

**FACTORS ASSOCIATED WITH BEHAVIORAL SYMPTOMS IN
PERSONS WITH DEMENTIA RESIDING IN ASSISTED LIVING**

by

Julie L. Ellis

A Dissertation Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

in Nursing

at

The University of Wisconsin–Milwaukee

December, 2006

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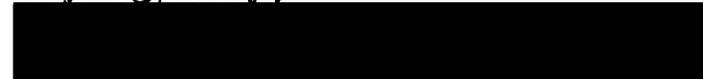
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ABSTRACT

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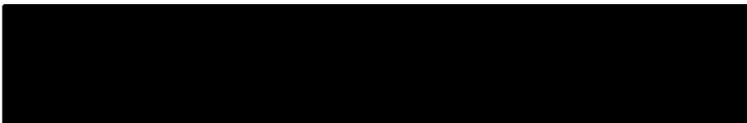
Under the Supervision of Dr. Christine Kovach

Factors associated with behavioral symptoms among persons with dementia residing in assisted living were investigated in this study using a descriptive, correlational design with a cross-sectional methodology. The purposes of the research were to a) describe the extent of pain, depression, co-morbid conditions, function and behavioral symptoms in a sample of residents with dementia in assisted living and b) identify the relationship between the of factors pain, depression, co-morbid conditions, and function to the extent of behavioral symptoms in the sample.

Using a convenience sampling method, 64 residents' age 73-98 residing in assisted living facilities were selected to participate in the study. Data were collected using a demographic data form, the Mini-Mental State Examination, Geriatric Depression Scale, Numerical Rating Scale, Coloured Analogue Scale, Checklist of Nonverbal Pain Indicators, Cumulative Illness Rating Scale- Geriatrics, Functional Behavior Profile, Cohen-Mansfield Agitation Inventory and a facility profile.

Relatively high levels of depression, pain, co-morbidity and behavioral symptoms were found in the study. Significant positive correlations were found between behavioral symptoms and depression and behavioral symptoms and co-morbid conditions and a negative correlation was found between functional level and behavioral symptoms. No significant correlations were found between mild- moderate versus moderate – severe

cognitive impairment and behavioral symptoms. Overall, the best predictors of the level of behavioral symptoms in persons with dementia residing in assisted living were depression, co-morbid conditions and functional status. Pain was not found to be a predictor of behavioral symptoms in this sample.



Major Professor

12/4/06

Date

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Dedication

I dedicate this research to my Lord and Saviour, Jesus Christ.

ACKNOWLEDGEMENTS

I would like to thank my committee chair, Dr. Christine Kovach for her inspiration and support of my research and my committee members, Dr. Rhonda Montgomery, Dr. Laurie Glass, Dr. Carol Ott and Dr. Karen Marek, for their suggestions, support and flexibility. A special note of thanks is owed to Sheryl Kelber for her extensive assistance with statistical analyses.

A special message of gratitude is provided to Milt and Joan Morris for a graduate scholarship provided early in my doctoral work which motivated and encouraged me, and to The American Association of Retired Persons (AARP) for a generous year of support as an AARP scholar that was critical to completion of my research.

I would like to thank my husband, David, for his support, and our wonderful daughter, Mary Catherine, who grew from age 7 to 14 through this doctoral journey and was always patient and supportive of her mom. I love you both.

My heart goes out in gratitude to the families who agreed to allow their loved ones to participate in this study and to the administrators, personal care workers, nursing assistants, nurses and all of the staff that work in assisted living for your willingness to participate in this research. I personally witnessed your dedication, passion and hard work; you are unsung heroes in elder care. Finally, I thank the beautiful souls that were residents in my study, who so bravely live each day with the difficult disorder of dementia. The hope of improving your lives drives my continued work.

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CHAPTER ONE

INTRODUCTION

Statement of Problem

Alzheimer's disease (AD) is a devastating, neurodegenerative disorder that affects 4.5 million Americans (Hebert, Scherr, Bieneas, Bennett & Evans, 2003). AD is the leading cause of dementia and it occurs primarily in the aged. Five to 10 percent of people age 65 and older and 20% to 47% of people age 85 and older have Alzheimer's dementia (Hill, et. al. 2002). The population of the United States is aging rapidly and it is projected that by 2050 the number of Americans with AD could reach 13.2 million if no cure is found (Hebert et. al., 2003).

The majority of people with AD live in the community (NIA, 2003). As dementia progresses, individuals become less independent and require an ever-increasing amount and intensity of care. Initially, families provide care but as the disease progresses, there is often a shift from informal to formal care which is provided in such settings as adult day care, assisted living facilities, and skilled nursing facilities (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999).

Medicare costs related to Alzheimer's disease are estimated to expand to \$49.3 billion per year by 2010 and Medicaid spending is projected to increase to \$33 billion which represents an 80% increase compared to costs in 2000 (Prigerson, 2003). In the community, the cost of care is incurred primarily by family caregivers (Moore, Zhu & Clipp, 2001). The national cost of informal caregiving for people with dementia is \$18 billion (Langa et. al., 2001).

When family members are unavailable or are no longer able to provide care for people with AD, skilled nursing facilities have been the primary option for institutional care since the passage of Medicare and Medicaid by the U.S. government in the 1960s. In the late 1980s, assisted living facilities were developed as a lower cost, supportive living option that are less restrictive than skilled nursing facilities (Mollica, 2001). Assisted living was designed to be both an alternative to the skilled nursing facility and a bridge in the continuum of formal long term care.

Assisted living facilities have been viewed as a revolutionary boon for the elderly—a blend of housing with supportive care and a limited amount of health care. While the nursing home was originally based on a medical model with a high degree of care and a low degree of independence (similar to a hospital setting), assisted living facilities have been based on a social model of care that stresses autonomy, privacy and dignity. Assisted living settings are newer and more home-like and the cost of residing in such settings is lower than the skilled nursing facility due in part to lower staffing levels. Alzheimer's care costs 21-30% less in assisted living than in a skilled nursing facility (Mollica, 2001). Consumers prefer assisted living to skilled nursing facilities, and federal and state agencies interested in controlling the escalating costs of long term care also favor assisted living (Lawton, 2001).

The average age of persons in assisted living is 84.5, and residents often enter with the goal of aging in place, which means the ability to stay in the same facility as care needs increase (Morgan, Gruber-Baldini, Magaziner & Hyg, 2001). Over the past decade, the assisted living industry has grown rapidly and residents have become increasingly more physically and cognitively impaired. At least 37% to 58% of persons

residing in assisted living have dementia (Magsi & Malloy, 2005; Rosenblatt et. al., 2004, Sloane, Zimmerman & Ory, 2001).

The demand for assisted living was overestimated by the industry and currently there is an excess of beds. This has created a trend toward accepting persons with higher acuity and keeping residents in assisted living longer as their health declines, essentially keeping persons in assisted living that would have lived in skilled nursing facilities in previous years (Doctrow, Mueller & Craig, 1999; Morgan, et. al., 2001).

Skilled nursing facilities and assisted living increasingly serve a population with a great overlap of needs and functional limitations (Zimmerman, et. al., 2003). One study found that residents residing in dementia units of assisted living facilities had a median length of stay of 10.9 months and 73% were eventually discharged to skilled nursing facilities (Kopetz, et. al., 2000). There is increasing use of hospice in assisted living with two-thirds of all assisted living facilities reporting that they contract with hospice agencies (NCAL, 1998).

There are no federal regulations governing assisted living. Each state has its own rules and most states have few regulations that govern admission and discharge from assisted living (Quinn, Johnson, Andress & McGinnis, 2003; Wisconsin Administrative Code, 2001). Ten states do not have regulations that define the clinical status of residents that an assisted living facility may serve (Mollica, 2000).

Behavioral symptoms are very prevalent in AD. In this study the term “behavioral symptoms” was operationalized as agitation. The term agitation will be used throughout this paper. Eighty-six to 88% of persons with AD exhibit physical agitation (Volicer & Hurley, 2003). Many assisted living facilities report that their dementia

residents exhibit agitation in that setting (Schonfeld, 2003). Agitation and the adverse sequelae associated with these behaviors are the most common reason for admission to assisted living (Sloane, Zimmerman & Ory, 2001). Agitated behaviors such as wandering and physical aggression are also a leading cause of transfer from assisted living to a skilled nursing facility (Aud, 2004; Hawes, Phillips, Rose, Holan & Sherman, 2003).

Agitation can be injurious to the person with dementia. For example, agitation has been associated with falling, scalding oneself, sustaining injuries from fighting or pushing, the occurrence of adverse consequences from refusal to take medication, and malnutrition and dehydration from refusal to eat or drink. Agitation in persons with dementia can also lead to a loss of function, social isolation and the use of physical and chemical restraints (Beck, et. al. 2002; and Kovach, 2000).

Purpose of the Study

The purpose of this research study was to examine the extent of and determine the relationships among the factors of pain, depression, co-morbid conditions, function and agitation in persons with dementia residing in assisted living. The theoretical framework underlying this study was the Need-driven Dementia-compromised Behavioral Model (NDB) (Algase et. al., 1996).

Research Questions

This study was guided by three primary questions and one secondary research question:

Primary Questions:

1. What is the extent of pain, depression, number and severity of co-morbid conditions, functional impairment and agitation in persons with dementia residing in assisted living facilities?
2. What is the prevalence of analgesic and psychotropic medications in persons with dementia residing in assisted living facilities?
3. What is the level of association of pain, co-morbid conditions and functional impairment to agitation in persons with dementia residing in assisted living facilities?

Secondary Question:

4. Are there differences in agitation between those with mild- moderate versus moderate-severe cognitive impairment?

This chapter will introduce three issues critical to the health care of people with dementia: a) agitation associated with dementia, b) physical and psychological problems associated with dementia, and c) assisted living as a model of care for people with dementia.

BACKGROUND/SIGNIFICANCE

Agitation in Dementia

First, it is necessary to define what is meant by the term “behavioral symptoms.” Cognitive decline in dementia is often associated with such behaviors as wandering, fidgeting, repeatedly asking the same questions, resistance to care, cursing, screaming, disrobing, hitting, and catastrophic reactions (Holtzer, et. al., 2003). A seminal research study was conducted in 1986 in which the term *agitated* was proposed as a synonym for behavioral symptoms in dementia (Cohen-Mansfield & Billig, 1986).

Prior to this time the literature did not specify a definition for agitation in dementia. Cohen-Mansfield and Billig (1986) defined agitation as “inappropriate verbal, vocal or motor activity that is not explained by needs or confusion per se.” All literature available at that time was reviewed, and the authors categorized agitation in four ways: aggressive-physical, aggressive-verbal, non-aggressive physical and non-aggressive verbal. In 1989, Taft described two critical components of agitation: 1) excessive motor or vocal activity and 2) the inappropriateness of the behavior.

Often the word “problems” is used for the term “behavioral symptoms.” This term, however, places the focus on the effect that symptoms have on caregivers as opposed to the effect they have on the person with dementia. For purposes of this paper, the term “agitation” will be used to describe aggressive, non-aggressive, verbal and nonverbal behaviors exhibited in dementia that are inappropriate to the situation. These are observable behaviors that may indicate mood, delusions, and hallucinations.

Physical and psychological issues in persons with dementia in assisted living

Research regarding the characteristics of persons in assisted living has revealed that at least one-third have dementia and there is a high prevalence of other physical and psychological problems such as arthritis, incontinence, functional impairment, and depression. Twenty percent of assisted living residents require hospitalization for various health conditions in any six-month period (Morgan, Gruber-Baldini & Magaziner, 2001). It is not known if disease acuity differs between varying levels of cognitive impairment in assisted living (Quinn, et. al., 2003).

There is a large body of research regarding acute and chronic pain in people with dementia who reside in the community and in skilled nursing facilities (Ferrell & Ferrell, 1996, Teno, Weitzen, Wettle & Mor, 2001). One recent study was identified that reported on pain in persons with dementia in assisted living. In that study, 39% of subjects self-reported pain and 34% were receiving an analgesic medication (Williams, Zimmerman, Sloane & Reed, 2005). There is a significant body of literature regarding depression in both cognitively intact and cognitively impaired older adults in skilled nursing facilities and among those who live in the community. There are some studies about depression in older adults who reside in assisted living. In one study, clinical depression among assisted living residents has been reported to be 13% and 18% of those residents are receiving antidepressants (Marroco, 1996; Watson, Garrett, Sloane, Gruber-Baldini & Zimmerman, 2003). In another study a higher depression rate of 24% was reported, and 36% of these patients were receiving an anti-depressant (Gruber-Baldini, et. al. 2005).

Assisted living as a model of care for persons with dementia

Assisted living facilities have been based on a social model of care. This setting has been suggested to be especially appropriate for those with dementia when the major reason for needing formal care is not health needs, but rather behavioral issues only (Lawton, 2001). This recommendation assumes, however, that the health needs of persons with dementia in assisted living are recognized and adequately addressed. This can be a challenge in persons with dementia due to alterations in communication and expression of needs. The assessment of physical and psychological needs such as pain and depression is a challenge in persons with dementia in any setting.

Nursing research in assisted living facilities is in the early stages of development (Aud & Conn, 2003; Mitty, 2003). Research to date suggests that individuals with dementia who reside in assisted living have significant agitation and many physical and psychological problems (Schonfeld, 2003; Zimmerman et. al., 2001). There is a need to understand the scope and characteristics of agitation in dementia residents in assisted living. in order to develop interventions to decrease agitation, improve comfort, maintain function, and delay the need for transfer to more restrictive levels of care.

Definition of Terms

Assisted Living- A state regulated and monitored residential long-term care option that provides or coordinate oversight and services to meet the residents' individualized scheduled needs, based on the residents' assessments and service plans and their unscheduled needs as they arise. (Assisted Living Workgroup, 2003)

Community Based Residential Facility (CBRF): One of two types of assisted living facilities in the state of Wisconsin. A place where five or more unrelated adults reside where care, treatment or services above the level of room and board is provided but not including more than three hours of nursing care per week per resident.(Wisconsin Administrative Code, Chapter 83 2001).

Residential Care Apartment Complex (RCAC): One of two types of assisted living facilities in the state of Wisconsin. A place where five or more adults reside that consists of independent apartments, each of which has an individual bathroom, sleeping and living areas, and provides not more than twenty-eight hours per week in total of services that are supportive, personal and nursing in nature. (Wisconsin Administrative Code, Chapter 89, 2000).

Skilled Nursing Facility (SNF): Provides 24 hour long-term care to individuals who require nursing care and supervision. Most nursing homes have services and staff to address issues such as nutrition, care planning, recreation, spirituality and medical care. These facilities are licensed by the state and regulated by the federal government.

Behavioral Symptoms- For purposes of this study this term was operationalized as agitation

Agitation: Inappropriate verbal, vocal or motor activity that is not explained by needs or confusion per se. (Cohen-Mansfield & Billig, 1986)

Dementia- Cognitive impairment, defined in this study as a Mini-Mental Status Examination score of 23 or lower.

FTE: Full-time equivalent

prn- “pro re nata” according to the condition arising, according to needs, used in written orders

Psychotropic medication – Pharmaceuticals that affect the psyche. Drugs used in the treatment of mental illness.

Summary

As the U.S. population ages, subsequently the incidence and prevalence of dementia will increase and there will be an ever-growing need for care options. Assisted living settings are an important part of the long-term care continuum for persons with dementia. It has been established that people with dementia have many physical and psychological needs. This research study was undertaken in order to contribute to the body of knowledge about this population in the assisted living setting.

CHAPTER TWO

Literature Review

Theoretical models that explain agitation in dementia

This chapter will discuss various theories that have been developed to explain agitation of people with dementia. The Need-Driven Dementia-Compromised Behavior Model (NDB) has been chosen as the theoretical framework for this research study (Algase et. al. 1996). The rationale for this choice will be explained as well as the literature that supports this model. It is important to use a theoretical framework to guide research because theory describes and defines issues and provides a model to aid in understanding phenomena. Use of theory to under-gird research helps to operationalize the variables of interest so that they can be tested and applied. (Polit & Beck, 2004).

The NDB model is a descriptive, middle-range theory. The main premise of the NDB model is that agitation is often due to unmet needs such as depression, functional impairment, pain and other symptoms that result from co-morbid conditions such as fatigue or nausea. The model proposes that agitation such as yelling, hitting or wandering occur because the person with dementia is attempting to express a need or is in pursuit of a goal that they are unable to communicate directly. Use of this particular model serves as a guide for research aimed at revealing processes that may lead to agitation.

There are several theories that attempt to explain the causes of agitation in persons with dementia. Some researchers have organized the frameworks into four main categories: behavioral, environmental, biological, and unmet needs (Cohen-Mansfield, 2000). More recent articles have added the psychiatric method (loosely a type of model),

and an integrated model (Volicer & Hurley, 2003). There is general agreement that all of these models can be used in varying degrees to explain agitation in dementia. There is some confusion in the literature regarding the broader categories (e.g. behavioral or environmental) into which the various models fit.

Six main theoretical explanations that attempt to explain agitation in dementia will be described in this chapter. Empirical evidence that supports or refutes each explanatory framework will be reviewed. The NDB model will be described in detail including a review of the literature that explains the model and provides evidence for its utility and the rationale for choosing this model as a framework for this study of the agitation of people with dementia residing in assisted living. The six main theories that attempt to explain the causes of agitation in dementia are:

1. A biological or direct-impact model
2. A classic behavioral model
3. Environmental theory
4. The psychiatric method
5. An integrated model
6. The Need-Driven Dementia-Compromised Behavioral Model
(NDB)

Biological or Direct Impact Model

While there have been many advances in the understanding of the neuropathological processes inherent in Alzheimer's dementia, these processes have been only loosely connected to agitation. The biological or direct-impact model suggests that agitation in dementia is directly attributable to neurological deterioration in the brain and

that severe brain deterioration tends to lead to behavioral disinhibition (Cohen-Mansfield, 2000).

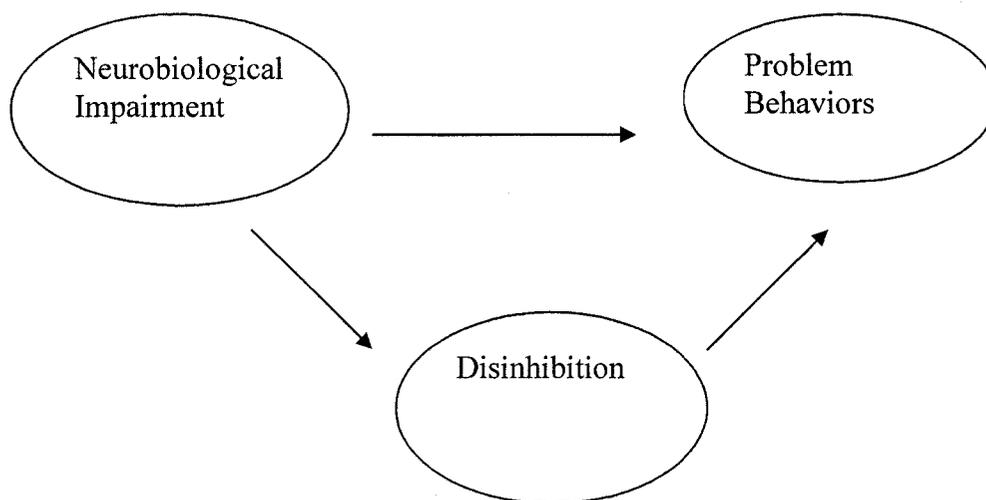


Figure 1 Direct Impact of Dementia Model (Cohen-Mansfield, 2000).

In neuropathological studies of persons with AD, it has been found that neurons in the brain are surrounded by amyloid plaques and abnormal dendrites and axons which contain bundles of filaments called tangles (Garand, Buckwalter & Hall, 2000; Mirra, Heyman & McKeel, 1991). Researchers have reviewed literature regarding the relationship between anatomic and neurochemical systems in the brain and agitated behaviors in dementia. A large body of data, drawn from postmortem brain studies and neurochemical and pharmacological outcome studies, has been used to explain the link between neuropathology and behaviors (Garand et. al., 2000). There is limited neuropathological research that links noradrenergic brain changes in AD to behaviors. In

one study, it was reported that there was a 50% loss of locus coeruleus cells in subjects with dementia. In individuals with dementia, there was a positive correlation between aggressive behavior and the degree of this cell loss (Matthews, et. al., 2002).

In AD there is a neurotransmitter deficit in the cholinergic system. Empirical evidence lends support to the connection of behaviors and neuropathological changes through the effect of neurotransmitter imbalance in the brain including the following: decreased levels of serotonin are related to depressive disorders and impulsive/aggressive behaviors, lower levels of acetylcholine can lead to agitation and psychosis, and high levels of norepinephrine can lead to the same symptoms plus hypervigilance. It has also been found that decreased levels of dopamine result in Parkinsonian symptoms including apathy (Garand, et. al., 2000; Lawlor, 1995). The current standard treatment of AD is the use of acetylcholinesterase inhibitors such as donepezil, based on evidence that there is a cholinergic deficit in AD (Chapman, Weiner, Rackley, Hynan & Zientz, 2004). Psychotropic medications used to treat agitation in patients with AD have limited effectiveness, improving agitated behaviors only 20% of the time (Schneider, Pollock & Lyness, 1990).

While neurotransmitter changes have been shown to affect behaviors and this provides support for a biological theory of agitation in AD. Pharmacologic treatment for AD and for agitation in AD have had only limited effectiveness which may point to the limited types of pharmacological agents available and/or that other factors in addition to neuropathological changes are responsible for agitated behaviors in AD.

Behavioral Model

The classic behavioral model proposes that behaviors are controlled by antecedents and consequences in the following manner:

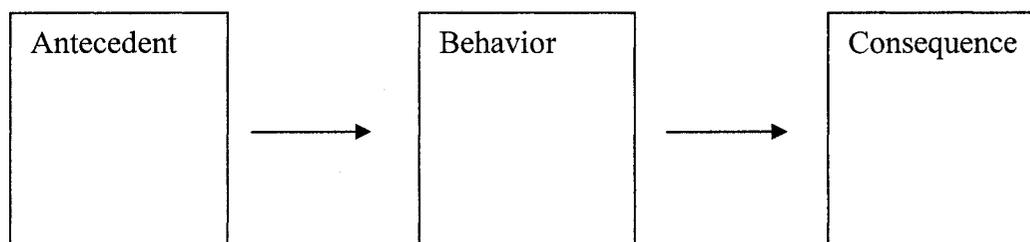


Figure 2 Behavioral Model (Teri & Logsdon, 1999, Volicer & Hurley, 2003)

The behavioral model describes how the person with AD responds to various antecedents such as the physical environment (e.g. noise or temperature) with various behaviors such as wandering or crying and how this can lead to consequences such as staff restraining the resident or other residents yelling at the resident. The consequences can also become antecedents to new behaviors in a cyclical pattern.

Environmental Theory

A third theoretical framework that has been developed to explain agitation in AD is an environmental theory that describes how the environment can influence the person with dementia. Lawton has explained that there is a continual interchange between the person and the environment that is difficult to separate into discrete entities (Lawton, 1986).

The environment has been classified on the basis of the demands it places on the person, some environments being high demand and others lower demand. The term “environmental press” (originally coined by psychologist Henry Murray) is used to refer to the demands of the environment (Lawton, 1986). From this work, a conceptual model called the Progressively Lowered Stress Threshold (PLST) was developed (Hall & Buckwalter, 1987). The PLST model assumes that by adulthood, people have a relatively stable stress threshold and dementia lowers this threshold (Smith, Gardener, Hall & Buckwalter, 2004). The PLST model proposes that the lowered stress threshold is due to neuropathological changes in the brain and this leads to agitation when the threshold is exceeded (Hall & Buckwalter, 1987). The PLST model led to the opening of Special Care Units for dementia residents. Evidence supporting this strategy has been inconsistent and contradictory (DeYoung, Just & Harrison, 2002; Holmes & Ramirez, 2003; Zimmerman et. al, 2001).

