞ If prevented part of the time, estimate how frequently it would happen if not prevented.*

*☞ Do not include rare behaviors that are clearly explained by situational factors.*

5. Constant unwarranted request for attention or help – verbal or nonverbal unreasoning nagging, pleading, demanding (indicate also for oriented people) \_\_\_\_\_

6. Repetitive sentences or questions – repeating the same sentence or question one right after the other (Do not include complaining – see item #18; even if oriented and even if possibly warranted) \_\_\_\_\_

7. Hitting (including self) – physical abuse, striking others, pinching others, banging self/furniture \_\_\_\_\_

8. Kicking – strike forcefully with feet at people or objects \_\_\_\_\_

9. Grabbing onto people or things inappropriately – snatching, seizing roughly, taking firmly, or yanking \_\_\_\_\_

10. Pushing – forcefully thrusting, shoving, moving putting pressure against \_\_\_\_\_

11. Throwing things – hurl, violently tossing up in air, tipping off surfaces, flinging, spilling food \_\_\_\_\_

12. Making strange noises – including crying, weeping, moaning, weird laughter, grinding teeth \_\_\_\_\_

13. Screaming – loud shrill, shouting, piercing howl \_\_\_\_\_

14. Biting – chomp, gnash, gnaw (people or self) \_\_\_\_\_

15. Scratching – clawing, scraping with fingernails (people or self) \_\_\_\_\_

Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour
1	2	3	4	5	6	7

8 – Would be occurring if not prevented (e.g., would pace if not restrained)

9 – Not applicable (e.g., cannot pace because cannot walk or move wheelchair)

*☞ If prevented part of the time, estimate how frequently it would happen if not prevented.*

*☞ Do not include rare behaviors that are clearly explained by situational factors.*

16. Trying to get to a different place – trying to get out of the building, off the property – sneaking out of room, leaving inappropriately, trying to get into locked areas, trespassing within unit, into offices, other resident's room or closet \_\_\_\_\_

17. Intentional falling – purposefully falling onto floor, include from wheelchair, chair or bed \_\_\_\_\_

18. Complaining – whining, complaining about self, somatic complaints, personal gripes or complaining about external things or other people \_\_\_\_\_

19. Negativism – bad attitude, doesn't like anything, nothing is right \_\_\_\_\_

20. Eating or drinking inappropriate substances – putting into mouth and trying to swallow items that are inappropriate \_\_\_\_\_

21. Hurting self or other – burning self or other, cutting self or other, touching self or other with harmful objects, etc. \_\_\_\_\_

22. Handling things inappropriately – picking up things that don't belong to them, rummaging through drawers, moving furniture, playing with food, fecal smearing \_\_\_\_\_

23. Hiding things – putting objects under or behind something \_\_\_\_\_

24. Hoarding things – putting many or inappropriate objects in purse or pockets, keeping too many of an item \_\_\_\_\_

25. Tearing things or destroying property – shredding, ripping, breaking, stomping on something \_\_\_\_\_

Never	Less than once a week	Once or twice a week	Several times a week	Once or twice a day	Several times a day	Several times an hour
1	2	3	4	5	6	7

26. Performing repetitious mannerisms – stereotypic movement, such as patting, tapping, rocking self, fiddling with something, twiddling with something, rubbing self or object, sucking on fingers, taking shoes on and off, picking at self, clothing, or objects, picking imaginary things out of air or off floor, manipulation of nearby objects in a repetitious manner \_\_\_\_\_

27. Making verbal sexual advances – sexual propositions, sexual innuendo, or “dirty” talk \_\_\_\_\_

28. Making physical sexual advances or exposing genitals – touching a persona in an inappropriate sexual way, rubbing genital area, inappropriate masturbation, when not alone in own room or bathroom, unwanted fondling or kissing \_\_\_\_\_

29. General Restlessness – fidgeting, always moving around in seat, getting up and sitting down inability to sit still \_\_\_\_\_

Appendix J  
**Bristol Activities of Daily Living Scale**

Instructions: Tick only one box per activity. Answers with respect to last 2 weeks.