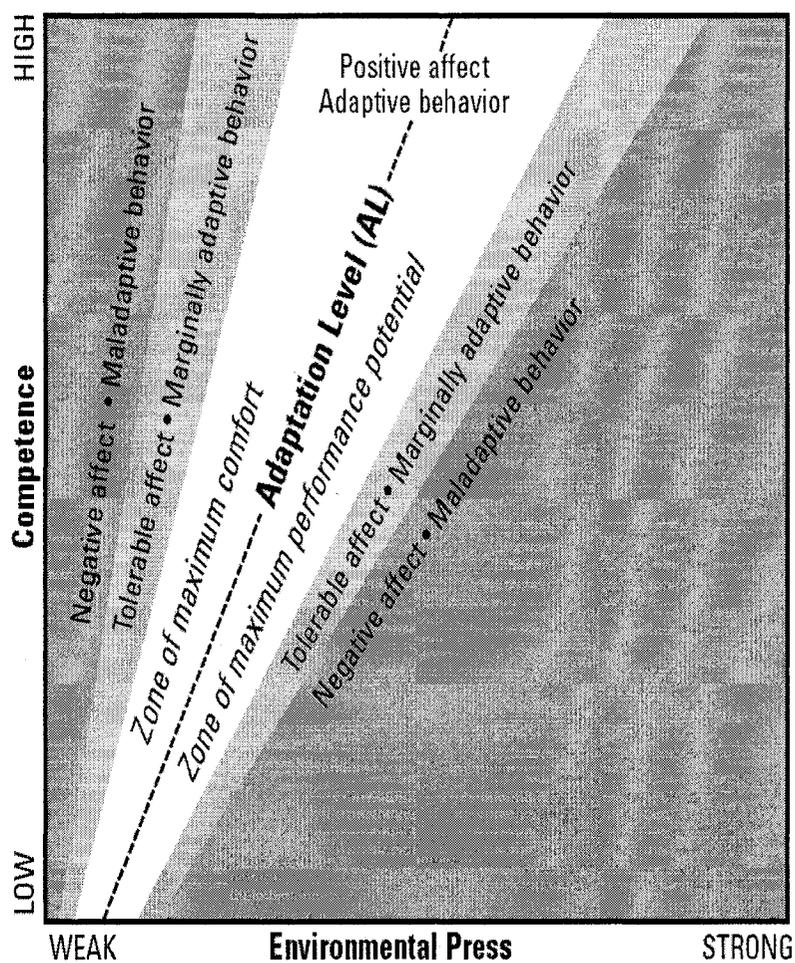


Figure 3 Ecological Model (from “Ecology and the Aging Process” by M.P. Lawton and L. Nahemow in C. Eisdorfer and M.P. Lawton (Eds.) *Psychology of Adult Development and Aging*. (1973).

Psychiatric Method

A fourth model used to explain agitation in dementia is the psychiatric method. This is more an approach than a distinct model. When behavioral and environmental strategies are not effective in managing agitation, a multimodal treatment is used that includes psychotropic medication (Tariot, 1999). Benzodiazepines or antipsychotics are used in emergency situations, antidepressants are used for depression and antipsychotics are also used for psychosis in dementia (Volicer & Hurley, 2003).

This “model” essentially describes standard medical care in dementia, especially in skilled nursing facilities and hospitals. A “trial and error” method is applied in which different psychotropic medications are tried based on a hunch regarding behavioral symptomatology and are adjusted based on the patient’s response. In a recent article in which the pharmacological management of neuropsychiatric symptoms of dementia was reviewed it was concluded that “pharmacological therapies are not particularly effective for management of neuropsychiatric symptoms in dementia” (Sink, Holden & Yaffe, 2005, p. 597).

Integrated Model

A fifth method used to explain agitation in dementia has been described as an integrated model. An example is Volicer and Hurley’s Comprehensive Model that proposes that there is a hierarchy of causes of agitation and that integrates both behavioral and psychiatric approaches in the assessment and management of agitation in dementia (Volicer & Hurley, 2003). At the core of the model is the dementing process which is modified by the personality of the patient. Dementia leads to primary consequences such as functional impairment, mood disorders, delusions and

hallucinations. These primary consequences lead to secondary consequences such as spatial problems, anxiety and the inability to initiate meaningful activities. Primary and secondary consequences of dementia are then viewed as causing peripheral symptoms such as agitation or insomnia (Volicer & Hurley, 2003).

Addressing secondary consequences through interventions, such as provision of meaningful activities, can then be used to manage agitation in dementia. This theory suggests that a primary disorder such as depression can lead to a secondary consequence such as inability to initiate activities. Correcting the primary consequence by use of an antidepressant can then ameliorate the peripheral symptoms caused by depression such as apathy or food refusal (Volicer & Hurley, 2003).

According to the Comprehensive Model, agitation in dementia is influenced by various environmental factors including: 1) care giving approaches (e.g., the use of distraction can be used to effectively deal with resistiveness to care, 2) the social environment (which can be altered by use of strategies such as special care units), and 3) process interventions which can also affect agitation (e.g., persons with dementia often do not understand the reason for the procedures such as blood drawing and this can lead to a catastrophic reaction). An example of an intervention drawn from this model is that as dementia reaches the later stages, it is suggested that there should be serious consideration regarding the number of medical procedures that should be performed (Volicer & Hurley, 2003).

The notion that the precursors of agitation in dementia is multi-factorial and is influenced by caregivers' reactions, the environment, and directly by neuropathology,

supports use of an integrative model. However, research that tests all of the individual components of the model is not fully developed.

The Need-driven Dementia-Compromised Behavior Model

Finally, there is a sixth model, the Need-Driven Dementia-Compromised Behavior Model (NDB) (Algase, et. al., 1996) which is a mid-range theory developed from a nursing perspective. This model was the theoretical underpinning for this research study. The NDB model alters the view of agitation from being problematic, disruptive or disturbing to caregivers and others to a perspective that frames these behaviors as potentially understandable and in need of being responded to appropriately (Kolanowski, 1999).

The NDB model was selected for this study because this perspective addresses agitated behaviors from the perspective of the person with dementia rather than the caregiver and allows nurses to determine unmet needs. When agitation is viewed as meaningful to the person with dementia, needs that are likely to precipitate agitation can be identified and nursing interventions can be developed to meet those needs.

The original article on the Need-Driven Dementia-Compromised Behavior Model (NDB) was published in 1996 (Algase, et. al., 1996). The NDB model proposes that relatively stable background factors interact with changeable proximal factors to cause agitation that is referred to as dementia-compromised behaviors. Behaviors are not perceived as random, but as having meaning that the person with dementia has difficulty communicating directly to others (Kolanowski, 1999).

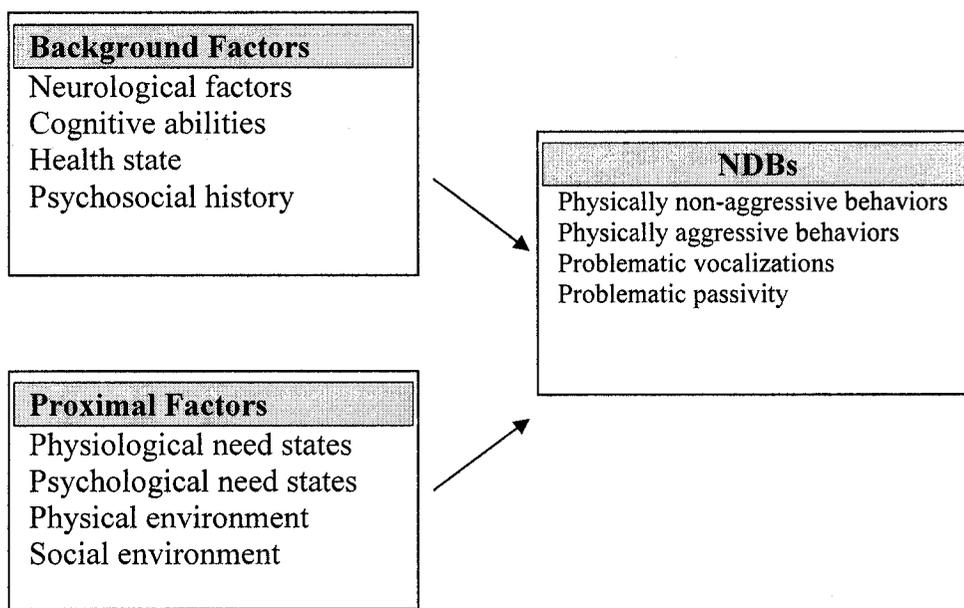


Figure 4 The Need-Driven Dementia-Compromised Behavior (NDB) Model (Algase et. al., 1996)

The type of background and proximal factors were identified through clinical experience and extensive literature review. Background factors include neurological phenomenon (central nervous system damage, neurotransmitter deficits and circadian rhythm disturbance), cognitive factors (attention, memory, language), health status (physical health, affective state, functional level) and psychosocial factors (demographics, history of psychosocial stress) (Beck & Vogelpohl, 1999). The immediate causes of the dementia-compromised behaviors are proximal factors such as depression and physiological needs such as pain, the physical environment (such as light, noise and temperature) and the social environment (staff, ward milieu) (Algase et. al., 1996; Beck & Vogelpohl, 1999; Kolanowski, 1999; Volicer & Hurley 2003).

Background factors are difficult to influence, as they are relatively stable. Proximal factors, however, are changeable and open to modification. Determining background factors can lead to development of risk profiles for NDBs. Knowledge and the ways in which common human needs contribute to agitation and isolation of proximal factors can lead to development of effective nursing interventions to address the unmet needs and diminish the resultant need-driven behaviors (Algase, et. al., 1996).

To date there are few studies that validate and refine the NDB model. One study examined problematic vocalizations (PVs) in institutionalized dementia residents within the context of the NDB model (Beck & Vogelphl, 1999). PV's included such behaviors as screaming, cursing or crying for help. These agitated vocal behaviors are a concern because they may indicate discomfort or distress and can lead to overmedication, retaliation or isolation (Beck & Vogelphl, 1999).

These authors reviewed evidence in the literature regarding background and proximal factors that are associated with PVs. The background factor of Circadian rhythm disturbance was found to increase end-of-day PV's and incontinence correlated with PVs, especially screaming and constant requests for help. PVs have been found to increase as cognition decreases until the final stage of Alzheimer's disease. The extent of co-morbid conditions has been found to correlate with constant complaining, and several studies have shown that gender may predict PVs, for example, males show more aggressive vocalizations such as cursing (Beck & Vogelphl, 1999).

The researchers also present a compilation of the evidence regarding proximal factors and PV's. Hunger may cause more frequent, repetitive requests for attention, toileting and incontinence correlate with screaming, and pain has been shown to correlate

with an increase in PV's. There is also evidence that psychosocial need states such as fear, anxiety and grief may play a role in vocalizations. One study reported that, on average, residents with dementia exhibited 2.4 behaviors during an 8 hour period and 48% of these were vocalizations, 29% were non-aggressive physical behaviors and 24% were aggressive physical behaviors (Beck & Vogelpohl, 1999).

The most frequent behaviors were screaming and yelling and these correlated positively with aggressive physical behaviors such as scratching, hitting and pinching. Being male, having a negative affect, and having disordered sleep patterns accounted for 39% of the variance in aggressive vocal behaviors. Cognitive impairment and disordered sleep patterns accounted for 28% of the variance in agitated vocal behavior. A limitation of the study was that a nonrandom sample was used (Beck & Vogelpohl, 1999).

In another study, part of the NDB model was tested by examining which pre-morbid factors predicted aggressive physical behavior in nursing home residents with dementia. In pilot work, the researchers found that physical aggression was related to the background factors of pre-morbid traits of neuroticism, extraversion, agreeableness and greater life stress (Kolanowski & Garr, 1999). The main study produced different findings that the authors attributed to the lower cognitive level of the sample compared with their pilot work.

In late-stage dementia, as functional ability drastically declines, many behaviors are diminished (e.g. yelling, hitting, pacing). As the person with dementia loses the ability to ambulate, they can no longer pace and wander. As they become first chair-bound and eventually bed-bound, they are less able to strike out at others. In the main

study, the authors found that only pre-morbid neuroticism predicted physical aggression in dementia. (Kolanowski & Garr, 1999).

In 2002, another study based on the NDB model tested a prescriptive intervention to address the issue of under-stimulation of residents with dementia in nursing homes (Colling & Buettner, 2002). Inadequate stimulation in the environment was examined as a factor that may trigger agitation. Previous findings showed that most disturbing behaviors occur during times of boredom and inactivity (Cohen-Mansfield & Werner, 1998) and it was hypothesized that the agitation may be due to residents' attempts to create their own activity (Colling & Buettner, 2002).

This intervention study based on the NDB model tested the efficacy of various recreational activities on agitation. Recreational activities were derived from the NDB model to function as proximal factors and were tested in a cross-over experimental design with repeated measures. Results reported were an improvement in positive affect and a decrease in the behavior of passivity when individualized activities were used (Colling & Buettner, 2002).

Based on this evidence, the authors tested original recreation items to determine if this would a decrease agitation related to boredom. Age and stage-appropriate items constructed by families and volunteers were found to positively affect the frequency and quality of visits by the family. In one of two sites there was a significant decrease in agitation among the subjects (Colling & Buettner, 2002).

The NDB model has also been used in studies of passive behaviors (PBs) in dementia such as issues of a decrease in gross motor movement, apathy, lack of interaction with the environment, lost of interest and withdrawal. One article described

how the NDB model could be used to address PB's (Colling, 1999). In the current study passive behaviors were not measured as they are not included in the CMAI.

Summary of Theoretical Frameworks

Several broad categories of theoretical approaches that contribute to explaining agitation in dementia have been proposed. Some of the models are domain specific and others are more comprehensive. These include the biological model, environmental models, (specifically Lawton's theory of Environmental Press and other theories that were derived from this such as the Progressively Lowered Stress Threshold by Hall and Buckwalter), behavioral models, the psychiatric method, integrated models and finally, the Need-Driven Dementia-Compromised behavior model (NDB). There are varying degrees of empirical evidence for each of the models. The causes of agitation in dementia are multi-factorial and each of the models contributes to the understanding of the phenomenon.

When a person with dementia exhibits agitation, it is probable that multiple phenomena occur. Brain pathology causes agitation directly, the environment creates under or over stimulation, behaviors are reinforced by caregivers, unmet needs are present because physical and psychological issues such as pain and depression often occur in AD, and due to the dementia, communication of needs is impaired. There is empirical evidence that some of the agitation in persons with AD is due to unmet needs such as discomfort (Kovach, Noonan, Griffie, Muchka & Weissman, 2002). The extent to which these models explain agitation in dementia needs further study.

The NDB model was chosen as the theoretical framework for this research study in assisted living facilities because it frames agitation from the perspective of the person

with dementia rather than as a problem for caregivers. This approach helps to prevent dismissal of the needs of the person with dementia. The NDB model incorporates the idea that agitation is multi-causal in origin and this makes it less likely that understanding of such behavior will be fragmented. The NDB model proposes that agitated behaviors are often symptoms of unmet needs and this contention is supported by empirical evidence.

Framing agitation in this way preserves the perspective of the person with AD. The NDB model allows for development of interventions to address unmet needs and this is particularly appropriate for nursing. The extent to which understanding of agitation is due to unmet needs may lead to improved nursing assessment in order to recognize unmet needs and nursing interventions that can meet those needs and improve the quality of life for persons with dementia in assisted living.

Literature Review

Agitation in dementia

Cognitive decline in Alzheimer's dementia is often associated with agitated behaviors such as wandering, fidgeting, repeatedly asking the same question, resistance to care, cursing, screaming, disrobing, hitting and catastrophic reactions (Holtzer, et. al., 2003; Talerico & Evans, 2000). Eighty-three to 86% of persons with AD exhibit at least verbal or vocal agitation and 53% exhibit physical agitation at some point during the disease (Mega, Cummings, Fiorella & Gornbein, 1996; Volicer & Hurley, 2003).

In a survey of assisted living administrators, it was reported that 83.5% of facilities had at least one resident with agitation. The most common behaviors were: refusal or resistance to care (14.5%), confusion and repetitive statements, (13.3%) and

verbal aggression toward staff, (12.5%) (Schonfeld, 2003). In a large study of assisted living residents it was reported that 37-49% of those with cognitive impairment had agitation compared with a finding of a 30% rate of agitation in skilled nursing facility residents. This may be attributable to the higher prevalence of end-stage dementia in skilled nursing facilities when agitation tends to decrease (Zimmerman, 2003).

In a year-long study of the characteristics and outcomes of residents in assisted living facilities with dementia, the following frequency of agitation was reported:

Hallucinations	9%
Crying spells	18%
Apathy	24%
Catastrophic Reactions	29%
Aggression	39%
Delusions	42%
Wandering	50%

(Kopetz et. al., 2000).

One multi-state study reported that 30% of residents exhibited agitation at least once in the previous two weeks before assessment. The most common behaviors were verbal symptoms such as constant requests for attention (22%), physical and non-aggressive behaviors such as pacing and wandering (21%), and resistance to care (12%). More agitation was found in those with dementia, depression, those on psychotropic medication and those with functional impairment (Gruber-Baldini, Boustani, Sloane & Zimmerman, 2004).

Pain and Dementia

It is well-documented in the literature that community-dwelling older adults have chronic pain. In a study of older adults with cognitive impairment living in the community, 85% reported some pain (Krulewitch, et. al., 2000). Prevalence studies of persistent pain in nursing home residents range from 39% to 46% % (Teno, Weitzen, Wettle & Mor, 2001).

Research has shown that pain is often under-diagnosed and under-treated in older persons (Scherder & Bouma, 1997). Sengstaken and King reported in 1993 that doctors failed to detect chronic pain in 34% of nursing home patients. Most studies have excluded the severely cognitively impaired, as this population was thought to be unreliable in terms of reporting pain (Cook, Niven & Downs, 1998). While there is some evidence that pain perception may decrease as AD advances, there remains a great deal of reported pain in persons with dementia (Farrell, Katz & Helme, 1996).

One Finnish study found that while pain is lower in elderly persons with dementia, it is still significant. This study of community-dwelling elderly, reported that 23% of persons with dementia reported daily pain compared with 40% of those without dementia (Mantyselka, Harikainens, Loutivvori-Laako & Sulkava, 2004).

Self-report has been the primary method for assessing pain in older adults. There is some evidence that cognitively impaired older adults are able to use standardized pain tools (Ferrell, Ferrell & Rivera., 1995). Communicative dementia patients' reports of pain have been found to be as valid as those of cognitively intact patients (Huffman &

Kunik, 2000). It has been reported that in patients with a MMSE score of <15, 86% could locate pain on themselves (Wynne, 2000).

In order to adequately assess pain in cognitively impaired older adults, it has been recommended that it is necessary to also attend to residents' behavior, vocalization and body language (Kovach, Griffie, Muchka Noonan & Weissman. 2000; Parke, 1998). Behaviors that may indicate pain fall into four categories: 1) *Nonverbal behaviors* such as restlessness, rubbing, guarding and bracing, 2) *vocalizations* such as crying, yelling, groaning and sighing, 3) *facial expressions* of pain such as frowning, grimacing and wincing and 4) *change in usual activity* such as aggression, altered sleep, fatigue and resistance to care (Ardey, Herr, Titler, Sorofman & Schmitt, 2003; Feldt, 2000; Kovach, Weissman, Griffie, Matson & Muchka, 1999). Vocal behaviors, such as moaning and groaning are a natural response of all human beings to pain regardless of cognitive status (Cohen-Mansfield, 2000).

There is limited research regarding the correlation between pain and agitation. One study reported that in cognitively impaired persons who exhibited aggressive behaviors, 76% had a pain-causing diagnosis, 44% of families of these patients reported that the patient had pain, and 66% of nursing assistants believed that the patient had pain. Aggression scores were higher in subjects with two or more pain-related diagnoses (Feldt, Ryden & Miles, 1998). A clinically and statistically significant difference between older adults with arthritis and those without in terms of aggressive behaviors has been reported. In those with arthritis, there were 14% aggressive behaviors, in those without a diagnosis of arthritis, 8% were aggressive. Patients with a past diagnosis of cancer had, on average, 19 aggressive behaviors per day (Feldt et. al., 1998).

Nonverbal persons with dementia may communicate pain through behavioral symptoms such as crying out, grimacing, restlessness, rubbing or guarding the body, increased irritability and resistance to care (Ryden & Feldt 1992; Sengstaken & King, 1993). There is evidence that under-treatment of pain may lead to aggressive behaviors (Ryden, Bossenmaier & McLachlan, 1991). In a study conducted in three skilled nursing facilities, 56% of the subjects that the nursing assistants identified as having pain had not received an analgesic in the past month (Feldt et. al., 1998). Nursing assistants may report that patients have more pain compared with nurses' reports of patient pain, because pain increases during patient movement and the assistants provide most of the direct care including transferring of patients.

Depression and Dementia

Depression is a disorder that may be measured on a spectrum or as a discrete disease entity (Lebowitz, et. al., 1997). Major depression occurs when 5 of the following symptoms are present for at least two weeks—depressed mood most of the day, markedly diminished interest in almost all activities, weight loss or gain, insomnia or hypersomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness or guilt, impaired concentration, recurrent thoughts of death or suicide (APA, 1994). Minor depression is a combination of the above symptoms that do not rise to the criterion level for major depression (APA, 1994).

Depression has been found to be correlated with social withdrawal, medical comorbidity, psychosis and agitation (Watson, Garrett, Sloane, Gruber-Baldini & Zimmerman, 2003). Elderly people with recent changes in the ability to perform activities of daily living (ADLs) also were found in another study to be three times more

likely to develop depressive illness (Ritchie, Gilham, Ledseret, Touchon & Kotzki., 1999). Change in ADL ability is often a reason for admission to assisted living (Zimmerman et. al., 2001). In people with depression and Alzheimer's disease, living in the community, an increased rate of agitation has been reported (Ritchie, et. al, 1999).

Depression is often under-diagnosed in the elderly. A large study of 20,900 Medicare records found that depression was diagnosed in only 5% of elderly patients in 1998 (Crystal, Sambamoorthi, Walkup & Akncgil, 2003). The Minimum Data Set (MDS) which is the federally mandated standard assessment tool that is used in skilled nursing facilities, has been found to miss 87% of all types of depression (Hendrix, Sakauye, Karabatsos & Daigle, 2003).

Depression is frequently misdiagnosed as dementia. Up to 32% of those who seek evaluation of dementia are actually depressed and cognitively intact (Marin, Sewell & Schlecter, 2002). When depression in the elderly presents as cognitive impairment it has been called pseudodementia . The person with dementia has permanent memory impairment while the person with pseudodementia has selective memory loss. The depressed person often does not cooperate during testing and this mimics dementia (Gallasi, Morreale & Pagni, 2001).

There are many studies about depression in older adults. Some report on major depression only, some include minor depression. Some studies describe depression in older adults living in the community, others in skilled nursing facilities and hospitals and some in assisted living facilities. Some studies report on depression in those with dementia, other studies include both those with dementia and those without.

Depending on the measurement instruments used, the prevalence of depression ranges from 10% to 38% (Doetch, Alger, Glaeser & Levenstei, 1994; Kukall, Koepsell & Inui, 1986). A large study of 498 elderly people from one urban and five rural clinics conducted between 1992 and 1998 reported 31% to be depressed. This study measured cognition and those with moderate to severe dementia were excluded (Schulman, Gariola, Kuder & McCulloch, 2002). Another study of residents in senior apartments reported a dementia rate of 7% and a depression rate of over 12% (Marocco, 1996).

One study measured only the rate of major depression in community-dwelling elders and reported a 2% depression rate (Koenig & Blazer, 1996). Higher rates of major depression have been found in skilled nursing facilities from 6% to 24% and minor depression rates of 35% (Katz & Parmalee, 1994).

There are contradictory findings regarding the link between co-morbid medical conditions and depression. One study found no connection (Schulman, et. al., 2002) while another reported that medical conditions such as metabolic disorders, heart disease, cancer, endocrine abnormalities, arthritis, infection and dementia can lead to depression (Kane, Ouslander & Abrasos, 1999). A major depression rate of 50% was reported in institutionalized elderly who are medically ill (Koenig & Blazer, 1996).

There are wide discrepancies in prevalence studies of depression in people with dementia due to methodological issues including inconsistencies in data collection methods. Some studies rely on caregivers for information while other studies rely on patient report (Cherminski, Petracca, Sabe, Krener & Starkstein, 2001). Depressed patients rate their symptoms as less severe than do their caregivers. They may lack insight into their symptoms (Cherminski et. al., 2001). In a three year study, older adults

with sub-clinical cognitive dysfunction had a rate of developing dementia of 16% at year three. Overall, 75% of subjects in this study showed at least two symptoms of depression. The rates of depression were 19%, 14% and 16% for the three years respectively (Ritchie, et.al, 1999).

There are many studies of depression in persons with dementia. One reported clinically significant depression rates of 15-30% (Teri and Wagner, 1992). An Italian study reported a depression rate of 50% (Gallassi, Morreale & Pagni, 2001). In a study of community-dwelling elderly with dementia, 40% had depression (20% mild, 9% moderate and 11% severe) while 12% of the matched controls without dementia had depression (7% mild, 5% moderate and 0% severe) (Lazarus, Newton, Cohler, Lesser & Schwen, 1987). Among those with dementia in skilled nursing facilities, depression rates have been reported to range from 14-39% (Cohen, Hyland & Frankowitz, 1995).

While there is a large body of data on depression in community-dwelling older adults and those in skilled nursing facilities, both with and without dementia, empirical evidence describing depression in people with dementia residing in assisted living is just emerging. One study of depression in older adults in assisted living reported rates of 25-36% (Morgan, et. al., 2001). A study that compared depression rates in community settings and assisted living elderly found significantly higher depression rates in assisted living (Grayson, Lubin & Van Whitlock, 1995). A multi-state study of 193 assisted living facilities reported that 13% of people with dementia in assisted living were depressed and only 18% of those were on antidepressants. When the definition of depression was broadened to include those with any symptoms of depression, such as an anxious expression or rumination, the rate increased to 33% (Watson, et. al., 2003).

One limitation of many depression studies is that they are cross-sectional. In another longitudinal analysis of people with AD it was found that 85% had depression at some point (Levy et. al, 1996). While some studies report higher depression rates in assisted living compared with the community and skilled nursing facilities, there is little empirical evidence that is theoretically driven regarding the association of depression with agitation in persons with dementia in assisted living.

Co-Morbid Conditions and Dementia

Older adults often have multiple co-morbid conditions and this can create various physical symptoms (e.g. pain, nausea, dizziness and other types of discomfort) that are hypothesized to increase agitation in dementia if these needs are unrecognized and unmet (Beck & Vogelpohl, 1999). In a study of 679 AD patients from multiple sites including outpatient centers, assisted living and nursing homes, 61% of patients were reported to have three or more co-morbid illnesses (Doraiswamy, Leon, Cummings, Marin & Newmann, 2002). Other studies in assisted living reveal the following prevalence of various health problems:

Hypertension	49%
Arthritis	42%
Vision problems	46%
Incontinence	30%
Cardiac, psychiatric, dizziness and imbalance	24-40%
Depression	23-26%
Diabetes	11%

Assistive devices for mobility required	51-56%
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Hospitalization required in a six-month period	20%
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(Morgan, Gruber-Baldini & Magaziner, 2001).

Another large assisted living study reported:

Cardiac disease	38-49%
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Cognitive impairment	23-42% (compared with 51% in nursing homes)
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(Zimmerman et. al., 2003).

In a study of the health characteristics of residents in personal care homes that compared those with dementia, or mild cognitive impairment and no dementia, no significant differences were found regarding physical health variables except that those without dementia had higher rates of falls and fractures (Quinn, Johnson, Andress & McGinnis., 2003). This may be due to admission selection. Those with dementia who are also frail and have physical ailments may be excluded from admission. In a report of six national studies in assisted living, Golant (2004) reported that facilities were more likely to admit and retain older, frail persons when they had less serious health care needs.

Function and Dementia

In the mid stages of dementia, individuals often develop motor problems and agitation (Kelley, 1998). In a longitudinal study conducted in Sweden of 1,745 people, age 75+, function was measured at baseline and every year for three years. At baseline, factors associated with functional dependence were age, dementia, cerebrovascular

disease, heart disease and hip fracture. Only age and dementia were associated with functional decline after three years (Aguero-Torres, et. al. 1998).

Functional decline in AD can lead to agitation (Hill, Backman and Fratiglioni, 1995). Decreased function in AD can lead to unmet needs. One study reported that the inability to ambulate leads to a diminished ability to toilet oneself and increased rates of incontinence (Jirovec & Wells, 1990). In nursing homes, impaired ambulation has been found to correlate with vocal agitation (Cariaga, Burgio, Flynn & Martin, 1991).

There are studies from assisted living that document the presence of agitation in dementia (Aud, 2004; Schonfeld, 2003) and many studies that document functional impairment in assisted living residents (Gruber-Baldini et al., 2004) but none that studied whether functional decline in AD predicted increased agitation in assisted living.

Research in Assisted Living

There is an emerging body of knowledge about assisted living, much of which is descriptive. Research to date suggests that persons with dementia who reside in assisted living facilities commonly exhibit agitated behaviors and many have health problems (Schonfeld, 2003; Zimmerman et. al., 2001). The largest comprehensive RC/AL study published to date is the Collaborative Studies of Long-Term Care (CS-LTC) in which two NIH funded studies of 2,834 residents from 233 facilities in four states, were integrated and conducted in cooperation (Zimmerman, et. al., 2001).

The CS-LTC examines and compares the relationship of the structure and process of care with population outcomes. The primary goals of the study were to examine adverse medical outcomes, change in functional status and use of health services over a

one year period to determine how they relate to resident characteristics and quality of care in RC/AL and nursing homes (Zimmerman, et. al., 2001).

In another large multi-state study of 1,500 assisted living administrators surveyed by telephone, wide variations were found in the degree to which facilities adhered to the philosophy of aging in place in assisted living. Seventy-six percent said that they would not retain residents with agitated behaviors such as wandering. The administrators estimated that 34% of residents had moderate to severe cognitive impairment (Hawes, Phillips, Rose, Holan & Sherman, 2003). The CS-LTC reports that 50% of residents have dementia (Gruber-Baldini et. al., 2004).

Conclusion

There is a need to examine the characteristics of persons with dementia in assisted living, and the presence of agitation and factors associated with these behaviors, in order to develop interventions that can reduce agitation with the goal of improving the comfort level of residents and enabling them to live as long as possible in assisted living.

No studies were found that measured pain, depression, function and co-morbid conditions and the relationship of these factors to the extent of agitation in dementia. This research was conducted to address this gap in the literature regarding persons with dementia in assisted living facilities.

CHAPTER THREE

Methodology

Purpose of the Study

The purpose of this study was to describe the physical and mental health of persons with dementia who reside in assisted living facilities and to examine the association between factors. Based on the Need-Driven Dementia-Compromised Behavior Model (NDB), it was hypothesized that there would be a positive association between increased agitation and physical and mental health needs, and a negative association between increased agitation and decreased function. In addition, this study described pharmacologic treatments provided to residents in the assisted living setting and examined differences in agitation between subjects' with mild to moderate versus moderate to severe dementia.

Research Questions

This study was guided by the following three primary research questions and one secondary question:

- 1) What is the extent of pain, depression, number and severity of co-morbid conditions, functional impairment and agitation in persons with dementia residing in assisted living facilities?
- 2) What is the prevalence of analgesic and psychotropic medications in persons with dementia residing in assisted living facilities?

3) What is the level of association of pain, depression, co-morbid conditions and functional impairment to agitation in persons with dementia residing in assisted living facilities?

Secondary research question:

4) Are there differences in agitation between those with a mild-moderate versus moderate-severe cognitive impairment?

Hypotheses:

The null hypotheses tested in this study were:

$$H_0 = r = 0$$

$$H_a = r > 0 \quad H_a = r < 0 \text{ (for the functional status factor)}$$

1. There is no association between the extent of pain and agitation
2. There is no association between the extent of depression and agitation
3. There is no association between number and severity of co-morbid conditions and agitation
4. There is no association between functional level and agitation
5. Controlling for co-morbid conditions and functional status there will be no association between depression, pain and agitation.

$$H_0: X_1 = X_2$$

6. There is no difference in the extent of agitation between those residents with a Mini-Mental State Examination score (MMSE) of 16 or below and those with a score of 17-23.

Alternative hypotheses were:

1. There is a positive relationship between the extent of pain and agitation

2. There is a positive relationship between the extent of depression and agitation
3. There is a positive relationship between number and severity of co-morbid conditions and agitation
4. There is a negative relationship between functional level and agitation
5. Controlling for co-morbid conditions and functional status, depression and pain will be positively associated with agitation.

$H_a \neq X_1 - X_2$

6. There is a difference in the extent of agitation between residents with a MMSE score of 16 or below and those with a score of 17-23.

Research Design

This descriptive, correlational study utilized a cross-sectional methodology. A convenience sample was used consisting of residents from small (≤ 20 beds) and large (> 20 bed) facilities. Depression, pain, number and severity of co-morbid conditions, functional level, agitation and psychotropic and analgesic medication use in persons with dementia were measured. Demographic variables were collected including age, gender, marital status, ethnicity and length of stay in the facility. Data were collected using questionnaires that were completed by the researcher in an interview with the residents, the staff, and through chart review. The researcher was the only data collector.

Strengths of the Research Design

This design was chosen in order to examine a relationship at a point in time among residents in assisted living facilities. Correlational studies are designed to determine the direction and magnitude of relationships among variables in a group of subjects. There are various strengths in this type of design. First, results of this type of

study can provide the information needed for designing a controlled experiment that can address cause and effect. Secondly, a correlational research design is practical and feasible. It can be used to gather information from a large number of subjects with comparatively minimal time and money. Thirdly, because this type of methodology is stated explicitly, it can be easily replicated. Finally, this design utilizes existing standardized questionnaires and instruments (Polit & Beck 2004).

Limitations of the Research Design

There are also limitations to this type of research design. Causal claims cannot be made. Correlational studies seek to determine those factors that vary together without altering the natural situation or attempting to make conclusions about whether one causes the other. Items on questionnaires can be confusing or perceived as irrelevant to subjects and can then result in meaningless data. Data may be relatively superficial and caregiver report can be less valid than direct observation. Finally, there is limited generalizability outside of a large Midwestern area and outside of Wisconsin based on the sample in this study (Polit & Beck, 2004).

Setting

“Assisted Living” in the state of Wisconsin consists of two types of facilities—Residential Care Apartment Complexes (RCAC) and Community Based Residential Facilities (CBRF). An RCAC is a place where five or more adults reside that consists of independent apartments, each of which has an individual bathroom, sleeping and living areas, and provides not more than 28 hours per week in total of services that are supportive, personal and nursing in nature (Wisconsin Administrative Code, Chapter HFS 89, 2001).

A CBRF is a place where 5 or more unrelated adults reside in where, treatment or services above the level of room and board is provided but not including more than three hours of skilled nursing care per week per resident. If a residents' condition is stable and services are available in the facility, a waiver may be granted for residents needing more than three hours of skilled care per week. There is no limit placed on supportive services. CBRFs are licensed by the state based on size and whether residents are ambulatory, semi-ambulatory, or non-ambulatory.

Facilities are categorized as being Class A or Class C depending upon whether or not their residents are mentally and physically capable of exiting the building without any help, such as verbal or physical prompting, in response to a fire or other emergency. In Class A facilities, the residents are capable of this action, whereas in Class C facilities, they are not (Wisconsin Administrative Code, 2001).

The philosophy of the RCAC is that of a shared responsibility role with the tenant. This requires a higher level of cognitive functioning because the RCAC tenant has to have the ability to accept a service or not, giving the tenant the right to control his/her environment. Residents of CBRF facilities tend to be more cognitively and physically impaired than those of RCAC facilities. CBRFs are able to house residents with more cognitive impairment than the RCAC. CBRF facilities were used in this study

Facilities were selected from the State of Wisconsin Community Based Residential Facility Directory. Facilities from Milwaukee, Ozaukee and Waukesha counties were chosen as a convenience sample. Both small (≤ 20 beds) and large (>20 beds) were included. Previous research suggests that there are greater levels of agitation

in persons with dementia in facilities smaller than 16 beds although the reasons for this is are not known (Schonfeld, 2003).

After consultation with assisted living directors in the Milwaukee metropolitan area, it was found that many facilities have 20 beds. Thus, the definition of a small facility for this study was defined as 20 beds or fewer rather than 16. The Wisconsin Administrative Code also specifies ≥ 21 beds as a larger size CBRF (Wisconsin Administrative Code, 2001, 258-4)

Large facilities (> 20 beds) were included in the study for representativeness. While the original study design called for half of the subjects to be drawn from small facilities and the other half to be drawn from large facilities, it became apparent that this was not feasible since it was more difficult to recruit small versus large facilities for the study. Administrators of small facilities were less willing to return calls or to agree to participate, so in the final sample 70% of subjects ($n=45$) were drawn from the larger facilities. For feasibility purposes facilities within a 30 mile radius of a large metropolitan area were selected.

Sample

The sample for this descriptive, correlational study was a convenience sample taken from 8 smaller size CBRFs and 7 large facilities, located in a large metropolitan area in Wisconsin. The sample included subjects that met the following eligibility criteria. The rationale for criteria appear in parentheses below:

- \geq age 65 (to control for potential differences in co-morbid conditions and pain)

- Had resided in the facility greater than four weeks (to control for relocation trauma)
- Known to have dementia (dementia was verified by the researcher using the Mini-Mental State Examination. Criteria for dementia is a score ≤ 23) (Murden, McRae, Kaner & Buckham, 1991)
- Except for dementia and depression, absence of major psychiatric disorders, such as schizophrenia (to control for confounding influence)
- Exhibited agitation in the past three months
- English speaking
- Additional exclusion added once in the field: a MMSE low cut-off score of $>$ or equal to 8 as it was discovered that below an 8, subjects were unable to complete the Geriatric Depression Scale.

Sample Size

For this study, the alpha was set at .05 and the power at .80. Effect size is a measure of the strength of the relationship between independent and dependent variables in the population. Power refers to the probability that effects that actually exist have a chance of producing statistical significance in data analysis (Tabachnick & Fidell, 2001). The effect size is the estimate of the magnitude of the relationship between the research variables. When relationships are strong, large samples are not needed to detect the effect at statistically significant levels. When relationships are modest in size, a larger sample size is needed to avoid a Type II error (wrongly accepting a false null hypothesis).

A power analysis was used to determine the sample size requirements for this study. Power analysis takes the estimated effect size into account. Sample size was

based on a moderate effect size of $R^2 = .13$ (Cohen, 1988). The following equation was utilized:

$$N = L/\gamma + k + 1$$

N = # of cases needed

L = tabled value for a specified α

γ = estimated effect size

k = number of predictor variables

k in this study was comprised of four independent variables: depression, pain, number and severity of co-morbid conditions and function. Based on the power analysis, it was determined that 60 subjects would be required.

Discussion of Pilot Study

The pilot study will be described prior to the proposed main study. A pilot study was conducted between April and June of 2005 at a large CBRF in a Midwestern metropolitan city. The pilot study provided important information regarding methods to be used in the main study. First, the pilot study will be presented with a description of methodological decisions informed by the results. Next, the procedures that were used in the main study will be presented.

Purposes of the Pilot Study

The purposes of the pilot study were to:

- a) examine accessibility of subjects, feasibility of consent and recruitment processes and instrument administration

- b) determine the range and variability of measures in a population of persons with dementia residing in assisted living
- c) to establish the reliability of the observational instrument

Pilot Study Sample

In order to recruit the pilot facility, the researcher chose a potential facility by convenience and called the administrator who agreed to participate. The researcher then sent a letter to the administrator (Appendix A) and an abstract of the study (Appendix B). Subjects were recruited by convenience, and informed consent was obtained for 12 residents. Of these 12 subjects, 2 did not meet the criteria for dementia as they had an MMSE of over 24, another resident was never available to interview, and a fourth was completely deaf and the researcher could not communicate in a way that would allow for completion of the instruments. This resulted in a total of 8 subjects that met criteria. Data were collected on these 8 subjects.

Three subjects were male and 5 were female in the pilot study. The average age was 84, with an age range from 68 to 92. Scores on the MMSE ranged from three to 22 with the average being 13. Excluding the extreme outlying score of three, however, the average MMSE score was 18. Seventy-Four percent of the 8 pilot subjects had at least one psychotropic medication prescribed. Sixty percent of the subjects were on an antidepressant (n=5). Fifty percent of the subjects were receiving cognitive enhancing medication such as Aricept (n=4). Fifty percent of the subjects were able to provide their own consent (n=4) and 50% (n=4) of subjects had consent provided by a surrogate decision maker.

Pilot Study Data Collection Methods

Research Instruments

Data were collected in the pilot study using the following instruments. The instrument changes made for the main study are also listed as follows:

Pilot Study Instruments	Main Study Instrument Changes
1) Mini-Mental State Examination (MMSE)	
2) Geriatric Depression Scale – Short Form (GDS-SF)	Geriatric Depression Scale (GDS)
3) Functional Assessment Staging Tool (FAST)	Functional Behavior Profile (FBP)
4) Modified Resistiveness to Care	Eliminated
5) Cumulative Illness Rating Scale-Geriatrics (CIRS-G)	
6) Numerical Rating Scale (NRS)	
7) Coloured Analogue Scale (CAS)	
8) Checklist of Nonverbal Pain Indicators (CNPI)	
9) Wisconsin Agitation Inventory (WAI)	Cohen-Mansfield Agitation
10) Facility Profile	Inventory (CMAI)
11) Demographic Data Form	

(Appendix H)

A description of each instrument, the method of data collection and evidence for validity and reliability is presented below. Based on pilot study results, 3 instruments were changed for the main study and one was eliminated. The GDS-SF was changed to the 30-item GDS long form, the FAST was changed to the Functional Behavior Profile (FBP), the Modified Resistiveness to Care Scale was eliminated and the Wisconsin

Agitation Inventory was changed to the Cohen-Mansfield Agitation Inventory (CMAI). The rationale for these changes is presented in this section.

Mini-Mental State Examination (MMSE)

Description of Instrument

The Mini-Mental State Examination (MMSE) (Appendix H) is a brief screening test of cognitive function comprised of 30 questions that has become a commonly used standard screening tool for cognition. The MMSE measures global cognitive status and includes questions regarding orientation, registration, recall, attention, calculation and language. The range of scores is 0-30. (Folstein, Folstein & McHugh, 1975). The MMSE was calculated to adjust for 7 subjects who could not complete some of the questions due to visual or physical impairment. These subjects could not see to read “close your eyes” or could not see to complete the drawing of the diagram. In these cases the subjects mean score was used.

Method of Data Collection

Approximately fifteen minutes were required to administer the MMSE. The researcher asked questions of the subject. One question required the subject to draw a figure on paper. Only correct answers were scored. Unanswered questions were scored as zero, since refusal to answer most likely indicates an inability to answer correctly. For the geriatric population, scores of 24-30 usually indicate uncertain or no cognitive impairment, 18-23 mild to moderate cognitive impairment and 0-17 severe cognitive impairment (Crum, Anthony, Bassett & Folstein, 1993; Tombaugh & McIntyre, 1992). However, data analysis revealed that the sample was most closely divided at 16 and

below (47% of the sample) and scores of 17-23 (53% of the sample) so, in the data analysis the secondary question was revised to compare groups with those levels.

Validity and Reliability

The MMSE is a valid screening tool for cognitive impairment in geriatric patients (Folstein, Folstein & McHugh, 1975). Studies have found that the inability to achieve a normal score (24 or higher) on the MMSE is a nonspecific indicator of cognitive impairment (Crum, et. al., 1993). The MMSE has demonstrated construct validity and measures of criterion validity have shown high levels of sensitivity for moderate to severe cognitive impairment (Tombaugh & McIntyre, 1992).

In a study that compared the validities of three cognitive instruments—the MMSE, the Abbreviated Mental Test (AMT) and Mental Status Questionnaire (MSQ)—sensitivities and specificities were 80% and 98% for the MMSE, 77% and 90% for the AMT and 70% and 89% for the MSQ, using a cognitive test battery, the CAMCOG (the cognitive section of the CAMDEX, the Cambridge Mental Disorders of the Elderly Examination) as a gold standard (MacKenzie, 1996). The MMSE had significantly fewer false positives than the AMT and MSQ.

The reliability of the MMSE has been established in many populations including older adults who are neurologically intact (Mitrushina & Satz, 1991 and Tombaugh & McIntyre, 1992). One study found test-retest reliability of 0.94 at 1-2 weeks and 0.85 at 3-4 weeks in persons over age 60 (Van Belle, et. al., 1990).

Geriatric Depression Scale – Short Form and Long Form

Description of Instrument

The original Geriatric Depression Scale (GDS) was developed in 1983 (Yesavage, et. al., 1983) to measure depressive symptomatology in elderly people. It is one of the most widely used depression scales (Montorio & Izal, 1996). The original scale has 30 questions. A shorter 15-item version entitled the Geriatric Depression Scale – Short Form (GDS-SF) has been developed. The GDS-SF asks questions such as “Are you basically satisfied with your life?” and addresses areas that are known to be affected in a person who is depressed. Each answer indicating depression scores one point. A maximum score of 15 is possible. In a population of community-dwelling older adults age 60 or older, a cutoff score of >5 has been found to result in the ability to identify major depression (Lyness, et. al., 1997).

The short form of the GDS was chosen for the pilot study because it was designed to be brief. It is important to keep total instrument administration time manageable for the older adult subject who may fatigue easily. It was found to be easy to administer in the pilot study and for the main study the original 30 questions GDS form was used as more research has been conducted using it and it is easy to administer and not taxing for the subjects. It has been reported that the GDS remains valid in individuals with a MMSE score of at least 15 (Katz, 1998).

Method of Data Collection

The GDS-SF was administered through an interview with the subject. Ten minutes were required to administer the GDS-SF. The GDS scale attempts to control

acquiescence response set by balancing positively and negatively worded statements. Some of the questions may be perceived as quite personal, so the researcher explained the procedure and the reasons why the screening tool was being used. An explanation was provided such as “The questions on the scale will look in some detail at how you may be feeling right now. Some of the questions may seem personal. If you feel anxious or upset then please let me know.” None of the pilot subjects declined to answer. Only one subject refused to answer all of the questions on the GDS in the main study. Another subject refused to participate at all in the study. The 30-item GDS was used in the main study. The range of scores was 0-30, with higher scores indicating more depression.

Validity and Reliability

In studies of depression in the elderly, the GDS was found to have reliability and validity equal to that of another instrument, the Beck Depression Inventory. Internal consistency of the GDS has been reported as 0.84 (Jefferson, Powers & Pope, 2001). Concurrent validity has been demonstrated with the Hamilton Rating Scale for Depression, $r=.82$. Test-retest reliability ranged from $r = .85$ to $r = .98$ at 7 to 10 days (Yesavage et. al., 1983). The GDS-SF has shown good agreement with the GDS-30 in defining severity of depression (Isella, Letizia & Appollonio, 2001).

In a study of hospitalized patients, the long and short forms of the GDS were compared. The short form consistently identified 94% of the participants using the long form as the standard (Aikman, 2001). The GDS-SF is valid when used with people with mild to moderate cognitive impairment (Sheikh & Yesavage, 1986). In another study of homebound ill elderly, the correlation between the Zung Self-rating Depression Scale and

GDS-SF was studied. The two scales were correlated $r = 0.76$, the internal reliability of the GDS was 0.825 (Iglesias, 2004).

In a population of community-dwelling older adults over age 60, major depression was identified with a score of >5 with 91% sensitivity and 81% specificity (Lyness et. al., 1997). A study of older adults admitted to a geropsychiatric unit, a score of >5 on the GDS-SF identified depression with 91% sensitivity and 54% specificity (Leshner, et. al., 1994). The GDS has been found to be reliable in residents in long-term care (Leshner, 1986, and Parmalee, et. al., 1989) and has been used in residential care homes and assisted living facilities (Cuijpers & Lammeren, 1999; Marocco, 1996).

Some researchers have questioned the adequacy of the GDS to measure depression in persons with dementia (Montorio & Izal, 1996). However, it was found in this study that all of the subjects with a score of 8 or higher on the MMSE were able to respond to the questions. No questions went unanswered, except that subjects sometimes provided an answer somewhere between “yes” and “no”. A comparison of the number of this type of response to a question by cognitive level on the MMSE was made and no statistically significant difference was found between those with a MMSE score of 8-16 versus those with an MMSE score of 17-23.

Functional Assessment Staging Tool (FAST)

Description of Instrument

The Functional Assessment Staging Tool (FAST) was developed to allow for the specific evaluation of functional changes throughout the entire course of AD (Sclan & Reisberg, 1992). The FAST is questionnaire comprised of 7 major functional levels and 11 sub-stages administered to caregivers. It was not found to be sensitive enough and the

instrument was changed to the Functional Behavioral Profile for the main study. (Appendix H).

Modified Resistiveness to Care

Description of Instrument

The Resistiveness to Care Scale lists 13 different agitated behaviors. It was administered to caregivers. There was little variability found in the pilot study and it was dropped for the main study. (Mahoney et. al.,1999) (Appendix H).

Cumulative Illness Rating Scale- Geriatrics (CIRS-G)

Description of Instrument

The Cumulative Illness Rating Scale was designed to measure co-morbidity in older adults (Miller, 1992). It is an estimate of the number and burden of illnesses. The CIRS rates 14 organ systems on a 5-point Likert scale as follows:

1= no impairment

2 = mild impairment

3 = moderate impairment

4 = severe impairment

5 = extremely severe impairment

A modified scale, referred to as the CIRS- G (for geriatric), was later developed for use with institutionalized elderly including those in congregate housing. The CIRS-G adds only a hypertension question to the original CIRS (Appendix H).

Method of Data Collection

The CIRS-G utilizes chart review to collect data. The severity of pathology is estimated. Higher ratings indicate greater severity. Two scores are derived. The total

score indicates overall burden of illness—based on total severity ratings across 14 categories (0-52). The Severity Index score is the total score divided by the number of categories endorsed. The Manual of Guidelines for Scoring was utilized in this study (Miller & Towers, 1991).

Validity and Reliability

The CIRS-G was validated in a long-term care facility that included skilled nursing and congregate apartments. Sixty-one percent of elderly subjects with dementia had three or more co-morbid illnesses and co-morbidity was found to increase with dementia severity (Parmalee et. al., 1999).

The CIRS-G was found to show good divergent validity and was found to be a valid indicator of health status among frail older institutionalized residents. The illness severity and co-morbidity composites performed equally well in predicting longitudinal outcomes. Item-level analyses suggest that the CIRS- G may be useful in developing differential illness profiles associated with mortality, hospitalization and disability (Parmalee, et. al., 1995). Other co-morbidity scales have been tested only on acutely ill patients in hospitals. Interclass correlations in geriatric populations have been reported as 0.78-0.88 (De Groot, Beckerman, Lankhorst & Bouter, 2003).