<b>1.</b>	<b>Food</b>	
a.	Selects and prepares food as required	
b.	Able to prepare food if ingredients set out	
c.	Can prepare food if prompted step by step	
d.	Unable to prepare food even with prompting and supervision	
e.	Not applicable	
<b>2.</b>	<b>Eating</b>	
a.	Eats appropriately using correct cutlery	
b.	Eats appropriately if food made manageable and/or using spoon	
c.	Uses fingers to eat food	
d.	Needs to be fed	
e.	Not applicable	
<b>3.</b>	<b>Drink</b>	
a.	Selects and prepares drinks as required	
b.	Can prepare drinks if ingredients left available	
c.	Can prepare drinks if prompted step by step	
d.	Unable to make a drink even with prompting and supervision	
e.	Not applicable	
<b>4.</b>	<b>Drinking</b>	
a.	Drinks appropriately	
b.	Drinks appropriately with aids, beaker/straw etc.	
c.	Does not drink appropriately even with aids but attempts to do so	
d.	Has to have drinks administered (fed)	
e.	Not applicable	
<b>5.</b>	<b>Dressing</b>	
a.	Selects appropriate clothing and dresses self	
b.	Puts clothes on in wrong order and/or back to front and/or dirty clothing	
c.	Unable to dress self but moves limbs to assist	
d.	Unable to assist and requires total dressing	
e.	Not applicable	
<b>6.</b>	<b>Hygiene</b>	
a.	Washes regularly and independently	
b.	Can wash self if given soap, flannel, towel, etc.	
c.	Can wash self if prompted and supervised	
d.	Unable to wash self and needs full assistance	
e.	Not applicable	
<b>7.</b>	<b>Teeth</b>	
a.	Cleans own teeth/dentures regularly and independently	
b.	Cleans teeth/dentures if given appropriate items	
c.	Requires some assistance, toothpaste on brush, brush to mouth, etc.	

d.	Full assistance given	
e.	Not applicable	
<b>8.</b>	<b>Bath/Shower</b>	
a.	Bathes regularly and independently	
b.	Needs bath to be drawn/shower turned on but washes independently	
c.	Needs supervision and prompting to wash	
d.	Totally dependent, needs full assistance	
e.	Not applicable	
<b>9.</b>	<b>Toilet/commode</b>	
a.	Uses toilet appropriately when required	
b.	Needs to be taken to the toilet and given assistance	
c.	Incontinent of urine <b>or</b> faeces	
d.	Incontinent of urine <b>and</b> faeces	
e.	Not applicable	
<b>10.</b>	<b>Transfers</b>	
a.	Can get in/out of chair unaided	
b.	Can get into a chair but needs help to get out	
c.	Needs help getting in and out of a chair	
d.	Totally dependent on being put into and lifted from chair	
e.	Not applicable	
<b>11.</b>	<b>Mobility</b>	
a.	Walks independently	
b.	Walks with assistance, i.e., furniture, arm for support	
c.	Uses aids to mobilize, i.e., walker, cane, etc.	
d.	Unable to walk	
e.	Not applicable	
<b>12.</b>	<b>Orientation – time</b>	
a.	Fully oriented to time/day/date etc.	
b.	Unaware of time/day etc., but seems unconcerned	
c.	Repeatedly asks the time/day/date	
d.	Mixes up night and day	
e.	Not applicable	
<b>13.</b>	<b>Orientation – space</b>	
a.	Fully oriented to surroundings	
b.	Oriented to familiar surroundings only	
c.	Gets lost in home, needs reminding where bathroom is, etc.	
d.	Does not recognize home as own and attempts to leave	
e.	Not applicable	
<b>14.</b>	<b>Communication</b>	
a.	Able to hold appropriate conversation	
b.	Shows understanding and attempts to respond verbally with gestures	
c.	Can make self understood but difficulty understanding others	
d.	Does not respond to or communicate with others	
e.	Not applicable	
<b>15.</b>	<b>Telephone</b>	

a.	Uses telephone appropriately, including obtaining correct number	
b.	Uses telephone if number given verbally/visually or pre-dialed	
c.	Answers telephone but does not make calls	
d.	Unable/unwilling to use a telephone at all	
e.	Not applicable	
<b>16.</b>	<b>Housework/gardening</b>	
a.	Able to do housework/gardening to previous standard	
b.	Able to do housework/gardening but not to previous standard	
c.	Limited participation even with a lot of supervision	
d.	Unwilling/unable to participate in previous activities	
e.	Not applicable	
<b>17.</b>	<b>Shopping</b>	
a.	Shops to previous standard	
b.	Only able to shop for 1 or 2 items with or without a list	
c.	Unable to shop alone, but participates when accompanied	
d.	Unable to participate in shopping even when accompanied	
e.	Not applicable	
<b>18.</b>	<b>Finances</b>	
a.	Responsible for own finances at previous level	
b.	Unable to write cheque but can sign name and recognizes money values	
c.	Can sign name but unable to recognize money values	
d.	Unable to sign name or recognize money values	
e.	Not applicable	
<b>19.</b>	<b>Games/hobbies</b>	
a.	Participates in pastimes/activities to previous standard	
b.	Participates but needs instruction/supervision	
c.	Reluctant to join in, very slow, needs coaxing	
d.	No longer able or willing to join in	
e.	Not applicable	
<b>20.</b>	<b>Transport</b>	
a.	Able to drive, cycle or use public transport independently	
b.	Unable to drive but uses public transport or bike, etc.	
c.	Unable to use public transport alone	
d.	Unable or unwilling to use transport even when accompanied	
e.	Not applicable	

Scoring: a = 0; b = 1; c = 2; d = 3; e = 0