Pain Instruments

Pain was measured in the pilot study with three instruments: two self-report measures-- a numerical rating scale (NRS), a visual analogue scale, called the Coloured Analogue Scale (CAS), and a behavioral pain instrument, the Checklist of Nonverbal Pain Indicators (CNPI). The reason that three instruments were utilized was that not all

subjects with dementia are able to use self-report measures, so a behavioral tool was included (Appendix H).

Numerical rating scales (in which patients are asked to rate their pain on a scale from 0 to 10) are the most commonly used pain instruments in the cognitively intact population. There is limited evidence that some people with dementia are able to use this scale and thus should be given the opportunity to use it. In addition, there are also limitations to observational tools. Many repeated observations are required which can be unfeasible. Pain is a subjective phenomenon as well and best assessed by self-report when an individual is able to self-report. For those who cannot understand the numerical rating scale, it has been found that a visual analogue scale, the CAS, is able to be completed by many older adults with dementia living in the community (Scherder & Bouma, 2000).

Numerical Rating Scale

Description of Instrument

A numerical rating scale is a self-report instrument in which an individual is asked to rate their pain on a scale of 0 to 5 or 0 to 10, with definitions of lower and upper limits provided such as “no pain” to “worse pain imaginable”.

Method of Data Collection

First, the researcher asked the subject a simple “yes” or “no” question, “Do you have any pain or aches or soreness?” The researcher added the words aches, and soreness as it has been found in clinical practice that older adults often differentiate the term “pain” from other terms such as “aches”. Aches and soreness, of course, are types of pain. If the subject states “yes”, then the researcher asked the subject to rate their pain on a scale

from 0 to 10. Zero being defined as no pain at all and 10 being terrible pain. Three minutes was required to administer the tool. Careful explanation of the instrument was provided to the subject.

Validity and Reliability

Previous research has established that self-reports of pain can be valid in people with mild and moderate cognitive impairment. Up to 83% of people with dementia have been found to be able to answer “yes” or “no” regarding whether they have pain and are able to locate the pain (Ferrell, Ferrell & Rivera, 1995; Parmalee, Smith & Katz, 1993). Residents must be able to translate pain into numbers, however, in order to rate the severity of pain. Fifty percent of nursing home residents with cognitive impairment were found in one study to be unable to rate their pain intensity using a numerical rating scale (Ferrell, et. al., 1995).

Coloured Analogue Scale

Description of Instrument

The Coloured Analogue Scale (CAS) is a type of visual analogue scale and was originally developed to provide a simple tool for obtaining pain ratings with children (McGrath et. al, 1996). Research has shown that the CAS can be reliably administered to dementia patients (Scherder & Bouma, 2000). The CAS consists of a 14.5 mm long triangular shape, varying in width and hue from 1 mm wide and light pink hue at the bottom to a 3 mm wide and deep red hue at the top. The scale is contained on an 18 X 5 inch plastic card. The different scale positions are marked by different colors and areas that facilitate the subject’s selection of a scale position which best reflects their pain intensity. (Appendix H).

Method of Data Collection

Subjects were shown the CAS and asked to indicate where the marker should be placed in order to match their pain level. The place on the triangle where the subject places the marker corresponds to a numerical 0 to 10 scale on the back of the instrument that the researcher recorded. If subjects complained of pain in more than one area, then one specific area was selected for the purpose of this study. Again, as with the NRS, simple instructions were provided. Visual impairment or color blindness may affect the accuracy of results.

Validity and Reliability

Scherder and Bouma studied 3 visual analogue scales for pain assessment in early to mid-stage dementia: the CAS, the Faces Pain Scale and the Facial Affective Scale (2000). In their study, the Faces Pain Scale could only be comprehended by 50% of early stage and 20% of mid-stage AD subjects and the Facial Affective Scale (FAS) could be comprehended by only 60% percent of the early AD subjects and only 30% of the mid-stage AD subjects. The CAS was comprehended by all of the early subjects and 80% of those with mid-stage AD (Scherder & Bouma, 2000). In another study of 60 subjects with dementia (20 early, 20 mid-stage and 20 late stage) all subjects were able to comprehend the CAS (Scherder, et. al., 2003).

Checklist of Nonverbal Pain Indicators (CNPI)

Description of Instrument

The CNPI is an observational scale that includes five nonverbal behaviors:

1. nonverbal vocalizations (moans, groans, grunts, and cries)
2. grimacing (furrowed brow, narrowed eyes, tightened lips)

3. bracing (clutching or holding onto siderails, bed)
4. restlessness (constant or intermittent shifting of position)
5. rubbing (massaging the affected area)
6. any verbal indicators of pain (words that express pain such as ouch or that hurts)

A score of 0= absent, 1 = present. The maximum score is 6 (Feldt, 2000). The CNPI was originally developed because of concerns that some cognitively impaired patients would be unable to use the scaled instrument or respond reliably to the yes/no questions about pain after hip fracture surgery (Feldt, 2000).

The CNPI was also created to allow for measurement of non-ambulatory elders (behaviors can be observed during transfer, repositioning as well as ambulation). The CNPI was used in this study because it was anticipated that some subjects would be unable to comprehend the NRS and CAS self-report tool. The CNPI is a useful tool when patients are unable to use self-report measures, however, the tool is best used when the patient moves as patients' exhibit fewer pain behaviors when sitting or lying still (Feldt, 2000).(Appendix H).

Method of Data Collection

During the pilot study, data were collected two different times on the same day: during the interview period when the researcher was completing the MMSE, GDS-SF, NRS and CAS, the researcher observed the subject using the CNPI to assess for pain. The researcher also observed the resident on the same day at another time when there was no interaction with the researcher (for example, as they walked down the hall).

During the main study, observations were made only once. If the subject was moving at the initial data collection, then observations were conducted at this time, however, if the subject was not moving at the time of the initial data collection, then the researcher observed the subject later that day.

Validity and Reliability

The CNPI has good face validity based on the body of literature that describes pain behaviors in older adults with dementia (Sengstaken & King, 1993). Facial grimaces, followed by restlessness were the most commonly observed behaviors (Feldt, 1996). Inter-rater reliability was found to be 0.60 to 0.80 when subjects were observed during standing, walking and sitting down with or without aid (Feldt, 1996).

Inter-rater reliability was established for the CNPI during the pilot study in June 2005. This was accomplished by having the researcher and a second advance practice nurse with geriatric expertise, complete the CNPI simultaneously. Scores were compared and when 0.90 consistency was obtained, inter-rater reliability was considered to be established for this study on this behavioral instrument.

Wisconsin Agitation Inventory (WAI)

Description of Instrument

The WAI was developed in order to measure agitation in persons with AD (Kovach et. al, 2004). Agitation was operationalized according to the 29 items of the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield and Billig, 1986). Agitation intensity parameters (a visual analogue scale of 0-100) were added (Kovach et. al., 2004). (Appendix H).

Facility Profile

Description of Instrument

The Facility Profile is a descriptive instrument designed by the researcher for this study in order to collect general information about the facility including: whether the facility was affiliated with a skilled nursing facility, how long the facility had been in operation, the number of beds and the average census. A description of the population of the facility was assessed including percentage residents by payer source, gender, average age and ethnicity. Facility staffing was measured also, including the total number of staff, number of direct care staff and number of registered nurses and whether staff had received training in behavior management. The model of resident aggregation was also measured by collecting data on whether there was a specific dementia unit and if so, how many beds, and whether persons with dementia are aggregated with cognitively intact residents. (Appendix H).

Method of Data Collection

The instrument was completed through an interview with the administrator.

Demographic Data Form

Description of Instrument

The Demographic Data Form (Appendix H) is a descriptive instrument developed for this study by the researcher. The instrument was used to collect information that described the subjects including age, gender, marital status, length of time in the facility, ethnicity and a list of medications, as these factors may be related to the factors measured in this study.

Method of Data Collection

The Demographic Data Form was completed by the researcher through chart review.

RESEARCH PROCESS

Procedures of the Pilot Study

Approval for the pilot study was obtained from the Institutional Review Board at the University of Wisconsin-Milwaukee. The administrator and the nursing director of the assisted living facility were asked by the researcher to obtain informed consent from potential subjects that met the eligibility criteria described earlier in this chapter. For those residents who were not their own decision –maker a cover letter was sent to families (Appendix C) with the Family Information and Informed Consent Form (Appendix D). The cover letter asked the decision-maker to return the signed consent to the administrator. The administrator and nursing director used a script provided by the researcher when obtaining informed consent from residents (Appendix E). They asked the resident to sign a Letter of Participation and Consent (Appendix F) and they offered to read this letter to the resident.

While the administrator and nursing director expressed support for the research, they told the researcher that they had difficulty finding adequate time to obtain informed consent from subjects. They suggested to the researcher that a more efficient method would be for the administrator or his/her designee to ask residents for their permission to have the researcher come to the facility and explain the study and obtain informed consent. The informed consent process was changed to this method for the main study.

The researcher met with those for whom informed consent had been obtained. The Mini-Mental State Examination (MMSE) (Appendix H) was administered. This took approximately 10 minutes. The Demographic Data Form (DDF) and Cumulative Illness Rating Scale – Geriatric (CIRS-G) were completed via chart review. Educational level was rarely found recorded in the charts and was dropped from the DDF for the main study. The Geriatric Depression Scale- Short Form (GDS-SF) was easily administered in approximately 5 to 10 minutes. Because the GDS-SF required such a short period of time to administer, the longer 30 item original GDS was used in the main study because more research has been done on it.

The 3 pain instruments: numerical rating scale (NRS), Coloured Analogue Scale (CAS) and Checklist of Nonverbal Pain Indicators (CNPI) were also easily administered. Very few pain responses on any pain instrument were elicited among the pilot study subjects. Many residents were receiving analgesic medication.

In the pilot study, agitation was observed directly using the Wisconsin Agitation Inventory (WAI). Use of this instrument involved serial sequences of observations. This resulted in under-reporting of agitation in the pilot and the instrument to measure agitation was changed to the Cohen-Mansfield Agitation Inventory, which uses caregiver report for the main study (Appendix H).

Main Study Research Instruments

For the main study, data were collected using the following instruments: (Appendix H)

- 1) Mini-Mental State Examination (MMSE)
- 2) Geriatric Depression Scale –Long Form (GDS-30)
- 3) Numerical Rating Scale (NRS)

- 4) Coloured Analogue Scale (CAS)
- 5) Checklist of Nonverbal Pain Indicators (CNPI)
- 6) Cumulative Illness Rating Scale – Geriatrics (CIRS-G)
- 7) Functional Behavior Profile (FBP)
- 8) Cohen-Mansfield Agitation Inventory (CMAI)
- 9) Facility Profile
- 10) Demographic Data Form

The instruments, except the Functional Behavior Profile and Cohen-Mansfield Agitation Inventory, were described previously in the pilot study section of this chapter. Based on the pilot study, 3 instruments were changed and one was eliminated. The Modified Resistiveness to Care instrument was eliminated and the Functional Assessment Staging Tool (FAST) was replaced with the Functional Behavior Profile (FBP). The Wisconsin Agitation Inventory (WAI) was replaced with the Cohen-Mansfield Agitation Inventory (CMAI) and the GDS 30 item replaced the GDS15. (Appendix H). The Geriatric Depression Scale has been described previously. The FBP and CMAI instruments are described below.

Functional Behavior Profile (FBP)

Description of Instrument

The Functional Behavior Profile (FBP) (Appendix H) was developed and standardized to describe the productive behaviors of people with AD as observed by their caregivers (Baum, Edwards & Morrow-Howell, 1993). The instrument focuses on what the resident *can* do, the level of the patient's performance. The FBP is comprised of 27 items used to record caregivers' recent observations. There are 3 subscales in the FBP;

task performance, social interaction and problem solving. Task performance measures the capability of doing things, social interaction measures engagement with others in conversations and social activities and problem solving measures the ability to make decisions and learn new tasks. Approximately 15 minutes were required to complete the FBP.

Method of Data Collection

The instrument was completed by the researcher through an interview with a direct care worker who was familiar with the resident. Each item is scored 0 to 4. Higher scores indicate better performance along a continuum from “never” to “usually”.

Validity and Reliability

The 3 subscales of the FBP have been correlated with other measures including the Zarit Memory and Behavior Problem Checklist, the Blessed Dementia Scale and the Katz ADL scale (Baum, Edwards & Morrow-Howell, 1993). Initially, the instruments’ developers reported internal consistency reliability (Cronbach’s alpha) of 0.96 for task performance, 0.93 for socialization and .94 for problem solving (Baum & Edwards, 2000). Subsequently, in a recent study of stroke patients, reliability was found to be 0.86 for the FBP including 0.82 for task performance, 0.86 for socialization and 0.74 for problem solving (Baum & Edwards, 2000).

Cohen-Mansfield Agitation Inventory

Description of Instrument

The Cohen-Mansfield Agitation Inventory (CMAI) was developed to measure agitated behavior in nursing home residents with dementia (Cohen-Mansfield & Billig, 1986)(Appendix H). The CMAI is comprised of 29 items based on observable behaviors.

A higher score indicates a higher degree of agitation. The CMAI is often used and has been suggested by some authors as the most effective tool to measure need-driven behaviors in dementia (Whall, 1999). The instrument's author has stated "it is not useful to calculate a total score by add all categories... you need to conceptualize your understanding of these behaviors in order to aggregate the behaviors in a meaningful way (Cohen-Mansfield, 1991).

Method of Data Collection

Data were collected through a personal interview with a staff member who knew the resident well, which was a nursing assistant in most cases. The CMAI is a questionnaire that is completed by caregivers who rate agitated behaviors on a 7-point frequency scale that ranges from "never" to "several times an hour". A higher score indicates higher agitation. Caregivers rated agitated behaviors that had occurred in the previous two weeks. A total agitation score was calculated as the sum of the individual item rating. The CMAI can be can be scored by allowing the caregiver to complete the instrument or it can be scored during an interview with the caregiver. In this study, the instrument was completed by means of an interview with a caregiver who was familiar with the resident.

Agitation, as measured by the CMAI yielded a large range of values, from very low to very high. Accordingly, after examining the distribution of the CMAI responses, items were dichotomized with responses ≤ 4 scored as 0 and items ≥ 5 scored as 1. This resulted in a potential range of scores from 0-29.

Validity and Reliability

Internal consistency, validity and reliability of the CMAI were studied with a sample of 90 nursing home residents (Finkel, Lyons & Anderson, 1992). The alpha was reported as 0.86, 0.91 and 0.87 by raters on the day, evening and night shift, respectively. Test-retest reliability was 0.80 ($p < .05$). One sub-section's reliability was 0.30 ($p < .05$) and scores on the other subsections ranged from 0.78 to 0.96 ($p < .05$). Test-retest of the CMAI over one month has been shown to be good ($r = .074$ to $.92$) (Koss, et. al., 1997). In a study of 2,445 residents in 45 nursing homes in Australia, reliability was found to be high (Miller, Snowdon & Vaughn, 1995).

In a study of 175 persons with dementia, agitation was assessed using the Agitated Behavior Mapping Instrument (ABMI) based on direct observation and the CMAI. There were significant Pearson Product Moment correlations between identical items on the two instruments and summary measures. It was reported that informant ratings can achieve moderate agreement with direct observation (Cohen-Mansfield & Libin, 2004).

MAIN STUDY

Subject Recruitment and Human Subjects

A description of the study and consent procedures was submitted to the Institutional Review Board for the Protection of Human Subjects (IRB) at the University of Wisconsin – Milwaukee prior to the pilot study and again prior to the main study. For the main study, the researcher called the administrator of the facility to explain the study and inquire whether he or she was willing to participate. If the administrator agreed to

participate in the study, a facility recruitment letter (Appendix A) and an abstract of the study (Appendix B) was mailed to them and the researcher met with the administrator or his or her designee prior to recruitment of subjects.

In order to protect the privacy of the residents residing in the facilities, the administrator first obtained verbal consent from any potential subjects indicating that they were willing to talk with the researcher for the purpose of learning about and potentially participating in the study. As required by the IRB, the administrator used a script when talking with the residents (Appendix E).

The administrator or his/her designee identified potential subjects who met the following criteria:

- ≥ 65 years of age
- Had resided in the facility for greater than four weeks
- Known to have dementia
- Absence of major psychiatric disorders other than dementia and depression
- Had exhibited agitation in the past three months
- English speaking

In early and mid-stage dementia many people are still able to make their own decisions including the decision to participate in a research study. As the dementia advances, the individual eventually loses decisional capacity and must have decisions made by a surrogate decision maker. There are two types of surrogate decision makers: A Durable Power of Attorney for Health Care (DPOA-HC) designee or a legal, court-appointed guardian.

A DPOA-HC form needs to be prepared before an individual loses decisional capacity. On a DPOA-HC form, an individual designates the name of a person they wish to make decisions for them should they become incapacitated (such as occurs with advancing dementia). It requires two physicians or a physician and a psychologist to declare a person incapacitated.

Once a form is signed by these providers indicating that an individual is incapacitated, a previously completed DPOA-HC is then considered activated. This is referred to as an “activated Durable Power of Attorney for Health Care”. The person listed as the designee on the DPOA-HC then becomes the surrogate decision maker for the individual. When there is no DPOA-HC, then a legal guardian is appointed by the courts to make decisions for the incapacitated person.

In the main study, those 4 potential subjects who were their own decision maker (did not have an activated DPOA-HC or legal guardian) were asked to participate in the study by the researcher after the administrator obtained verbal consent for the researcher to talk with the resident. For those 4 residents who were unable to be their own decision-maker, consent was obtained from the DPOA-HC or legal guardian. In order to comply with federal privacy regulations, the administrator or his/her designee sent the Family Member Information and Informed Consent Form (Appendix D) to the surrogate decision maker along with a cover letter from the administrator (Appendix C). The Family Member Information and Informed (Appendix D) was also sent, as a courtesy, to the families of residents that were their own decision maker and that had agreed to participate in the study.

A stamped return envelope addressed to the researcher was included for those families that were surrogate decision makers. Receipt of this form allowed family members an opportunity to ask questions of the researcher and express approval or disapproval regarding their family members' participation in the study. A few families did call the researcher to ask questions and clarify their understanding of the study.

For those few subjects who could provide their own consent, once verbal consent to talk with the resident was obtained, the researcher met with the potential subject individually and explained the study using a script (Appendix G). The researcher offered to read the Letter of Participation and Informed Consent Form (Appendix F) to the resident and obtained the signature of subject. Data collection began after this form was signed by the subject, or a signed informed consent form was received from the surrogate decision maker. In the latter case, verbal assent was also obtained from the subject before data were collected.

Participants were under no pressure to participate in the study. They were free to refuse to answer questions or to terminate the process at any time. This research posed no more than minimal risk and yielded generalizable knowledge about the needs of persons with dementia residing in assisted living. The confidentiality of data was protected by using subject code numbers on the data collection forms.

During data collection, the master list of code numbers and subjects' names were kept in a locked file accessible only to the researcher and committee chair and were destroyed by the researcher after data collection was complete. All data in reports of the study will be presented in summary form. Original data will be kept on file for a three-year period by the researcher after the research is completed and then will be destroyed.

Data Collection Process

Data collection occurred on one day for an individual subject. Informed consent was obtained by the researcher before data collection. Informed consent for the majority of the subjects (96%, n=61) was obtained from family members.

The MMSE was completed first. If the score was <24 and >8 , the subject was included in the study. Next, a GDS was completed and the three pain instruments were administered. Total time spent with the subject was 20 to 30 minutes. The subject was asked about fatigue and the need for a break after the MMSE. If needed, the researcher was willing to allow for a break and would have returned in 15 to 20 minutes. All subjects, except two who refused to participate, seemed to enjoy talking with the researcher, and more time was spent after data collection in general conversation in order to not end the session abruptly. The subjects seemed to welcome the interaction.

The subjects' chart was then reviewed in order to complete the CIRS-G and Demographic Data Form (Appendix H). The researcher then interviewed a staff member in order to complete the Functional Behavior Profile and the Cohen-Mansfield Agitation Inventory (Appendix H). Attempts were made to interview staff on the same date as the data were collected and this was possible for almost all of the subjects. When this was not possible, the researcher arranged to return within the same week to complete data collection. Whenever possible, the researcher controlled for facility-level bias by dividing the sample among different caregivers. Either before data collection or after, the researcher interviewed the administrator to complete the Facility Profile (Appendix H).

Data Management

Before leaving the facility, data were checked and there were no missing values. Scores were computed for the MMSE, GDS, NRS, CAS, CNPI, CIRS-G, FBP and CMAI. Descriptive data from the Facility Profile were used to summarize results relative to facility characteristics. Data were coded and entered into SPSS 14.01, the Statistical Package for the Social Sciences for Windows® Software. Data are stored in the researcher's home in a locked file.

The calculated scores on all instruments were compared to the scores on the CMAI. Data collected was used to determine whether pain, higher depression, co-morbid conditions and lower functional scores correlated with increased agitation as measured with the CMAI.

Data Analysis

Data analysis was comprised of both descriptive and inferential testing. Because of an interest in comparing those with mild to moderate and moderate to severe cognitive impairment, the MMSE was dichotomized into higher and lower levels based on an examination of the frequency of distribution, the cut-off for moderate to severe cognitive impairment was ≤ 16 and the range for mild to moderate was 17-23.

Debate exists in the literature regarding whether measures that contain rating of items and summed scores are inherently ordinal or interval. Methodological studies have suggested that treating them as interval measures is not likely to result in major distortions as long as the scales approximate interval characteristics ((Polit, & Beck 2004). Descriptive data from the Facility Profile were used to summarize results relative

to facility characteristics. T-tests were conducted to measure differences between variables based on gender.

Hierarchical multiple regression analysis is a method for investigating the influence and the degree of the influence of more than one independent (or predictor) variable on a dependent (criterion) variable using principles of correlation and regression. The technique is also a method for assessing the relative contribution of the independent variables in predicting the dependent variable (Tabachnick & Fidell, 2001). This statistical technique was used in this study.

Distribution of all variables were examined and tested for skew prior to statistical analyses. Skew was found in the CMAI and a square root transformation was applied. Frequencies and percentages were used to describe the data. Means were used as the measure of central tendency and the standard deviation range was used to describe dispersion of data. The independent variables of pain, depression, severity index of co-morbid conditions and functional levels were entered into a hierarchical multiple regression model in a series of steps. The order of entry was guided by the NDB theory and logic. Background factors, stipulated in the NDB model as stable factors that are less amenable to intervention, were entered into the regression model first (functional status and co-morbid conditions). The proximal factors of depression and pain, which are less stable and more amenable to change through intervention, were then entered. Pain was entered into the model last because of an interest in examining the unique percentage in agitation associated with pain.

Research Question One

What is the extent of pain, depression, number and severity of co-morbid conditions, functional impairment and agitation in persons with dementia residing in assisted living facilities?

This question was answered using descriptive statistics including means, standard deviations, range, frequencies and percentages.

Research Question Two

What is the prevalence of analgesic and psychotropic medications in persons with dementia residing in assisted living facilities?

This question was analyzed using frequency counts and descriptions of categories of drugs ordered.

Research Question Three

What is the level of association of pain, depression, number and severity of co-morbid conditions and functional impairment to the extent of agitation in persons with dementia residing in assisted living facilities?

First, the association between the factors was examined. Bivariate correlations were calculated using Pearson Product Moment correlations to examine the relationships between the variables. A hierarchical multiple regression analysis was then performed.

Research Question Four

Are there differences in agitation levels between those with mild to moderate versus moderate to severe cognitive impairment?

The t-test was used in order to examine differences in agitation based on the degree of cognitive impairment.

Study Limitations

There are several limitations to this study. In addition to those stated earlier in the proposal, the study relied on caregiver report of agitation as compared with direct observation. The method of direct observation of behavior was used in the pilot study and found to underreport agitation due to behavioral observations occurring on only one day. Direct observation of behavior on multiple days was judged to not be feasible in the main study with the need for 60 subjects.

The generalizability of the findings of the study is limited by the characteristics of the study. All facilities were located in southeastern Wisconsin and operated according to Wisconsin's regulations for licensed CBRFs. Facilities in other states operate under different regulations and this limits generalizability to other states. Another limitation of the study was that a convenience sample of both facilities and subjects was used. Randomization was not used to select facilities or subjects and thus this sample cannot be considered to represent all CBRFs in Wisconsin.

Summary

Many older adults with dementia and agitation reside in assisted living. Research in this area is in the early stages. Depression, pain, co-morbid conditions and functional decline are common in the elderly in the community and in skilled nursing facilities. There is limited evidence regarding the extent to which these factors are present in assisted living residents and this creates a need for further research. It is important to determine the relationships between those factors and agitation. Increased knowledge in this area may lead to improved assessment of and interventions for unmet needs in this

population. This may result in improved quality of care which may enable people with dementia to reside longer in assisted living.

This chapter has outlined the methodology used in the pilot study, and the final methodology used in the main study. The sample consisted of residents with dementia age 65 and older residing in a CBRF in a large metropolitan area in Wisconsin. Participants were limited to those who were English speaking, had resided in the facility for greater than 4 weeks and had exhibited agitated behaviors in the previous 3 weeks.

The data collection protocol was described including considerations of the protection of the rights of subjects. This included informed consent from the subject or their surrogate decision-maker, lack of identifying information on study instruments and limitations to data access only by the researcher. Study instruments and data analysis methods were also described.

CHAPTER FOUR

Results of Data Analysis

The purpose of this study was to describe the extent of pain, depression, co-morbid conditions and agitated behaviors of dementia residents in assisted living and to examine the association between those factors. In this study, behavioral symptoms have been operationalized as agitation and this term has been used throughout this paper. There were 3 primary and one secondary research question identified for this study. They were as follows:

Primary Questions:

1. What is the extent of pain, depression, number and severity of co-morbid conditions, functional impairment and agitation in persons with dementia residing in assisted living facilities?
2. What is the prevalence of analgesic and psychotropic medications in persons with dementia residing in assisted living facilities?
3. What is the level of association of pain, co-morbid conditions and functional impairment to agitation in persons with dementia residing in assisted living facilities?

Secondary Question:

4. Are there differences in agitation between those with mild- moderate vs. moderate-severe cognitive impairment?

This chapter provides a description of the sample and the facilities as well as findings in relation to the research questions. Data analysis included both descriptive and inferential statistics including frequencies, means, standard deviations, t-tests, Pearson Product Moment Correlations and a hierarchical multiple regression analysis. Data were coded and analyzed using SPSS for Windows® version 14.0.1 software package.

Description of Sample

Consistent with eligibility criteria, participants in the study were individuals age 65 and older with dementia residing in a Community-Based Residential Facility (CBRF), which is a type of assisted living facility in the State of Wisconsin. Following procedures approved by the Institutional Review Board of the University of Wisconsin – Milwaukee, written consent was obtained for 96 residents. Family members provided consent for all but 3 subjects (4%) who retained their right to self-determination and provided their own written consent. Thirty-two residents for whom consent was obtained were not included in the study for the following reasons:

- a) Mini-Mental State Exam (MMSE) score was > 23 (n=7)
- b) Mini-Mental State Exam (MMSE) score was < 8 (n=11)
- c) No agitation recorded on the CMAI (n=6)
- d) Subject had been hospitalized or admitted to a skilled nursing facility (n=3)
- e) Subject refused to participate (n=2)
- f) Consent was received after data collection was complete (n=3)

Sixty-four residents met the criteria for inclusion in the study. The exact number of informed consent requests sent by administrators to potential subjects was not measured and is not known. Some facilities informed the researcher of how many were sent and of those there was approximately a 50% response rate. A higher percentage of males were recruited (30%), higher than the average of males that reside in assisted living (23%). This may be due to the higher likelihood of males having spouses available to provide consent. In addition to written consent, verbal assent was also obtained from all subjects. The initial exclusion criteria did not specify a lower cut-off score for the MMSE, but rather simply the ability to be interviewed. During the study it was found that a resident with a MMSE score less than 8 was unable to complete the Geriatric Depression Scale and the exclusion criteria relative to low MMSE scores was modified in order to be able to measure depression in the sample.

The subjects were interviewed in person by the researcher at their facility of residence. The subjects were drawn from 15 different CBRFs from a large Midwestern metropolitan city in Wisconsin. The number of subjects drawn from any one facility ranged from 1 to 18.

Descriptive statistical analyses were used to determine frequencies, percentages, means and standard deviations of the sample characteristics. Demographic characteristics are presented in Table 1 and indicate that 70% (n=45) of subjects were female, predominantly widowed (77%, n=49) and ranged in age from 73-98 with a mean age of 85 years (SD=6 years). Approximately half (n=33) of the residents had resided in the facility for less than one year. Slightly more than half of the sample (52%, n=33) had a MMSE score of 17-23 indicating mild to moderate cognitive impairment. All subjects

were Caucasian which mirrored the total resident population of these facilities where 98% were Caucasian (Table 1).

Table 1

Demographic Characteristics of Sample (N=64)

Characteristic	Classification	n	%	Mean, SD, Range
Age	70-79	13	20.3	Mean: 85 yrs SD= 6.1 yrs Range: 73-98
	80-89	40	62.5	
	90-98	11	17	
Gender	Male	19	29.7	
	Female	45	70.3	
Marital Status	Single	6	7	
	Married	7	11	
	Divorced	2	3	
	Widowed	49	77	
Length of Stay	1 mo – 1 yr	27	42	Mean: 1.64 yrs SD = .6 mos. Range: 1-3 yrs
	13 mos-36 mos.	33	52	
	>36 mos.	4	6	
Cognitive Status	Mini-Mental State Examination			Mean: 16 SD= 3.83 Range: 8-23
	8-16	34	53	
	17-23	30	47	

Facility Characteristics

The response rate (participation rate) of all facilities was 22%. Telephone calls were made by the researcher to the owner or administrator of 26 large and 41 small

facilities (67 in total). Agreement rates for study participation were 26% to 19% for the large and small facilities respectively.

Facility characteristics are presented in Table 2. There were 15 different facilities operated by 10 different owners, some proprietors owned more than one facility. Greater than half of the facilities (n=10) were between 6 and 10 years old. Eight facilities (53.3%) were categorized as small with 20 or fewer beds and 7 facilities (46.7%) were categorized as large with 21 or greater beds (bed size range: 13-77). The total number of paid staff varied from 10-65 with over half of the facilities (60%, n=9) employing 1 to 10 direct care staff (see Figure 5).

The number of RN full-time equivalents ranged from 0-3 with a mean of 0.77 (SD=0.84) which is less than one full-time RN. The median RN FTE was 0.3 (i.e. 3 eight hour shifts every two week period). Facility administrators reported that the majority of facility staff (mean 85%, SD=3.5) had received training in the area of behaviors associated with dementia.

Seven facilities (47%) had only private pay residents. The other 8 facilities had some residents with governmental funding. The most frequently reported programs were Family Care or Community Options Program (COP), two sources of assisted living funding in Wisconsin. Of the facilities housing residents receiving some governmental funding, there was a wide variation between facilities, from 15% to 75%. Twenty percent (n=3) of the facilities were associated with a skilled nursing facility and 60% of all facilities (n=9) had a dedicated dementia unit. Eighty percent of facilities (n=12) reported that all residents were Caucasian. Of the 20% (n=3) of facilities that reported

some residents that were other than Caucasian, each facility reported two non-Caucasian residents (10-13%) (Table 2).

Table 2

Facility Characteristics (N=15)

Characteristics Classification		f	%	Mean, SD, Range
Facility Age	1-5 yrs	5	33	Mean: 9 yrs SD=4.5 yrs Range: 2-16 yrs
	6-10 yrs	10	67	
Number of CBRF beds	<20	8	53.3	Range 13-77 beds
	21+	7	46.7	
% Males in facility	0-20%	9	60	Mean: 22.8% SD=11.7 Range: 7-45% Median: 20%
	21-45%	6	40	
% Females in facility	50-80%	9	60	Mean: 77% SD=11.7% Range: 55-93% Median: 82%
	81-93%	6	40	
Average Age of all residents in facility	82-90	15		Mean= 85yrs SD= 1.9 yrs Range: 82-90 Median: 85
Total Number Paid Staff	10-20	11	73.3	Mean: 21.67 SD: 16.4 Range: 11-65 Median: 15
	21-65	4	26.7	
Number Direct Care Staff	1-10	9	60	Mean: 12 SD=6.6 Range: 7-30 Median: 8.5
	11-19	5	33	
	20-30	1	7	

Table 2

Facility Characteristics (N=15)

Characteristics	Classification	f	%	Mean, SD, Range
Number of RNs (Full-time Equiv)	0-1	12	80	Mean: .77 FTE SD =.84 FTE Range: 0-3.0 FTE Median: .3 FTE
	>1	3	20	
Number of Staff with Behavioral Training	0-50%	3	20	Mean: 84.67 SD =3.5 Range: 0-100%
	51-100%	12	80	
% Private Pay	25-50%	2	13.3	Mean: 81.53% SD=1.9 Range: 25-100%
	51-100%	13	76.7	
% Family Care or COP funding (Community Options Program)	0-15%	10	66.7	Mean: 18.47% SD =25% Range: 0-75%
	16-75%	5	33.3	
Number Associated with a Skilled Nursing Facility	Yes	3	20	
	No	12	80	
Number of Facilities with a Dementia unit/ or dementia focus	Yes	9	60	
	No	6	40	
Ethnicity	Caucasian		100	Mean 98.5%
	Other		10-13	

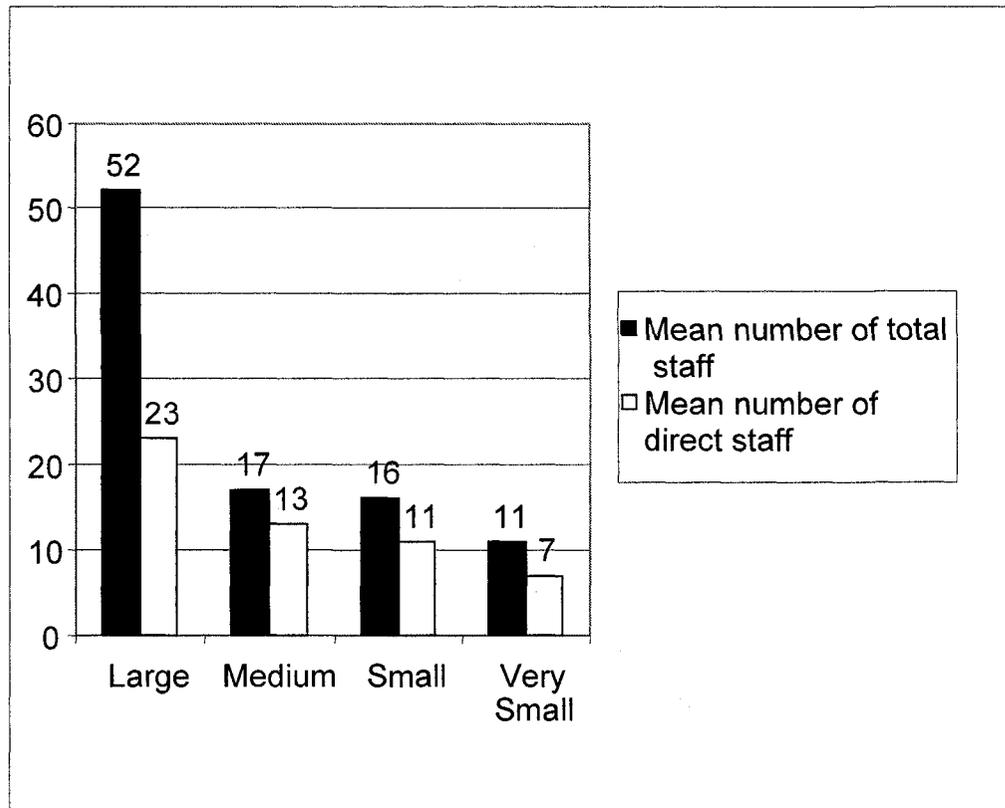


Figure 5 Number of Staff Versus Bed Size

Findings Related to Research Questions

Research Question One

The first research question which explored the extent of pain, depression, co-morbid conditions, function and agitation in dementia residents in assisted living is described. In addition to describing the variables, comparisons are made between select demographic characteristics and these variables. Methodological analyses for the variables are also presented.

Extent of Pain

Slightly over half (51%, n=33) of the subjects reported “yes” to the question of whether they had any pain. Of those subjects, 14 (42%) were unable to complete the Numerical Rating Scale (NRS). Subjects either did not respond to the verbal request to rate their pain or responded with an unrelated statement. Nineteen subjects (58%) who said “yes” they had pain, were able to assign a number to their pain. Sixty-eight percent of subjects that were able to complete the NRS (n=13), reported a pain score of 4 to 10 which indicates moderate to severe pain (Table 3).

Only two subjects (3%) of the 33 who answered “yes” to the question of whether they had pain or not were unable to complete the CAS. Two other residents (3%) could not use the instrument due to visual difficulties. Of the 29 subjects that were able to complete the CAS, 68% (n=20) reported pain in the moderate to severe range of 4 to 10 (Table 3).

Pain behaviors of all 64 subjects were measured using the Checklist of Nonverbal Pain Indicators (CNPI). Pain behaviors were measured at rest and during movement. While the range of possible total scores on the CNPI was 0 to 12, the actual measured scores ranged from 0 to 10. Fifty-two percent (n=33) of subjects had no observed pain behaviors on the CNPI. Thirty-seven percent (n=24) of subjects had behaviors associated with pain while at rest. Six percent of these subjects (n=4) had moderate to high pain levels with 4 to 6 pain behaviors on the CNPI at rest. The frequency of observed pain as measured by the CNPI increased from 37% (n=24) at rest to 49% (n=31) during movement. Of those subjects with a CNPI score of 4 to 6, there was also an increase in the percentage of subjects from 6% (n=4) at rest to 9% (n=6) during movement (Table 3).

Table 3

Comparison of Findings on Three Pain Instruments

Instrument	Classification	f	%	Mean, SD, Range
NRS				
Stated No Pain		31	48	Mean: 2
Stated Yes to Pain		33	52	SD = 3.1
Unable to complete		14	22	Range: 0-10
	1-3 score	6	9.4	Median: 0
	4-6 score	7	11	
	7-10 score	6	9.7	
CAS				
Stated No Pain		31	48	Mean 2.33
Stated Yes to Pain		33	52	SD: 2.95
Unable to see		2	6	Range: 0-9.5
Unable to complete		3	9	Median: 0
	1-3 score	9	14	
	4-6 score	12	19	
	7-10	8	13	
CNPI total score				
	0	33	52	Mean: 1.98
	1-3	12	19	SD = 2.57
	4-6	15	23	Range: 0-12
	7-10	4	6	
(components of CNPI)				
CNPI-at rest				
	0	40	62	Mean: .81
	1-3 score	20	31	SD=1.28
	4-6	4	6	Range: 0-6
				Median: 0
CNPI-with movement				
	0	33	52	Mean: 1.17
	1-3	25	39	SD=1.45
	4-5	6	9	Range: 0-6
				Median: 0

Comparison of Pain Behaviors at Rest and During Movement

Table 4 depicts the statistical correlations between the pain scales. The correlation between the NRS and CAS was very high $r=.924$ (.000) ($p<.01$). The CAS was moderately positively correlated with the CNPI $r=.672$ (.000) ($p<.01$). The internal consistency alpha coefficient, calculated for the item CNPI was 0.683 at rest and 0.671 during movement which demonstrates a moderate level of internal consistency for this sample.

Table 4
Correlation Between Three Pain Scales

	NRS	CAS	CNPIR
NRS		.924**	.445**
CNPI	.546**	.714**	.766**
CNPI-Rest		.555**	
CNPI-Movement	.592**	.714**	.766**

** ($p<.01$)

Differences in extent of pain based on gender were examined and no statistically significant difference in level of pain between males and females on the NRS ($t(48) = -.344$ $p=.732$), CAS ($t(62) = -.805$ $p=.424$) or the CNPI ($t(62) = -1.183$ $p=.241$) was found.

Extent of Depression

The range of scores on the GDS was 0 to 25 with a mean of 8.6 and a standard deviation of 6.3 (N=64). Previous studies have indicated that a score of 11 or greater suggests depression (Yesavage et. al, 1983). In this study, 19 subjects (29.6%) had a score of 11 or higher (Table 5). No significant differences were found between males and females on the GDS ($t(62) = .923$ $p=.359$).

A comparison of the degree of depression between those with higher agitation (i.e. any scores of 5 or greater) and those with lower agitation (scores of 1-4), was calculated using a t-test. No significant differences were found in depression between those with lower and higher levels of agitation ($t(62) = 1.265$ $p=.211$).

Table 5 lists the frequency of depressive responses to each item on the GDS. The 5 questions that most frequently elicited depressive responses concerned: emptiness, trouble with decision making, lack of excitement, mind not as clear as previously and difficulty starting new projects. The alpha coefficient for the GDS was 0.835, which indicates a high level of internal consistency.

The following anecdotal example presents evidence which suggests that subjects with significant cognitive impairment were able to understand the questions on the GDS: A subject with a MMSE score of 9 made the following comments in response to the questions:

Question: “Do you find life very exciting?”

Answer: “No, I don’t know of anything exciting. Dancing and a play—
that would be exciting”

Table 5

Frequency of Depressive Responses to Items on the GDS (N=64)

Variables	Classification	f	%
1. Emptiness		45	70
2. Trouble with Decision Making		40	63
3. Life is Exciting		33	52
4. Mind not as clear as it used to be		28	44
5. Hard to start new projects		28	44
6. Prefer to stay in room		28	44
7. Trouble concentrating		27	42
8. Dropped interests and activities		27	42
9. Frequent Boredom		27	42
10. Not full of energy		25	39
11. Prefer to avoid social gatherings		21	33
12. Other people are better off		21	33
13. Upset over little things		20	31
14. Feel Restless and Fidgety		20	31
15. Often Feel Helpless		19	30
16. Feel like crying		19	30
17. Enjoy getting up in the morning		19	30
18. Worry about little things		19	30
19. Hopeful about future		18	28
20. Feel Downhearted and Blue		18	28
21. Happiness		17	27
22. Satisfied with life		15	23
23. Wonderful to be alive		13	20
24. Feel worthless		13	20
25. More memory problems than most		12	19
26. Worry about past		10	16
27. Cant' get thoughts out of head		9	14
28. Hopelessness		9	14
29. Afraid something bad will happen		7	11
30. Good spirits most of the time		6	9

Number and Severity of Co-Morbid Conditions

The number and severity of co-morbid conditions was measured by the Cumulative Illness Rating Scale (CIRS-G) (Miller et. al. 1992) using chart review. The CIRS-G measures 14 different body and mind co-morbid conditions on a Likert scale as follows:

- 0 indicates no impairment in that area
- 1 indicates mild problems or a past problem in that area
- 2 indicates moderate problems, requiring “first line” therapy
- 3 indicates that the disease has risen to a level of significant disability or uncontrollable chronic problems
- 4 indicates severe disease requiring immediate treatment or end-organ failure

Results of findings on the CIRS-G are presented in Table 6.

Table 6

Number and Severity of Co-Morbid Conditions (N=64)

<u>Variables</u>	<u>Classification</u>	<u>f</u>	<u>%</u>	<u>Mean, SD, Range</u>
CIRS-G Total score	0-10	6	9	
	11-19	33	52	
	20-29	25	39	
Number of subjects with conditions causing significant disability or that are chronic and uncontrollable	0-3	40	62.5	
	4-10	24	37.5	
Number of subjects with conditions	0	41	64	
	1	20	31	

Table 6

Number and Severity of Co-Morbid Conditions (N=64)

<u>Variables</u>	<u>Classification</u>	<u>f</u>	<u>%</u>	<u>Mean, SD, Range</u>
requiring immediate treatment or end-organ failure	2	3	4.7	
Severity Index Score/Total number of categories endorsed	1.5-3.0	64	100	Mean: 2.33 SD =.295 Range:1.5-3.0

Thirty-eight percent (n=24) had more than 4 conditions serious enough to cause significant disability, chronic uncontrollable problems or problems that required immediate treatment or end-organ failure. Twenty-three subjects (36%) had at least one severe condition that either required immediate care or was end-organ failure. There was a significant difference found between males and females on the Severity Index of the CIRS-G ($t(62) = 2.245$, $p=.028$). Males had higher numbers and severity of co-morbid conditions than females. Males had a mean of 2.45 on the severity index (SD=.277) while females had a mean of 2.28 (SD=.289).

There was also a statistically significant difference in co-morbid conditions (as measured by the severity index on the CIRS-G) between subjects who did and did not display daily agitation ($t(62) = 1.99$, $p=.051$). The mean for those with daily agitation was 2.37 (SD=.302). For those with no daily agitation the mean was 2.19 (SD=.22). A breakdown of the frequency of conditions on the fourteen organ systems is presented in Table 7.

Table 7

Frequency Ranking of Severe Co-Morbid Problems (n=64)

Items	f	%
Psychiatric (Dementia, depression, anxiety)	37	58
Musculoskeletal/Integument	32	50
Heart Disease	26	41
Genitourinary	23	36
Vascular	22	34
Eye, Ear, Nose and Throat	15	23
Endocrine-Metabolic	14	22
Upper GI	11	17
Respiratory	11	17
Neurological	6	10
Kidney	5	8
Lower GI	2	3
Blood	0	0
Liver	0	0

Note: Severe is operationalized in the CIRS-G as a condition with associated significant disability, an uncontrollable chronic problem or severe enough in nature to require immediate treatment or end-organ failure.

Functional Level

The functional level of subjects was measured with the Functional Behavior Profile (FBP) (Baum, Edwards & Morrow-Howell, 1993). Possible scores on the FBP range from 0 to 12. The subjects' abilities are rated on a scale from 0 to 4 meaning never, rarely, sometimes, usually and always. The higher the score, the higher the functional level of the subject. On the FBP, function is rated in 3 subscales: task, social and problem-solving. The 3 sub-scores are totaled. One can use the subscale scores separately or use a total score. The sample in this study had moderate functional scores. As shown in Table 8, the scores on the FBP ranged from 3.0-11.3 with a mean of 8.49 and a standard deviation of 1.98.

Table 8

Functional Level (N=64)

Variables	Classification	f	%	
FBP total score	3.0-5.0	4	6.4	Mean: 8.49
	5.1-7.0	6	9.5	Median 8.8
	7.1-8.9	24	37.8	SD =1.98
	9.0-11.3	29	45.9	Range: 3-11.3
Task Subscale	0-1.99	12	18	Mean: 2.78
	2.00-2.99	19	30	SD =.845
	3.00-4.00	33	52	Range33-4.0
Social Subscale	0-1.99	2	3	Mean: 3.06
	2.00-2.99	19	30	SD =.659
	3.00-4.00	43	67	Range1.57-4.0
Problem-Solving Subscale	0-1.99	10	15.6	Mean: 2.66
	2.00-2.99	17	26.6	SD =.659
	3.00-4.00	37	57.8	Range: 7 – 21

A comparison of the level of function in the sample based on gender was calculated using the t-test. No significant differences were found between males and females participating in this study on the FBP ($t(62) = -1.863$ $p=.067$).

Coefficient alphas for the FBP and its subscales are reported in Table 9. The alpha coefficient for the FBP was .937 ($p<.05$) which demonstrates a high level of internal consistency for this sample. The FBP subscale alphas ranged from 0.685 to 0.873. The magnitude of the alpha coefficients for the FBP subscales indicates a moderate level of internal consistency for this sample (Table 9).

Table 9

Functional Behavioral Profile and subscales: Alpha Coefficients

Scale	Questions	Alpha
FBP –Total	All	.937
FBP-Task	1-9	.873
FBP- Social	10-15	.685
FBP-Problem-solving	16-27	.890

Extent of Agitation

The extent of agitation was measured using the 29-item Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield & Billig, 1986). As stated by Cohen-Mansfield in the *Instruction Manual for the Cohen-Mansfield Agitation Inventory* "...it is not useful to calculate a total score by adding all categories... you need to conceptualize your understanding of these behaviors in order to aggregate the behaviors in a meaningful way" (Cohen-Mansfield, J.,1991, p. 5). Agitation, as measured by the CMAI yielded a

large range of values, from very low to very high. Accordingly, after examining the distribution of the CMAI responses, items were dichotomized with responses ≤ 4 scored as 0 and items ≥ 5 scored as 1. This resulted in a potential range of scores from 0-29. A higher score indicates a higher degree of agitation. This method was conceptually meaningful, as behaviors that occur daily or more frequently are a reflection of more extreme or chronic agitation. The scores ranged from 0-10 with a mean of 2.46 (SD=2.37) (Table 10).

Table 10

Extent of Agitation (N=64)

<u>Instrument</u>	<u>Classification</u>	<u>n</u>	<u>%</u>	<u>Notes</u>
CMAI	0	13	20	Mean: 2.46 SD=2.37 Range: 0-10 Median: 2.0
	1-2	27	42	
	3-4	13	20	
	5-10	11	18	

Most Frequent Behaviors
(Behaviors that occurred: daily, several times per day or several times per hour)

Asking Repetitive Questions	22	34
Pacing	17	27
Attention Seeking	16	25
Negativism	12	19
Complaining	11	17

Table 10

Extent of Agitation (N=64)

Instrument	Classification	n	%	Notes
CMAI	Disrobing	11	17	
	Noises (e.g crying)	11	17	
	General Restlessness	9	15	
	Repetitive Behaviors	7	11	
	Cursing	6	10	

Thirty-eight percent (n=24) of the subjects had 3 to 10 behaviors that occurred daily or more frequently, obtained by summing the two latter groups. The most frequently reported behaviors are listed in Table 10. The three most frequently observed agitated behaviors were repetitive questions, pacing and attention seeking. A third of the subjects (n=22) ask repetitive questions daily or more frequently, 27% (n=17), pace at least daily and 25% of the sample (n=16) seek attention at least daily.

A comparison of the level of agitation in the sample based on gender was calculated using the t test ($t(62) = -1.265$ $p = .211$). No significant differences were found between males and females participating in the study. A comparison of the level of cognition on the MMSE was calculated using the t test between dichotomized groups on the CMAI—those subjects with no behaviors that occurred daily (scores of 1-4 only) and those with any behaviors that rose to the level of 5 or greater (at least daily behaviors). The group with lower agitation levels (no daily agitation) had significantly higher cognition scores ($t(62) = 2.099$ $p = .040$).

Because the data on the CMAI were not normally distributed, a square root transformation was performed in order to perform inferential statistics. The alpha coefficient for the Cohen-Mansfield Agitation Inventory was 0.737 ($p < .05$), a moderately high level of internal consistency.

Research Question Two

The second research question was: of persons with dementia who reside in assisted living facilities, what is the prevalence of analgesic and psychotropic medications usage? Descriptive statistics were used to characterize the use of these types of medications in the population sample (Table 11). When both scheduled and prn medications are considered together, the mean number of medications used by the sample population was 13 with a range of 4 to 25 medications, and a standard deviation of 5. When scheduled medications are considered separately, the mean number of medications used was 9 with a range of 1 to 16 medications, and a standard deviation of 4, when prn medications are considered separately, the mean number of medications used was 4 with a range of 0 to 11+ and a standard deviation of 3 (Table 11).

Analgesic Medication

Sixteen subjects (25%) had a scheduled analgesic ordered. The majority of subjects (94%, $n=60$) had at least one prn analgesic medication ordered. A comparison of the extent of agitation based on whether subjects were receiving a scheduled pain medication was calculated using a t-test. Significant differences were found between those who were and were not receiving a scheduled pain medication and those who were not ($t(62) = -2.469, p = .016$). Those who were not receiving scheduled pain medication had a mean CMAI score of 2.06 ($SD=2.09$) while those receiving a scheduled pain

medication had a CMAI of 3.68 (SD=2.77). Subjects with scheduled pain medication displayed significantly more agitation (Table 11). Of the 16 subjects who were receiving scheduled pain medication, 11 reported pain. Fifteen of the 16 subjects were able to complete the CAS and 10 reported pain. On the CNPI during movement 10 of the 16 subjects had pain behaviors rated between 1 and 5.

No statistically significant differences were found between those who were receiving scheduled pain medication on the CNPI-Movement ($t(62)=.543$ $p=.589$) function ($t(62) =.079$ $p=.937$), depression ($t(62)=-1.560$ $p=.124$) and co-morbidity ($t(62)=-1.228$ $p=.224$). It should be understood that the use of multiple t-tests can increase the chance of Type I error.

Psychotropic Medication

The number of psychotropic medications per subject ranged from 0 to 5 and included the following categories: Antidepressants, antipsychotics, antianxiety medication and sleeping medication. The vast majority (77%, $n=49$) of subjects were receiving at least one psychotropic medication, and a quarter (23% $n=15$) of subjects were on three or four psychotropic medications. Fifty-four percent ($n=35$) were taking an antidepressant. Almost all subjects (78%, $n=48$) were taking at least one Alzheimer's medication (e.g. Namenda, Aricept). Alzheimer's medications are considered to be cognitive enhancing medication and are therefore not included in the category of psychotropic medication (Table 11). Previous research reported that neuroleptic medications (any drugs that act on the central nervous system) improve agitation only 20% of the time (Schneider, Pollock & Lyness, 1990). It is not known to what extent the cognitive enhancing medications affected pain and depression in this sample.

Table 11
Analgesic and Psychotropic Medication Usage (N=64)

Characteristic	Classification	f	%	Mean SD, Range
Total # Medications ordered	0-5	2	3	Mean: 12.64 SD=4.99 Range:4-25
	6-10	23	36	
	11-15	23	36	
	16-25	6	25	
Number of Scheduled Medications	0-5	14	22	Mean: 8.52 SD=3.95 Range: 1-16
	11-15	18	28	
	16-25	2	3	
Number of prn Medications	0-5		42	Mean: 3.92 SD=2.53
	6-10		20	
	11 or more		2	
Number of Psychotropic Medications	0	14	22	
	1-2	34	55	
	3-4	15	23	
# of Antidepressant Medications	0	29	45	
	1	30	48	
	2	5	6	
(Remeron (13) Effexor (3) Paxil (3), Celexa (1), Nortryptiline (1)				
Number of Psychotropic Medications NOT an antidepressant	0		16	Range: 0-4
	1-4		84.4	

Research Question Three

Question three addressed the association of pain, depression, co-morbid conditions and functional impairment to agitation in persons with dementia residing in assisted living facilities. Hierarchical multiple regression analysis was used to examine

the contribution of the independent of predictor variables (pain, depression, co-morbidity and function) to the dependent variable of agitation.

All of the variables that were entered into the regression analysis were checked for normality of distribution. Skewness was found in one of the measures—the CMAI. To address this, a square root transformation was performed on the CMAI. Because of an interest in comparing those with and without pain, the CNPI during movement data were dichotomized as pain versus no pain, and entered into the regression equation as a dummy variable. Thirty-three subjects had no pain and 31 had pain. On the GDS, 18 subjects had between 1 and 3 responses that were between a “yes” and a “no”. The method of mean substitution was used in scoring those subjects (Kelber, personal communication, September 2006).

Multiple regression analysis requires either interval or ratio level scaling of tools. Although the Geriatric Depression Scale (GDS) is considered ordinal, it has been noted in multiple studies that treating psychological scales as interval level measures is not likely to introduce major distortions if the scale approximates interval level characteristics (Polit & Beck, 2004). The Geriatric Depression Scale has been treated as interval level in multiple other studies and in this study approximated a normal distribution.

Bivariate Correlations

As the first step in the process of hierarchical multiple regression, bivariate correlations were conducted (Table 12 and Table 13). There was no evidence of multicollinearity when bivariate correlations were performed. Scatterplots were examined for linearity and no evidence of a curvilinear relationship was found. Significant positive correlations were found between agitation and the independent variables of depression, co-morbidity and pain. A statistically significant negative correlation was found between function and agitation. No significant difference was found between gender and agitation ($t(62) = -1.265, p=.211$).

Table 12

Pearson Correlation Coefficient Between Agitation and the Predictor Variables

Variables	CMI5 7	CMAI (square root transformation)
Pain	.271*	.162
Depression	.307*	.281*
Co-Morbidity	.260*	.286*
Function	-.285*	-.312*
Cognition	-.095	-1.86

*($p < .05$)

Table 13

Pearson Correlation Coefficients Between Independent Variables

Variables	Depression	Pain	Co-Morbid Conditions	Function
Depression		.247*	-.012	-.182
Pain			.027	-.155
Co-Morbid Conditions				-.194

* (p<.05)

Hierarchical Multiple Regression Analysis

Hierarchical multiple regression analysis was then performed to examine the contribution of the co-morbid conditions, functional status, depression and pain to the extent of agitation. Order of entry of variables was determined based on the NDB theoretical framework and stability of the variables. Co-morbid conditions and functional level were entered in the first two steps as control variables. Co-morbid conditions and functional status would be considered background variables in the theory of Need-Driven Dementia-Compromised behavior as they are relatively stable variables that are less amenable to nursing intervention. Depression and pain are both proximal factors within the NDB model and are of particular interest because of the potential for intervention and modification of the problem. These variables were entered last.

Overall, the model was statistically significant ($F [df =4, 59] = 3.87 p=.007$) with 15.4% of the variability in agitation accounted for by the variables in the model. Co-morbid conditions and functional status accounted for 12.2% of the variance, followed by depression that added 4.6% of variance to the model at Step 3. As depression and severity

of co-morbid conditions increased, the extent of agitation increased. Function was inversely associated with agitation. As function decreased agitation increased. The presence of pain which was entered as the final step did not significantly contribute to the model (Table 14).

Table 14

Hierarchical Multiple Regression Predictor Variables of Pain, Depression, Co-morbid Conditions and Function with Criterion Variable of Agitation (N=64)

Step Variable Entered	standardized β	R ² change	Total Adj R ²
Step One			
Co-morbidity	.286*	.067*	.067*
Step Two			
Co-morbidity	.235*		
Functional Level	-.266*	.055*	.122*
Step Three			
Co-morbidity	.247*		
Functional Level	.219*		
Depression	.244*	.046*	.168*
Step Four			
Co-morbidity	.248*		
Functional Level	-.221*		
Depression	.249*		
Pain with movement	-.023	-.014	.154
F=3.878 df (4, 59) p<.007			
Total adj R ² = .154			

Secondary Research Question:

To answer the secondary question of whether there are differences in agitation between those with a MMSE score of 16 or below and those with a score of 17-23 a

comparison was made based on cognition with a t-test. Those with higher cognitive levels were less likely to exhibit daily agitation.

A comparison of the level of cognition on the MMSE was calculated using the t-test between dichotomized groups on the CMAI between those subjects with no behaviors with a score of 5 (daily) or greater and those with any behaviors that reached a score of 5 (daily) or greater. It was found that those with no behaviors that occurred daily had statistically significant higher MMSE scores ($t(62) = -2.099$ $p = .040$). The mean MMSE of subjects with any agitation that occurred daily or greater was 15.56 ($SD = 3.95$). For those subjects that had no behaviors that occurred daily or greater the mean MMSE score was 18.00 ($SD = 2.61$).

Summary of Findings

The data from a sample of 64 dementia residents residing in assisted living were used to describe the extent of agitation, pain, depression, co-morbid conditions and function. These factors were chosen based on the NDB model which suggests that physical and psychosocial issues commonly found in older adult with dementia can lead to unmet needs and subsequent agitation.

Fairly high levels of agitation were found among the sample. Positive relationships were found between agitation and pain, depression and co-morbidity and a negative relationship was found between both depression and function, and between depression and co-morbid conditions. There was a significant positive relationship found between depression and pain. Function was negatively correlated with only one of the pain instruments—the CNPI ($r = .249$ ($p < .05$)). Overall, the best predictors of the extent of

agitation in this sample were depression, co-morbid conditions and function. Pain was not predictive of agitation in this sample.

The findings are interesting in light of the high degree of medication usage found in this study. Nursing assistants primarily administered medications. Subject's had on average 13 medications ordered (SD = 5), 9 of which were scheduled. Most subjects 78% (n=49) were receiving a psychotropic medication. Fifty-four percent of subjects were receiving an antidepressant and 62% (n=40) were receiving a psychotropic medication that was not an antidepressant. In addition to these medications 77% (n=48) of subjects were also receiving cognitive enhancing Alzheimer's medication such as Namenda or Aricept. One quarter (n=16) of the subjects were receiving a scheduled analgesic.

Chapter Five

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

Chapter five presents conclusions of the study including a) a discussion of findings b) study strengths and limitations and c) recommendations, including implications for nursing practice and future research.

This study was based on the Need-Driven Dementia-Compromised Behavior Model (NDB) which supported the hypothesis that there would be relationships among the study variables. Previous research has suggested that the background factors of comorbid conditions and functional impairment as well as the proximal factors of pain and depression are common in persons with dementia and can be associated with agitation (Gruber-Baldini, Boustani, Sloane & Zimmerman, 2004). Individuals with dementia are often unable to communicate unmet needs directly and this leads to agitation. This had been found in residents in skilled nursing facilities (Burgio, Sculley, Haden & Hsu, 2001; Holtzer et. al., 2003). Accordingly, it was hypothesized that unmet needs would be a concern in the assisted living setting where the population is similar to that of the skilled nursing facility (Zimmerman et. al., 2003) and there is less nursing care available (Mitty, 2003).

Discussion of Findings

Sample Characteristics

When comparing the results of this study to previous studies, there are many demographic similarities. The average age of the sample was 85, which was consistent with a large national assisted living study which reported an average age of 84.5 (Morgan, Gruber-Baldini, Magaziner & Hyg, 2001). Previous studies have reported that

the average length of stay in assisted living is 2.8 years (Morgan et. al., 2001). In the current study, the average length of time subjects had resided in the facility at the time of data collection was 1.6 years. All of the subjects in this study were Caucasian. Only 20% (n=3) of study facilities had any residents that were not Caucasian. Ninety-eight percent of all residents in study facilities were Caucasian, only two percent were other than Caucasian (n=6). Previous studies report that 3-9% of assisted living residents are non-white (Morgan et. al., 2001). It is possible that racial separation exists in assisted living. A large study in the states of Florida, Maryland, New Jersey and North Carolina found that 58% of assisted living facilities house no African Americans, 27% have less than 25% yet, 15% of facilities have a quarter of residents that are African American. It is not clear if quality of care differs among these facilities. African Americans may choose facilities that provide more culturally appropriate care and may be more likely to be cared for at home (Howard et. al., 2002).

Also, there were differences between the demographics of this sample and that reported in previous studies. Thirty percent (n=19) of study subjects were male, a higher rate than other studies, which have reported 23% of assisted living residents as male (Gruber-Baldini & Magaziner, 2001). This may be due to males having more involved family members such as spouses who were more willing to give consent than those with a distant relative as their closest relative. . In this sample, 77% of subjects were widowed (n=49), higher than previously reported rates of 67-73%. Only 7% (n=6) of the sample was single/never married which is lower than the 19% reported in other studies (Morgan et. al., 2001).

Another difference was that in the current study half of the subjects had a MMSE of 16 or lower indicating moderate to severe dementia and half had a score of 17-23 indicating mild to moderate dementia. The mean MMSE was 16. In other studies, of persons with AD in assisted living, 60% were reported to have moderate to severe dementia (Mollica, 2001). In one study, a mean MMSE score of 12 was reported (Kopetz, 2000), lower than in the current study. While subjects with low cognitive levels (as low as a MMSE of 8) were included overall, cognitive levels in the current study were higher than reported in previous studies. The low cut off score on the MMSE may have resulted in the higher mean MMSE found in the current study.

Facility Characteristics

Previous researchers have categorized assisted living facilities into three types 1) <16 beds 2) traditional homes built before 1987 and c) 'new model' homes built after 1987 that have 24 hour RN presence (Zimmerman et. al., 2001). In the current study 33% (n=5) of the facilities were less than 16 beds and all of the study facilities were built between 1989 and 2004, so none in the study would be considered 'new model'. Nationally, 60% of facilities have been in operation less than 10 years, which is consistent with the current study in which the average age of facilities was 9 years old.

There are no federal regulations regarding staffing in assisted living (Hodlewsky, 2001). By design, staffing decisions are left to facility administrators because assisted living serves a population with diverse needs. State regulations are continually changing, but only 17 states require a nurse and do not specify whether this need be an RN or LPN (Mitty, 2003; NCAL, 2000).

In Wisconsin, HFS Chapter 83 states only ...”the ratio of staff to residents shall be adequate to meet the needs of the residents as defined in their assessments and individual service plans...” and that at least one ...”qualified resident care staff member” shall be present in the facility when one or more residents are in the facility (Wisconsin Administrative Code 2001 HFS Chapter 83, 83.15 258-11). A national assisted living survey reported that 55% of facilities have an RN on staff part or full time (Mitty, 2003). This research study had higher rates of RN coverage. Ninety percent (n=14) of facilities in this study reported weekly RN coverage. The mean was 0.77 FTE (SD = 0.84) RN staffing (Table 2).

Measurement of staffing levels proved to be a challenge. Some assisted living facilities are attached to independent apartments and share staff. As would be expected, administrators expressed some difficulty in separating the number of direct care staff and nursing staff by level of care as there is often cross-coverage. Total amount of staff was found to increase based on bed size (larger facilities have more staff, Figure 5).

The total number of AL facilities with specialized dementia units is not known but rates from 18 to 30% in RC/AL have been reported (Sloane, Zimmerman & Ory, 2001). Sixty percent of the facilities in this study (n=9) had dementia units, a higher rate than previously reported. Because dementia and agitation were inclusion criteria for participation in the study, this tended to select for facilities with dementia units.

The payer source of the individual subjects was not measured. However, payer source was measured at the facility level. Slightly over half (53%, n=8) of the facilities had some residents with governmental funding. The mean percentage of residents with such funding was 35%. Higher levels of governmental funding were reported in this

study than in other studies. Although more than 40 states have Medicaid programs that subsidize services for low income older adults including assisted living (Mollica, 2001), previous studies have revealed that less than 5 percent of all residents in assisted living are subsidized by governmental funding (Nolin & Mollica, 2001). This Wisconsin study included more residents with governmental funding than previously reported studies.

Pain

The rate of self-reported pain (52%, n=33) is higher in this study than in the one other study found in the literature that reported pain prevalence in assisted living at 39% (Williams, Zimmerman, Sloane & Reed, 2005). The current study reported a lower usage of pain medication (22%, n=16) than the Williams et. al., study, which reported 34% of subjects were receiving pain medication.

In the current study, the CAS was found to be a better instrument for self-report of pain in this population as more residents were able to complete the CAS than the NRS. These findings support previous studies which reported that the majority of people with mild to moderate dementia are able to complete the CAS. (Scherder et. al., 2003).

Because previous research has shown that self-report pain instruments can have questionable validity in persons with cognitive impairment (Montoroio & Izal, 1996), a behavioral measure, the CNPI was used with all 64 subjects. During movement, pain was found to increase which is consistent with prior research (Feldt, 1998). In the current study, measuring pain during movement proved to be a challenge. During data collection, the subjects were at rest (usually sitting, sometimes lying down) so this allowed 20 minutes for observation of the subject at rest, however the subjects were often reluctant or non-ambulatory and difficult to move after the interview. The researcher

stayed in the facility until subject movement was observed naturally, which generally occurred (but not in all cases) at the next mealtime. Observations during movement were thus brief and may have resulted in under-observation of pain behaviors.

Based on previous research and the NDB model, it was hypothesized that higher pain levels would be associated with more agitation (Feldt, et. al, 1998). While pain during movement on the CNPI was significantly correlated with agitation on the CMAI ($r=.271$ (.30) $p<.01$) when entered into the hierarchical regression model pain was not found to predict agitation. Because all subjects sampled had agitation and half ($n=33$) did not have pain, there may not have been enough subjects with agitation and pain to detect a significant association. A larger sample size of persons with pain is needed for further research.

Previous research in skilled nursing facilities or hospitals has revealed that undertreatment of pain may lead to aggressive behaviors (Ryden et. al., 1998). Very few physically aggressive behaviors were found in the current study. This may be due to facility admission and discharge criteria- although these factors were not measured. This finding could also possibly be related to psychotropic medication usage.

A finding of interest in this study was that 22% ($n=16$) of the subjects that were receiving scheduled analgesics exhibited higher levels of agitation than those not receiving pain medication. This finding would seem to contradict the NDB model which would suggest that the proximal factor of pain may be an unmet need that increases the proximal factor of pain and that treatment of such pain would meet the need and result in decreased agitation. This finding must be viewed in light of other study findings, however, specifically, the extensive presence of co-morbid conditions. It is likely that

pain was under-treated in this sample. Of note is that over half of subjects reported pain, yet only a quarter of all subjects were receiving an analgesic. Although 94% (n=60) of subjects had a prn (as needed) analgesic ordered (most often acetaminophen), anecdotal chart review for prn usage revealed that residents received prn analgesics only 0 to 3 times per month.

Depression

Rates of depression in the current study were found to be similar to some previous studies. Thirty percent of subjects (n=19) in the current study were found to have major depression. A prior study of depression in assisted living reported depression rates of 25% to 30% (Morgan et. al., 2001). The depression rate in the current study is higher, however, than that reported in a large multi-state study specific to persons with dementia in assisted living in which a depression rate of 13% was reported, with only 18% of subjects receiving an antidepressant (Watson et. al., 2003). Subjects in the current study had a high rate of antidepressant usage with 54% (n=35) receiving the antidepressant medication.

Some researchers have reported that the GDS may be less valid in persons with dementia (Montorio & Izal, 1996), as people who do not admit to memory loss also may deny depressive symptoms on the GDS. In the current study, 80% of subjects (n=51) stated that their memory was “ok” on the GDS. Twenty percent (n=13) reported that they felt that their mind was not as clear as it used to be and this is 10% less than the rate of depression. If subjects did deny depressive symptoms, this would most likely underestimate depression. Regarding the accuracy of the GDS in measuring depression in the

current study it should be noted that no differences were found in the extent of depression and the degree of cognitive impairment.

The study was cross-sectional; higher rates may be found if depression was measured over time. Whether subjects had received different antidepressants prior to the currently ordered medication was not measured. It is standard practice to try different antidepressant medication if a drug is not effective in decreasing depression. It is not known if that standard was applied in this sample.

The Cronbach's alpha coefficient on the GDS in the current study was 0.835 which revealed internal consistency. If many subjects did not comprehend the GDS, one would expect a low alpha coefficient. There was also a high completion rate of the GDS, only two subjects refused to participate in the study. Subjects with a MMSE of ≥ 8 were able to complete the GDS. While some subjects responded answered some questions with a response between "yes" and "no" on the GDS, no differences in the number of such responses were found based on lower or higher levels of cognitive impairment. The subject with only mild cognitive impairment was as likely to give an ambivalent response to a question, than was a subject with moderate or severe cognitive impairment.

Measurement of depression is a challenge in persons with dementia. This current study utilized a self-report instrument. Another measurement option would have been caregiver report, but as depression is a subjective experience, that method has limitations as well. The areas on the GDS more commonly endorsed with a depressive answer may lead to information regarding factors that lead to depression. One previous study

reported that most behaviors occur during times of inactivity and boredom (Cohen-Mansfield & Werner, 1998). This is consistent with areas commonly reported on the GDS in the current study (Table 5).

Co-Morbid Conditions

The extent of co-morbid conditions in the current study sample was considerable. Thirty-six percent of subjects had a condition that required immediate treatment or was considered end-organ failure, and 38% had 4 or more conditions that were chronic or not controlled. The co-morbidity rates reported in this study are higher than those found in a previous study that found that 27% of subjects had moderate to severe co-morbidity rates (Sloane et. al, 2002). Anecdotally, serious illnesses and health conditions were observed by the researcher (e.g. g-tube feedings, severe skin rashes, dyspnea, reported chest pain and suprapubic catheters). The fact that the average age is 85 in assisted living would be consistent with prevalent end of life issues. The extent of co-morbidity found implies that there is a serious need for adequate nursing assessment and intervention in this population.

Another indicator of morbidity was the higher number of scheduled medications in the study population. Subjects were receiving an average of 9 medications (SD=3.94). Almost half of subjects (n=29) were on more than 11 or more medications. In a previous study the average number of medications in assisted living residents was reported as 6 (Sloane, et. al., 2002).

Higher SI scores predicted greater agitation. This is consistent with previous research which reported that the presence of co-morbid conditions correlated with constant complaining (Beck & Vogelpohl, 1999). Findings in this study are consistent

with the NDB model. Co-morbid conditions are background factors (presence of chronic disease cannot be changed or cured) but can also lead to proximal factors such as many types of discomfort (e.g. hypo or hyperglycemia, incontinence, skin irritation, nausea and dizziness) in addition to pain.

An interesting finding was that males had higher levels of co-morbidity, yet no differences were found between gender and agitation. It is possible that facility admission and discharge criteria selected for either extreme illness or agitation but not both on any one resident as the needs for care of such clients exceed the abilities of the facility.

The literature reports that arthritis and hypertension are the most common health conditions in assisted living at 44-45% and 42-49% respectively (Morgan et. al., 2001). The current study found similar rates of arthritis (50%), but the CIRS-G included skin in the musculoskeletal category and thus the rate in that area was higher than reported in previous studies (Table 7). Lower levels of hypertension (34%) were reported in the current study, than in previous studies (Morgan et. al., 2001). No prior studies were identified in which the CIRS-G was used in assisted living for comparison. Therefore, it is difficult to compare rates of co-morbidity as different instruments measure conditions in different ways.

Functional Level

This sample was found to be moderately functionally impaired on average. It is difficult to compare functional status between studies because there is lack of conceptual clarity of the term “functional status” and its cognitive dimension (Knight, 2000). No

other studies were found in which the FBP was used in an assisted living setting for comparison.

Other studies have reported that 15-37% of assisted living residents have three or more ADL deficits and 50-60% use a mobility device (Zimmerman et. al., 2001). The following describes the functional deficit rates in the current study: 28% could stay on task for only 5 minutes or less, 22% could rarely or never manipulate small items 25% could rarely or only sometimes act appropriate to the situation and 22% could rarely or never make simple independent decisions.

Previous research has reported that functional impairment is negatively associated with increased agitation (Hill, Bachman & Fratiglioni, 1995). The current study supports previous findings. The lower the functional score, the higher the agitation score. This finding is consistent with the NDB model, as those with a lower functional status may be less able to express needs and this can lead to unmet needs and increased agitation.

Agitation

The results of this study support and add to the findings in several other assisted living studies. The average subject exhibited an average of 2 behaviors that occurred at least daily or more often (several times per day or hourly) (Table 10). Eighty percent (n=51) of subjects exhibited at least one agitated behavior on a daily basis. This is a considerable amount of agitation. Considering that 47% (n=8) of study facilities had 20 or fewer residents it is clinically meaningful. Even one resident who is agitated several times an hour is a challenge for staff. The most frequent behaviors were asking repetitive questions 34% (n=22), pacing 27% (n=17), attention seeking 25% (n=16) and negativism 19% (n=12). If daily agitation in even one resident in a 20 bed facility could be

eliminated it would have a tremendous impact on not only the quality of life of the resident but the staff and other residents in the environment.

Physical aggression was rarely reported in the study and none of the subjects exhibited such behavior on a daily basis. The admission and discharge criteria of the study facilities were not measured, so it is not known if residents with such behaviors were likely to be discharged or not admitted. Previous studies have reported greater physical aggression in males (Zimmerman, 2001). In the current study, no gender differences were found based on agitation.

The number of behaviors was similar to a longitudinal study of dementia residents in which 2.4 behaviors in an 8 hour period were found including vocalizations and non-aggressive physical behaviors. However, a difference was found in the rarity of physically aggressive behaviors compared to previous research in skilled nursing facilities (Beck & Vogelpohl, 1999). Compared with the CS-LTC data specific to dementia areas there was found to be:

- 1) less pacing in this study 27% (versus 28-44%)
- 2) higher attention seeking behaviors 25% (versus 11-20%)
- 3) higher occurrence of asking repetitive sentences 34% (versus 18-20%)
- 3) lower rates of general restlessness 15% (versus 26-44%)
- 4) similar amounts of cursing 10% (versus 6-30%) (Sloane, Zimmerman & Ory, 2001).

Analgesic Medication Usage

Those subjects on a scheduled analgesic had higher agitation. Eleven subjects were receiving a non-narcotic and 5 were receiving narcotic medication. Even though

almost a quarter of subjects were receiving a scheduled analgesic, 52% of subjects (n=33) reported “yes” to the question of pain and 49% (n=31) observed pain behaviors on the CNPI. The fact that 11 of the 16 subjects receiving a scheduled pain medication reported pain, indicates that subjects may not have been receiving adequate pain management.

Psychotropic Medication

The vast majority (90 %, n=57) of the subjects were on Alzheimer’s medication, such as Namenda or Aricept (n=24 for both). Seventy-eight percent (n=49) of the sample was receiving at least one scheduled psychotropic medication, still there was considerable agitation found in this sample. It is possible that agitation levels would have been greater if the use of psychotropic medication was lower, but also this study suggests that use of psychotropic medication does not alleviate all agitation. This finding supports the notion that agitation is multi-factorial in nature and not only due to the biochemical changes inherent in the neuropathology of AD.

Bivariate Correlations between the Independent Variables

Pain and depression were found to be significantly correlated. The CNPI at rest and function were positively correlated. Pain and co-morbid conditions were not correlated. Depression was positively correlated with the FBP task subscale, but not the FBP as a whole. Depression did not correlate with co-morbid conditions, nor did function correlate with co-morbid conditions (Table 13).

Hierarchical Multiple Regression Analysis

Higher depression, co-morbid conditions and lower functional scores were significant predictors of agitation in this sample. These 3 factors contributed to 15% of the variance in agitation. These findings are consistent with previous literature as

outlined in this paper and with the NDB model. It was hypothesized that pain would positively correlate with agitation but it was not statistically significant. Because only 33 (half of the sample) said “yes” they had pain, the sample size relative to those with pain was not of sufficient power to determine whether pain was a significant predictor of agitation. A larger sample size of persons with pain is needed to assess the relationship between pain and agitation. Also, agitation was measured by asking about the behavior over the past two week time period, while pain was measured on one day. If 15% of agitated behaviors in a population of residents with dementia could be reduced by assessment and intervention regarding depression, co-morbid conditions and function, this would have a strong impact on the quality of care for residents in the assisted living setting.

Secondary Question

Previous research reported that problematic vocalizations increase as cognition decreases until the final stages of Alzheimer’s disease (Beck & Vogelpohl, 1999). It was hypothesized that those with lower cognitive levels might have more agitation. Those with lower levels of cognitive function were found to have more daily agitation.

Methodological Findings

It was found that subjects with dementia were able to make logical comments in relation to questions on the GDS, including those with scores between 8 and 15. Certain questions on the GDS were more likely to be answered with a depressive response than others. For example, boredom and social isolation were frequently responded to with a depressive response. This may lead to potential information that could guide interventions for depression in this setting such as increased availability of activities.

Smaller assisted living facilities were more difficult to recruit than larger facilities. Administrators from smaller facilities were less likely to return calls and to agree to participate. This may be due to increased time constraints as personnel in smaller facilities have many different roles.

The Coloured Analogue Scale (CAS) was easy to administer and most of the subjects, even with low cognitive levels, were able to complete it. This supports previous research which has recommended this instrument in persons with dementia (Scherder & Bouma, 2000), and this study suggests it may be a useful pain instrument for assisted living residents with dementia.

Strengths of the Study

This was one of the first studies to examine factors related to agitation in persons with dementia in assisted living from a theoretical perspective.

- Facilities were drawn from the suburban areas of a metropolitan city.
- The study included a diversity of payer sources with a higher rate of those with governmental funding than reported in previous studies.
- Having one data collector increased consistency in application of measurement instruments. The data collector (the researcher) has 27 years of nursing experience (22 exclusively with older adults).
- There were no missing data for caregiver report instruments (FBP, CMAI) because the researcher interviewed the caregivers, this also allowed for the researcher to explain the instrument and answer any questions.
- The subjects were interviewed in order to complete the GDS. This resulted in no missing data, as compared with the method of having

subjects complete the forms on their own. Only two subjects refused to participate. The remainder were all very willing to be interviewed, many subjects desired to continue interacting with the researcher after the interview was complete.

- The sample size exceeded the required number of subjects for multiple regression analysis.

Limitations of the Study

Interpretation of the results of this study must be viewed in the light of the following limitations. A moderate sample of 64 subjects was recruited from 15 facilities. Generalizability of study findings is limited to the large Midwestern city from which the sample was drawn. Because regulations in assisted living vary by state, there is also limited generalizability outside of Wisconsin. This study was a nonrandomized convenience sample. Only those facilities whose owners or administrators were willing to participate and only those subjects whose families provided consent were included. Little is known about the facilities and subjects that did not participate in the study.

A larger percentage of the subjects (70%, n=45) were drawn from the large rather than smaller facilities (29%, n=19). Many administrators did not return telephone calls, some provided reasons including a recent change in administrator, state surveyors in the facility, undergoing construction and too few residents with agitation. Adding admission and discharge criteria to the Facility Profile would have been useful. However, the current form was already perceived as time-consuming by the administrators and increasing the length of the form would most likely have resulted in missing data.

There were a few limitations related to measurement. Co-morbid conditions were measured via chart review which has limitations compared with adding a physical examination which was not feasible in this study as the researcher was the only data collector. Measuring agitation by caregiver report has limitations such as selective memory and time pressure. The direct care workers were very busy and may have hurried through answers on the FBP and CMAI in some cases. Direct observation of behaviors may have been a more reliable method, but was not feasible in this study. The reliability of the GDS in persons with a MMSE score of below 15 has been questioned by previous researchers.

The two instruments completed by caregivers (FBP and CMAI) are comprised of Likert scales. There was a possibility of response set bias in this type of instrument. There was also the possibility of social desirability response set bias on the GDS since the researcher was the only data collector. This can occur when subjects desire to present a favorable image (Montorio & Izal, 1996). It is a limitation when depression studies are cross-sectional. In a longitudinal study it was found that 85% of persons with AD experienced depression at some point (Levy et. al., 1996). Finally, use of multiple t-tests may increase the possibility of a type I error. Thus, significant t-tests must be viewed with caution.

RECOMMENDATIONS

On the basis of the preceding conclusions, the following recommendations for nursing practice and future research are offered.

Implications for Practice

This study supports previous findings that dementia residents in assisted living have many physical and psychological needs including depression, pain, functional impairment and co-morbid conditions. This suggests a need for adequate nursing assessment and intervention, yet, there is only a limited amount of nursing care available in assisted living. As the population in assisted living is becoming sicker and frailer, this would suggest that nursing time may need to increase. It has been reported that increasing RN time in assisted living decreases transfer to nursing homes (AHRQ, 2004). The use of pharmacological and non-pharmacological treatment for pain was not measured in this study. However, such strategies as massage, heat, ice and acupuncture may be helpful.

Identification of background factors may lead to development of risk profiles for NDBs. Visual analogue scales especially the CAS, were found to be feasible for use in dementia residents in assisted living. There may be a need to increase analgesic usage in this population. The high depression rate in light of the high use of antidepressant medication suggests a possible need to increase use of non-pharmacologic strategies to manage depression such as psychosocial interventions and suggests a role for social workers and psychologists in this setting. Also it may be helpful for nurses to work closely with physicians to inform them when antidepressant therapy is not working, so that different medication can be tried. This also suggests a role for nurse practitioners and for increase referral to geriatric psychiatrists.

Recommendations for Future Research

The results of this study point to the need for future research studies. A randomized study with a larger sample size is recommended. A larger sampling from smaller facilities would allow for comparisons between facilities based on size. This sample was homogenous. It is recommended that future studies include more diversity in the areas of ethnicity, non-English speaking, those who are hard of hearing, central city and rural populations. More specific information regarding facility admission and discharge criteria as it relates to the study variables would aid in interpretation of results of studies of assisted living populations.

Various measurement issues arose in the study. Direct observation of behaviors is recommended. Use of multiple methods to assess depression, especially for those with lower levels of cognitive function is recommended. It may be useful to use qualitative methods to study the nursing assistants who knew the residents well and could be a rich source of data. A qualitative study could also be conducted with the many comments made during the GDS completion in order to better understand depression in dementia. Co-morbid conditions could be studied by adding a physical examination to chart review.

Because the staff was busy with multiple tasks in this setting, providing a stipend to the facilities and caregivers is recommended in future research to engage staff to take the time to complete instruments. Regarding medication usage, antidepressant use could be studied in more detail. Specifically it would be useful to know if more than one antidepressant medication is tried over time. Regarding analgesic usage, specific use of prn analgesic medication should be studied and compared with the extent of pain and

agitation. A serial trial intervention of pain management could be studied. A larger sample size of subjects with pain should be studied in order to assess whether pain predicts agitation.

Summary

This study supports previous research which has reported that persons with dementia have considerable physical and psychological issues including pain, depression, co-morbid conditions, functional impairment and agitation. This poses a challenge to the healthcare system and to society as the number of older adults with dementia continues to increase. When formal care is needed, assisted living facilities cost less than skilled nursing facilities, and the social model is attractive to families and residents.

The assisted living industry is challenged by the responsibility of providing adequate nursing assessment and management for a population with increasing physical and psychological needs while maintaining cost control. The literature suggests that agitation can be a cause of discharge from assisted living facilities. The findings that depression, co-morbid conditions and functional impairment contribute to agitation suggest that it is essential to assess and manage these issues in the dementia population in assisted living.

Conclusion

The purpose of this research study was to describe the factors of pain, depression, co-morbid conditions, functional status and agitation of people with dementia in assisted living and to examine the association of the first four factors to agitation. The primary predictors of agitation were found to be depression, co-morbid conditions and lower

functional level. While more than half of subjects reported pain, it was not predictive of agitation in this study.

Based on analysis of study data the following conclusions are reached:

- 1) Residents with AD in assisted living have high levels of pain, depression, co-morbid conditions and a moderate amount of functional impairment.
- 2) There is a high prevalence of psychotropic medication usage and analgesic medications may be underused.
- 3) People with more severe cognitive impairment are more likely to exhibit daily agitation.
- 4) Residents with dementia in assisted living have many medical problems.

References

- Agency for Healthcare Research and Quality AHRQ (2004) at [URL://www.ahrq.gov](http://www.ahrq.gov)
Number 281 January p. 76. Accessed July, 2006.
- Aguero-Torres, H., Fratiglioni, L., Zhenchao, G., Viitanen, M, von Strauss, E & Winblad, E. (1998). Dementia is the major source of functional dependence in the elderly: 3-year follow-up data from a population-based study. *American Journal of Public Health* 88 (10),1452-1456.
- Aikman, G.G., & Oehlert, M.E.(2001). Geriatric Depression Scale: Long form versus Short Form. *Clinical Gerontologist*,22 (3/4) 63-70.
- Algase, D.L., Beck, C., Kolanowski, A., Whall, A., Berent, S., & Richards, K. et. al. (1996). Need-Driven Dementia-Compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease*, November/December, 10-19.
- American Psychiatric Association.(1994). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.) Washington D.C.
- Ardery, G. Herr, K.A., Titler, M.G., Sorofman, B.A., & Schmitt, M.B. (2003). Assessing and managing acute pain in older adults: A research base to guide Practice. *Medsurg Nursing* 12 (1),7-18.
- Assisted Living Workgroup Steering Committee (2003). *Assuring quality in assisted Living: Guidelines for federal and state policy, state regulations, and operations*. Washington D.C: American Association of Homes and Services for the Aged.
- Aud, M.A. & Conn, V.S. (2003). A call for nursing research in assisted living facilities. *Journal of Gerontological Nursing*, 29 (2), 3.

- Aud, M.A. (2004). Residents with dementia in assisted living facilities. The role of behavior in discharge decisions. *Journal of Gerontological Nursing* June 30 (6), 6-26.
- Baum, C.M. & Edwards, D.F. (2000). Documenting productive behaviors: Using the functional behavior profile to plan discharge following stroke. *Journal of Gerontological Nursing*, 26 (4) ,4-44.
- Baum, C.M., Edwards, D.F. & Morrow-Howell, N. (1993). Identification and Measurement of productive behaviors in senile dementia of the Alzheimer Type. *The Gerontologist*, 33, 403-408.
- Beck, C.K., & Vogelpohl, T.S. (1999). Problematic vocalizations in institutionalized Individuals with dementia. *Journal of Gerontological Nursing* 25 (9), 17-27.
- Beck, C.K., Vogelpohl, T.S., Rasin, J.H., Uriri, J.T., O'Sullivan, P., Walls, R., et. al. (2002). Effects of behavioral interventions on disruptive behavior and affect in dementia nursing home residents. *Nursing Research* 51 (4), 219-228.
- Burgio, L., Scilley, K., Hardin, J & Hsu (2001). Temporal patterns of disruptive vocalization in elderly nursing homes residents. *International Journal of Geriatric Psychiatry* 16, 378-386.
- Cariaga, J., Burgio, L., Flynn, W. & Martin, D. (1990). A controlled study of disruptive vocalizations among geriatric residents in nursing homes. *Journal of American Geriatrics Society* 39, 501-507.
- Chapman, S., Weiner, M.F., Rackley, A., Hynan, L.S. & Zientz, J. (2004). Effects of cognitive-communication stimulation for Alzheimer's disease patients treated

with Donepezil. *Journal of Speech, Language and Hearing Research* (47) 1149-1163.

Cherminski, E., Petracca, G.I., Sabe, L., Kremer, J & Starkstein, S.E. (2001). The specificity of depressive symptoms in patients with Alzheimer's Disease. *The American Journal of Psychiatry* 158 (1) 68-72.

Cohen, C.I., Hyland, K. & Framowitz, I. (1995). Depression among nursing home Residents with dementia: Final Report. Albany, New York State Department of Health, Bureau of Long-Term Care Services.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* 2nd Ed. Hillsdale NJ: L. Erlbaum Associates.

Cohen-Mansfield, J. & Billig, N. (1986). Agitated behaviors in the Elderly I: A Conceptual review. *Journal of the American Geriatrics Society*, 34 (10) 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* Sept 19 (9) 881-91.

Cohen-Mansfield, J. & Werner, P. (1998). The effects of an enhanced environment on nursing home residents who pace. *The Gerontologist* 38, 199-208.

Cohen-Mansfield, J. (1991). Instruction manual for the Cohen-Mansfield Agitation Inventory (CMAI). Rockville MD: The Research Institute of the Hebrew Home Greater Washington.

Cohen-Mansfield, J. (2000). Theoretical frameworks for behavioral problems in dementia. *Alzheimer's Care Quarterly*, Fall, 8-21.

- Colling, K.B. & Buettner, L.L. (2002). Simple pleasures: Interventions from the Need-driven dementia-compromised behavioral model. *Journal of Gerontological Nursing, 25 (9)* 27-32.
- Colling, K.B. (1999). Passive behaviors in dementia: Clinical application of the Need-Driven Dementia-Compromised behavior model. *Journal of Gerontological Nursing 25 (9)*,7-32.
- Cook, A.K., Niven, C.A., & Downs, M.G. (1999). Assess the pain of people with cognitive impairment. *International Journal of Geriatric Psychiatry 14 (6)*,421-425.
- 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 educational level. *Journal of the American Medical Association 269: 23* 86-91.
- Crystal, S., Sambamoorthi, U., Walkup, J.T. & Akncgil, A. (2003). Diagnosis and Treatment of depression in the elderly Medicare population: Predictors, disparities and trends. *Journal of the American Geriatrics Society, 51 (2)*.1718-1728.
- Cuijpers, P. & Lammeren, P.V. (1999). Depressive symptoms in chronically ill elderly people in residential homes. *Aging and Mental Health 3(3)*,221-226.
- De Groot, V., Beckerman, H, Lankhorst, G.J. & Bouter L.M. (2003) How to measure co-morbidity: A critical review of available methods. *Journal of Clinical Epidemiology 53 (3)*,221-9.

- DeYoung, S., Just, G., & Harrison, R. (2002). Decreasing aggressive agitated, or disruptive behavior: Participation in a behavior management unit. *Journal of Gerontological Nursing* 28 (6),22-32.
- Doctrow, J.L., Mueller, G.R. & Craig, L.M. (1999). Survival of the fittest: Competition, consolidation and growth in the assisted living industry. *Journal of Real Estate Portfolio Management*, 5 (3),225-234.
- Doetch, T.M., Alger, B.H., Glasser, M. & Levenstei, J. (1994). Detecting depression in elderly outpatients: Findings from depression symptom scales and the Dartmouth COOP charts. *Family Medicine* 26: 519-523.
- Doraiswamy, P.M., Leon, J., Cummings, J.L., Marin, D. & Newman, P.J. (2002). Prevalence and impact of medical co-morbidity in Alzheimer's disease. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 57: M173-M177.
- Farrell, M.J., Katz, B. & Helme, R.D. (1996). The impact of dementia on the pain experience. *Pain* 67, 7-15.
- Feldt, K.S. (2000). The checklist of nonverbal pain indicators (CNPI). *Pain Management Nursing* 1 (1) March 13-21.
- Feldt, K.S., Ryden, M.B. & Miles., S. (1998) Treatment of pain in cognitively impaired versus cognitively intact patients with hip fracture. *Journal of the American Geriatric Society* 46 (9),1079-85.
- Feldt, K.S., Warne, M.A. & Ryden, M.B. (1998). Examining pain in aggressive cognitively impaired older adults. *Journal of Gerontological Nursing* 23 (11),4-22.

- Ferrell, B.A., Ferrell, B.R. & Rivera, L. (1995). Pain in cognitively impaired nursing home patients. *Journal of Pain Symptom Management* 10, 591-598.
- Ferrell, B.R. & Ferrell, B.A. (Eds.) (1996). Pain in the elderly. Task force on pain in the elderly. Report of the International Association for the study of pain. Seattle, WA
- Finkel, S.I., Lyons, J.S., & Anderson, R.L. (1993). A brief agitation-rating scale (BARS) for nursing home elderly. *Journal of the American Geriatrics Society Jan* 41 50-2.
- 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.
- Gallassi, R., Morreale, A. & Pagni, P. (2001). The relationship between depression and cognition. *Archives of Gerontology and Geriatrics Suppl* 7 163-171.
- Garand, L., Buckwalter, K.C. & Hall, G.R. (2000). The biological basis of behavioral symptoms in dementia. *Issues in Mental Health Nursing*, 21 ,91-107.
- Golant, S. (2004). Do impaired older persons with health care needs occupy U.S. assisted living facilities? An analysis of six national studies. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*: 59: S68-S69.
- Grayson, P., Lubin, B & Van Whitlock, R. (1995). Comparison of depression in the community-dwelling and assisted living elderly. *Journal of Clinical Psychology* 51 (1),18-21.
- Gruber-Baldini, A.L., Boustani, M., Sloane, P.D. & Zimmerman, S. (2004). Behavioral Symptoms in residential care/assisted living facilities: Prevalence, risk factors

- and medication management. *Journal of the American Geriatrics Society*, 52 (10),1610-1617.
- Gruber-Baldini, A.L., Zimmerman, S., Boustani, Watson, Williams & Reed (2005). Characteristics associated with depression in long-term care residents with dementia. *The Gerontologist* 45(1),50-55.
- Hall, G.R. & Buckwalter, K.C. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing*, 1 (6),399-406.
- Hawes, C, Phillips, C.D., Rose, M., Holan, S. & Sherman, M. (2003). A national survey of assisted living facilities. *The Gerontologist* 43: 875-882.
- Hebert, L.E., Scherr, P.A., Bienias, J.L., Bennett, D.A. & Evans, D.A. (2003). Alzheimer's disease in the U.S. population: Prevalence estimates using the 2000 Census, *Archives of Neurology*, 6 (18),1119-1122.
- Hendrix, C.C., Sakuye, K.M., Krabatsos, G. & Daigle, D. (2003). The use of the Minimum Data Set to identify depression in the elderly. *Journal of the American Medical Directors Association* 4 (6): 308-12.
- Hill, J.W., Futterman, R., Duttagupte, S., Mastey, V., Lloyd, J.R. & Fillit, H. (2002). Alzheimer's disease and related dementias increase costs of co-morbidities in managed medicare. *Neurology* 58 (1),62-70.
- Hill, R.D., Backman, L. & Fratigioni, L. (1995). Determinants of functional abilities in dementia. *Journal of the American Geriatrics Society* 43, 1092-1097.

- Holmes, D. & Ramirez, M. (2003). Models for individuals with Alzheimer disease: Beyond the special care framework. *Journal of Social Work in Long-term Care* 2(1/2) 175-81.
- Holtzer, R., Tang, M., Devanand, D.P., Albert, S., Wegesin, D., & Mander, K., et. al. (2003). Psychological features in Alzheimer's disease: Course and relationship with cognitive status. *Journal of the American Geriatrics Society* 51 (7),953-960.
- Howard, D., Sloane, P., Zimmerman, S., Eckert, K., Walsh, J., & Buie, V., et. al. (2002). Distribution of African Americans in residential care/assisted living and nursing homes: More evidence of racial disparity? *American Journal of Public Health* 92 (8) 1272-1277.
- Huffman, J.C. & Kunik, M.E. (2000). Assessment and understanding of pain in patients with dementia. *The Gerontologist*, 40,574-581.
- Iglesias, G.H. (2004). Geriatric Depression Scale Short Form and Zung Self-Rating Depression Scale: A study of homebound elders. *Clinical Gerontologist* 27 (3).
- Isella, V., Letizia, V.M., & Appolonio, I.M. (2001). Screening and quantification of Depresión in mild-to-moderate dementia through GDS short forms. *Clinical Gerontologist* 24 (3/4),115-25.
- Jefferson, A.L., Powers, D.V. & Pope, M. (2001). Beck Depression Inventory-II(BDII) and the Geriatric Depression Scale (GDS) in older women. *Clinical Gerontologist* 22 (3/4) 3-12.
- Jirovec, M.M. & Wells, T.J. (1990). Urinary incontinence in nursing home residents with dementia: The mobility-cognition paradigm. *Applied Nursing Research*, 3 (3) 112-117.

- Kane, R, Ouslander & Abrasos (1999). *Essentials of Clinical Geriatrics* (4th ed) New York: McGraw Hill.
- Kane, R. & Wilson, K.B. (1993). Assisted living in the United States: A new paradigm for residential care for frail older persons. Washington D.C.: American Association of Retired Persons.
- Katz, I.R. & Parmalee, P.A. (1994). Depression in elderly patients in residential care settings, in *Diagnosis and treatment of depression in late life: Results of the NIH Consensus Development conference* (Eds.) Schneider, L.S., Reynolds, C.F. II. Washington D.C. American Psychiatric Press 463-490.
- Katz, I.R. (1998). Diagnosis and treatment of depression in patients with Alzheimer's disease and other dementias. *Journal of Clinical Psychiatry* 59 (9), 38-44.
- Kelber, S. (2006). University of Wisconsin-Milwaukee, personal communication.
- Kelly, S. (1998). Handbook of psychopathology, revised, Stillwater, OK: National Clearinghouse of Rehabilitation Materials.
- Knight, M. (2000). Cognitive ability and functional status. *Journal of Advanced Nursing* 31 (6), 1459-1468.
- Koenig, H.G. & Blazer, D.G. (1996). Minor depression in late life. *American Journal Of Geriatric Psychiatry*, 4 (Suppl) S14-S21.
- Kolanowski, A.M. & Garr, M. (1999). The relation of premorbid factors to aggressive physical behavior in dementia. *Journal of Neuroscience Nursing* 31 (5), 278-284.
- Kolanowski, A.M. (1999) An overview of the need-driven dementia-compromised behavior model. *Journal of Gerontological Nursing* 25 (9), 7-9.

- Kopetz, S., Steele, C.D., Brandt, J., Baker, A., Kronberg, M., & Galik, E. et. al. (2000). Characteristics and outcomes of dementia in an assisted living facility. *International Journal of Geriatric Psychiatry* 15, 586-593.
- Koss, E., Weiner, M., Ernesto, C, Cohen-Mansfield, J., Ferris, S.H., & Grundman, M., et. al. (1997). Assessing patterns of agitation in Alzheimer's disease patients with the Cohen-Mansfield Agitation Inventory. The Alzheimer's Disease Cooperative Study. *Alzheimer Disease and Associated Disorders 11 Suppl. 2*: S45-50.
- Kovach, C.R. (2000). Sensoriastasis and imbalance in persons with dementia. *The Journal of Nursing Scholarship* 32 (4), 379-384.
- Kovach, C.R., Griffie, J., Muchka, S., Noonan, P.E. & Weissman, D.E. (2000). Nurses' Perception of pain assessment and treatment in the cognitively impaired elderly. It's not a guessing game. *Clinical Nurse Specialist* 14 (5), 215-220.
- Kovach, C.R., Noonan, P.E., Griffie, J., Muchka, S. & Weissman, D.E. (2002). The Assessment of discomfort in dementia protocol. *Pain Management Nursing* 3 (1), 16-27.
- Kovach, C.R., Taneli, Y, Dohearty, P., Schlidt, A.M., Cashin, S & Silva-Smith, A.L. (2004). Effect of the BACE intervention on agitation of people with dementia. *The Gerontologist* 44 (6), 797-806.
- Kovach, C.R., Weissman, D.E., Griffie, J., Matson, S. & Muchka, S. (1999). Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management* 18 (6), 412-419.
- Krulewitch, H., London, M.R., Skakel, J., Lundstedt, G.J, Thomason, H. & Brummel-Smith, K. (2000). Assessment of pain in cognitively impaired older adults: A

- comparison of pain assessment tools and their use by nonprofessional caregivers. *Journal of the American Geriatrics Society* 48 (12), 1607-11.
- Kukall, W.A., Koepsell, T.D., & Inui, T.S. (1986). Depression and physical illness among elderly general medical clinic patients. *Journal of Affective Disorders* 10, 153-162.
- Langa, K.M., Chernew M.E., Mohan, Herzog, A., Ufsteval, M.B. et. al. (2001). National estimates of the quantity and cost of informal care for the elderly with dementia. *Journal of General Internal Medicine* 16 (11), 770-778.
- Lawlor, B.A. (1995). Possible neurobiological basis for behavioral symptoms. In B.A. Lawlor (Ed.), *Behavioral complications in Alzheimer's Disease* (pp. 91-101). Washington, D.C.: American Psychiatric Press.
- Lawton, M.P. & Nahemow, L. (1973). Ecology and the Aging Process. In Eisdorfer C. & Lawton M.P, (Eds.) *Psychology of Adult Development and Aging*.
- Lawton, M.P. (1986). *Environment and Aging*. Second Ed. Classics in Aging. Reprinted, Series I Volume I, Center for the study of Aging. Albany: New York.
- Lazarus, L.W., Newton, N., Cohler, B., Lesser & Schwem, C. (1987). Frequency and presentation of depressive symptoms in patients with primary degenerative dementia. *American Journal of Psychiatry* 144: 41-45.
- Lebowitz, B.D., Pearson, J.L., Schneider, L.S., Reynolds, II, C.F., Alexopoulos, G.S. & Late life. *Journal of the American Medical Association* 278, 1186-1190.
- Leshner, E.L. (1986). Validation of the Geriatric Depression Scale among nursing home residents. *Clinical Gerontologist* 4, 21-28.

- Levy, M.L., Cummings, J.L., Fairbanks, L.A., Bravi, D., Calvani, M & Carta, A. (1996). Longitudinal assessment of symptoms of depression, agitation and psychosis in 181 patients with Alzheimer's disease. *American Journal of Psychiatry* 153:11, 1438-1443.
- Lyness, J.M., Noel, T.K., & Cox, C. et. al.(1997). Screening for depression in elderly primary care patients. *Archives of Internal Medicine* 157: 449-454.
- Mackenzie, D.M., Copp, P., Shaw, R.J. & Goodwin, G.M. (1996). Brief cognitive Screening of the elderly: A comparison of the Mini-mental State Examination (MMSE), Abbreviated Mental Test (AMT) and Mental Status Questionnaire (MSQ). *Psychological Medicine* 26 (2), 427-430.
- Magsi, H. & Malloy, T. (2005). Underrecognition of cognitive impairment in assisted living facilities. *Journal of the American Geriatrics Society* 53 (2), 295-8.
- Mahoney, E.K., Hurley, A.C., Volicer, L, Bell, M., Gianotic, P, Harshorn, M., et. al. (1999). Development and testing of the Resistiveness to Care Scale. *Research in Nursing and Health*, 22, 27-28.
- Mantyselka, P., Harikainens, S., Loutivuori-Laako, K. & Sulkava, R. (2004). Effects of dementia on perceived daily pain in home-dwelling elderly people: A Population-based study. *Age and Ageing* 33 (5), 496-9.
- Marin, D., Sewell, M & Schlecter, A. (2002). Alzheimer's disease. Accurate and early Diagnosis in the primary care setting. *Geriatrics*, 57, 427-33.
- Marrocco, G.F. (1996). Dementia and depression: A study of prevalence in an elderly Residential setting. Doctoral Dissertation: Teachers College Columbia University.

- Matthews, K., Chen, C., Esiri, M., Keene, J., Minger, S. & Francis, P. (2002).
Noradrenergic changes, aggressive behavior, and cognition in patients with
dementia. *Society of Biological Psychiatry* 51, 407-416.
- McGrath, P.A., Seifert, C.E., Sppechley, K.N., Booth, J.C., Stitt, L. & Gibson, M.C.
(1996). A new analogue scale for assessing children's pain: An initial validation
Study. *Pain*, 64, 435-443.
- Mega, M.S., Cummiings, J.L., Fiorello, T. & Gornbein, (1996). The spectrum of
Behavioral changes in Alzheimer's disease. *Neurology*, 46: 130-136.
- Miller, M.D. & Towers, A. (1991). A manual of guidelines for scoring the Cumulative
Illness Rating Scale for Geriatrics (CIRS-G). University of Pittsburgh.
Pittsburgh, PA.
- Miller, M.D., Paradis, C.F., Houck, P.R., Mazunder, & S., Stack, et. al.(1992). Rating
chronic medical illness in Burden in geropsychiatric practice and research:
Application of the Cumulative Illness Rating Scale. *Psychiatry Research* 41, 237-
248.
- Miller, R.J., Snowdon, J., & Vaughn, R. (1995). The use of the Cohen-Mansfield
Agitation Inventory in the assessment of behavioral disorders in nursing homes.
Journal of the American Geriatrics Society 43, 546-9.
- Mirra, S.S., Heyman, A. & Mckeel, D. (1991). The consortium to establish a registry for
Alzheimer's disease (CERAD). Part II: Standardization of the neuropathological
assessment of Alzheimer's disease. *Neurology* 41, 459-466.
- Mitrushina, M. & Satz, P. (1991). Reliability and validity of the mini-mental state exam
in neurologically intact elderly. *Journal of Clinical Psychology* 47 (4), 537-543.

- Mitty, E. (2003). Assisted Living and the role of nursing. *American Journal of Nursing* 103 (8), 32-44.
- Mollica R.L. (2000) State assisted living policy 2000. National Academy for State Health Policy: Portland, ME.
- Mollica, R. (2001). State policy and regulations. In S. Zimmerman, P.D. Sloane & J.K. Eckert (Eds.), *Assisted Living Needs, practices, and policies in residential care for the elderly*. (pp. 9-33). Johns Hopkins University Press: Baltimore, MD.
- Montorio, I. & Izal, M. (1996). The Geriatric Depression Scale: A review of its development and utility. *International Psychogeriatrics* 8, 103-112.
- Moore, M.J., Zhu, C.W. & Clipp, E.C. (2001). Informal costs of dementia care: Estimates from the National Longitudinal Caregiver Study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 56: S219-S228.
- Morgan, L.A., Gruber-Baldini, A.L., Magaziner, J. & Hyg (2001). Resident characteristics In S. Zimmerman, P.D. Sloane, & J.K. Eckert, (Eds.). *Assisted Living: Needs, practices, and policies in residential care for the elderly* (pp. 144-172). Johns Hopkins University Press.
- Murden, R.A., McRae, T.D., Kaner, S., & Bucknam, M.E. (1991). Mini-Mental State Exam scores vary with education in blacks and whites. *Journal of the American Geriatric Society* February 39 (2), 149-55.
- National Center for Assisted Living (1998). *Facts and Trends: The Assisted Living Sourcebook 1998*. Washington D.C.: American Health Care Association.

- National Center for Assisted Living (2003) *Assisted living State Regulation, Review 2003*
American Health Care Association, Washington D.C.
- Nolin, M.A. & Mollica R.L. (2001). Residential care/assisted living in the changing health environment. In Zimmerman, S., Sloane, P.D. & Eckert J.K. *Assisted Living: Needs, practices and policies in residential care for the elderly*. Johns Hopkins University Press: Baltimore, MD.
- Ory, M., Hoffman, R.R., Yee, J.L., Tennstedt, S. & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist* 39 (2), 177-185.
- Parke, B (1998). Gerontological nurses' ways of knowing. Realizing the presence of pain in cognitively impaired older adults. *24 (6)*, 21-28.
- Parmalee P.A., Lawton, M.P., Katz, I.R. (1989) Depression scale among the institutionalized aged. *Psychological Assessment* 1 :331-338.
- Parmalee, P.A., Thras, P.D. & Katz, I.R. et. al, (1995). Validation of the Cumulative Illness Rating Scale (CIRS) in a geriatric residential population. *Journal of the American Geriatric Society* 43, 130-137.
- Polit, D.F. & Beck, C.F. (2004) *Nursing Research: Principles and Methods*. 7th ed. Philadelphia: Lippincott, Williams & Wilkins.
- Potts, H.W., Ritchie, M.F. & Kaas, M.J. (1996). Resistance to care. *Journal of Gerontological Nursing*, 22 (11), 11-16.
- Prigerson, H. (2003). Costs to society of family caregiving for patients with end-stage Alzheimer's disease. *The New England Journal of Medicine*, 349 (20), 1891.

- Quinn, M.E., Johnson, M.A., Andress, E.L. & McGinnis, P. (2003). Health characteristics of elderly residents in personal care homes: Dementia, possible early dementia, and no dementia. *Journal of Gerontological Nursing*, 29 (8), 16-23.
- Ritchie, K., Gilham, C., Ledseret, B., Touchon, J. & Kotzki, P. (1999). Depressive illness, depressive symptomatology and regional cerebral blood flow in elderly people with sub-clinical cognitive impairment. *Age and Ageing* 28 (4), 385-391.
- Rosenblatt, A., Samus, Q, Steele, C, Baker, A., Harper, M., Brand, J. et. al. (2004) The Maryland Assisted Living Study: Prevalence, recognition and treatment of dementia and other psychiatric disorders in the assisted living population of central Maryland. *Journal of the American Geriatrics Society* 52 (10), 1618-1625.
- Ryden, M.B., & Feldt, K. (1992). Goal directed care: Caring for aggressive nursing home residents with dementia. *Journal of Gerontological Nursing* 11, 35-42.
- Ryden, M.B., Bossenmaier, M. & McLachlan, C. (1991). Aggressive behavior in cognitively impaired nursing home residents. *Research in Nursing and Health* 14, 87-95.
- Scherder, E.J. & Bouma, A. (1997). Is decreased use of analgesics in Alzheimer's Disease due to a change in the affective component of pain? *Alzheimer's Disease and Associated Disorders* 11: 171-174.
- Scherder, E.J. & Bouma, A. (2000). Visual analogue scale for pain assessment in Alzheimer's disease. *Gerontology*, 46, 47-53.

- Scherder, E.J., Slaets, J., Deijen, J., Garter, Y, Ooms, M.E., & Ribbe, M. et. al. (2003). Pain assessment in patients with possible vascular dementia. *Psychiatry* 66 (2), 133-145.
- Schneider, L, Pollock, V.E. & Lynes, S.A. (1990). Meta-analysis of controlled trials of neuroleptics in dementia. *Journal of the American Geriatrics Society*, 38, 553-563.
- Schonfeld, L. (2003). Behavioral problems in assisted living facilities. *The Journal of Applied Gerontology*, 22 (4), 490-505.
- Schulman, E., Garioloa, G., Kuder, L & McCulloch, J. (2002). Depression and Associated characteristics among community-based elderly people. *Journal of Allied Health* 31 (3), 140-146.
- Sclan, S.G. & Reisberg, B. (1992). Functional assessment staging (FAST) in Alzheimer's disease: Reliability, validity and ordinality. *International Psychogeriatrics* 4 (91), 55-69.
- Sengstaken, E.A. & King, S.A. (1993). The problems of pain and its detection among geriatric nursing home residents. *Journal of the American Geriatrics Society*, 41, 541-544.
- Sheikh, J.I. & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS) Recent evidence and development of a shorter version. *Clinical Gerontologist* 5 (1/2), 165-173.
- 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, Zimmerman, S., Brown, L., Ives, T. & Walsh, J. (2002). Inappropriate medication prescribing in residential care/assisted living facilities. *Journal of the American Geriatrics Society* 50: 1001-1011.
- Sloane, P.D., Zimmerman, S. & Ory, M.G. (2001). Care for persons with dementia. In Zimmerman, S., Sloane, P.D. & Eckert, J.K. *Assisted Living: Needs, practices and policies in residential care for the elderly* (pp. 242-270). Johns Hopkins University Press: Baltimore: MD.
- Smith, M., Gardener, L., Hall, G. & Buckwalter, K. (2004). History, development and future of the Progressively Lowered Stress Threshold: A conceptual model for dementia care. *Journal of American Geriatrics Society* 52 (10), 1755-1760.
- Tabachnick, B.G. & Fidell, L.S. (2001). Using multivariate statistics. Alan & Bacon needham: MA.
- Taft, L. (1989). Conceptual analysis of agitation in the confused elderly. *Archives of Psychiatric Nursing* 3 (2), 102-107.
- Talerico, K.A. & Evans, L.K. (2000). Making sense of aggressive/protective behaviors in persons with dementia. *Alzheimer's Care Quarterly* 1 (4) 77-88.
- Tariot, P.N. (1999). Treatment of agitation in dementia. *Journal of Clinical Psychiatry* 60: (Suppl 8):11-20.
- Teno, J.M., Weitzen, S., Wettle, T. & Mor, V. (2001). Persistent pain in nursing home residents. *Journal of the American Medical Association* 285, 2081-2085.
- Teri, L. & Logsdon, R.G. (1999). Treatment of behavioral and mood disturbances in Dementia. *Generations* Fall 23 (3), 1-9.

- Teri, L. & Wagner, A. (1992) Alzheimer's disease and depression. *Journal of Consulting and Clinical Psychology* 60, 379-391.
- Tombaugh, T.N. & McIntyre, N.J. (1992). The Mini-mental state examination: A comprehensive review. *Journal of the American Geriatrics Society* 40, 922-935.
- Van Belle, G., Uhlmann, R.F., & Hughes, J.P. et. al. (1990). Reliability of estimates of changes in mental status test performance in senile dementia of the Alzheimer type. *Journal of Clinical Epidemiology* 43, 589-595.
- Volicer, L. & Hurley, A.C. (2003). Review article: Management of behavioral Symptoms in progressive degenerative dementias. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 58: M837-M845.
- Watson, L.C., Garrett, J.M., Sloane, P.D., Gruber-Baldini, A.L. & Zimmerman, S. (2003). Depression in assisted living: Results from a four-state study. *American Journal of Geriatric Psychiatry* 11 (5), 534-542.
- Whall, A.L. & Kolanowski A.M. (2004). Editorial: The need-driven dementia-compromised behavior model-A framework for understanding the behavioral symptoms of dementia. *Aging and Mental Health* 8 (2), 106-108.
- Whall, A.L. (1999). The measurement of need-driven dementia-compromised behavior: Achieving higher levels of inter-rater reliability. *Journal of Gerontological Nursing* 25 (9), 33-37.
- Williams, C.S., Zimmerman, S., Sloane, P.D. & Reed, P.S. (2005). Characteristics associated with pain in long-term care residents with dementia. *The Gerontologist* 45 (1), 68-73.

Wisconsin Administrative Code (2000). Residential Care Apartment Complexes Chapter HFS 89.

Wisconsin Administrative Code (2001). Community-based residential care facilities. Chapter HFS 83, 258-2.

Wynne, C. (2000). Comparison of pain instruments in cognitively impaired nursing home residents. *Geriatric Nursing Jan-Feb 21 (1)*, 20-23.

Yesavage, J.A., Brink, T.L., Rose, R.I., Lum, O., Huang, V., Adey, M, et. al. (1983). Development and validation of a geriatric depression screening scale: A preliminary report. *Journal of Psychiatric Research 17*, 37-49.

Zimmerman, S., Gruber-Baldini, A., Sloane, P., Eckert, J., Hebel, J.R. & Morgan, L.A. et. al., (2003). Assisted Living and nursing homes: Apples and oranges? *The Gerontologist, 43*, 107-117.

Zimmerman, S., Sloane, P.D., Eckert, J.K., Buie, V.C., Walsh, J.F., & Koch, G.G. et. al. (2001). An overview of the collaborative studies of long-term care In Zimmerman, S., Sloane, P.D. & Eckert, J.K. *Assisted Living: Needs, practices and policies in residential care for the elderly* (pp. 117-143). Johns Hopkins University Press: Baltimore, MD.

Appendix A

(date)
(name of administrator)
(name of facility)
(address)
(city, state, zip code)

Dear (name of administrator)

I am a doctoral student at the University of Wisconsin – Milwaukee College of Nursing. For my dissertation research I am exploring how depression, pain, co-morbidity, cognitive and functional level correlate with behavioral symptoms in persons with dementia who reside in assisted living facilities. I would like to include your facility as a research site.

If you agree to participate in the study, your involvement will consist of providing access to your staff, having the staff identify those residents that may meet criteria for this study and asking for their permission for me to talk with them and sending out a letter that I will provide to the family member/proxy for those residents. A one-page facility profile will also need to be completed.

Confidentiality will be preserved throughout the study and in all reports. Your name, the name of your facility, and the names of any residents mentioned during the interview will not be revealed. I anticipate that the findings of this study will lead to a better understanding of residents with dementia in assisted living facilities and to interventions that will make it possible for some residents with dementia to postpone relocation to skilled nursing facilities.

I look forward to meeting with you,

Julie L. Ellis MS RN C
Doctoral Candidate- Nursing

APPENDIX B

Abstract

“Factors Associated with Behavioral Symptoms in Persons with Dementia Residing in Assisted Living”

Principal Investigator: Julie L. Ellis MS RN C, doctoral candidate University of Wisconsin – Milwaukee

Introduction

Many people who reside in assisted living facilities have dementia. People with dementia often exhibit agitated behavioral symptoms such as wandering, pacing, crying, yelling and resistance to care. These behaviors can decrease residents' quality of life, increase social isolation, cause frustration for staff and result in premature nursing home placement. Behavioral symptoms are often due to unmet needs such as pain and other symptoms due to co-morbidities and depression. This research will explore factors associated with agitation in residents with dementia. Increased understanding of behavioral symptoms can lead to the development of interventions to better recognize unmet needs and reduce the symptoms. This may forestall early nursing home placement.

Purpose

This is a dissertation study in partial fulfillment of a PhD in nursing. The purpose of this study is to examine the levels of depression, pain, co-morbidity and functional status and behavioral symptoms in residents with dementia in assisted living and to study the relationship of the first four factors to behavioral symptoms.

Staff Participation

The assisted living assistant administrator or his/her designee will determine which residents meet criteria for inclusion, ask for their assent to have the researcher meet with them to explain the study and obtain informed consent, and send their families a cover letter and an Information and Informed Consent Form. He/She will also be asked to complete a brief facility profile. The researcher will collect information about subjects' co-morbidity, medications and demographics from the medical record. The researcher will interview the direct care worker to complete a functional assessment form and a behavioral assessment form. This will take approximately 25 minutes.

Resident Participation

Great care will be taken to get all needed consents from family members and residents before any contact is made with the resident. Following consent, the researcher will administer a screening instrument to assess cognitive impairment. Those with cognitive impairment, no longstanding psychiatric illness and time in the facility greater than one month will be eligible to participate. The researcher will administer a brief depression instrument and pain assessment instruments to those enrolled. Administering all instruments to the subjects will take 30 minutes in total.

Outcomes

All information regarding particular residents will be kept completely confidential. Only grouped information will be shared in publications or presentations. Participation in this project is a way for your facility to be part of furthering the understanding of the needs of people with dementia in assisted living. This may lead to development of interventions to reduce behavioral symptoms and improvement of the lives of assisted living residents with dementia throughout the nation. The researcher understands the real world challenges of providing the social model of assisted living and meeting resident needs and respects the excellent care provided at your facility. By partnering in this research endeavor progress can be made toward the goal of enabling residents with dementia to stay longer in the assisted living setting.

APPENDIX C**Cover Letter from Administrator to accompany The Family/Guardian Information and Consent Form**

Date

Administrator
Address if facility

Dear (insert facility name) resident,

Julie Ellis, a geriatric clinical nurse specialist and doctoral student from the University of Wisconsin – Milwaukee will be conducting a research study in (facility) between December 2005 and May 2006) and your family member has been invited to participate.

This research will help nurses better understand the needs of people with memory changes that reside in assisted living facilities. Your family member has been selected to participate because they have lived in assisted living for more than one month and have some memory changes.

Whether or not your loved one participates is completely voluntary and your decision either way will not change your relationship with (Facility) in any way. Participating in this study will take only a small amount of your family member's time and can help nurses and assisted living facilities in the nation provide better care for people with memory changes.

I support Julie Ellis in conducting her research here at (Facility). If you choose to participate please read the attached Information form and sign the Informed Consent Form and return to me by (date).

Sincerely,
Administrator

APPENDIX D

The Family/Guardian Information and Consent Form

Factors associated with behavioral symptoms in persons with dementia residing in assisted living

I would like to invite your family member to be part of a research study that will consider issues that are associated with behavioral symptoms in persons with memory changes. Your family member was selected as a possible participant because he/she has some memory changes. My name is Julie Ellis and I am a geriatric clinical nurse specialist and doctoral candidate at the University of Wisconsin – Milwaukee College of Nursing.

Background Information

The purpose of this study is to better understand things that may increase behavioral symptoms such as wandering, crying, pacing, or resisting cares, in persons with memory loss that live in assisted living. This study will look at whether pain, depression and the number of illnesses a person has are associated with more behavioral symptoms.

Procedure

If you agree to allow your family member to participate, I will meet with your family member for approximately 30 minutes to test their memory and ask some brief questions about depression and pain. I will also review their medical record and interview the staff about their functional level and behavioral symptoms

Risks and Benefits of Being in the Study

There is little risk involved for your family member if they agree to be in this study. If your family member says that they don't want to be in the study at any time, they will be withdrawn from the study. If I observe that your family member is having a lot of pain, I will let the nurse manager know. The study will not affect the care or the treatment that your family member would normally receive at (name of CBRF).

There is no direct benefit to your family member for being part of the study. A potential benefit is that nurses may learn more about things that increase behavioral symptoms in people who live in assisted living, especially those who are confused, which could lead to better treatment in the future.

Confidentiality

The records of this study will be kept private. No personal names will be used. Participants will be given a code number. In any sort of report that will be published, no information would be included that would allow someone to identify them. Research records will be kept in a locked file and only the researcher will have access to the records.

Voluntary Nature of the Study

Your decision whether or not to have your family member be part of this study will not affect your current or future relationship with (name of CBRF). If you decide to participate your family member is free to refuse to answer any of the questions or to withdrawn completely from the study at any time.

Contacts and Questions

The researcher conducting this study is Julie L. Ellis. You may ask any questions that you have now. If you have questions later, you may contact her at [REDACTED]. If you have any complaints about your treatment as a participant in this study, please write or call:

Chris Furness
Human Protections Administrator
University of Wisconsin – Milwaukee
Graduate School-IRB Office

[REDACTED]
Milwaukee, WI [REDACTED]
[REDACTED]

Although Chris Furness will ask your name, all complaints are kept in confidence.

APPENDIX E**Script (Used in Pilot Study)**

Administrator/designee to read this to residents that meet criteria for participation in the study.

(Resident's name), a nurse who is a student at the University of Wisconsin – Milwaukee, named Julie Ellis, is going to do a study here at (name of CBRF). She is looking for people that live in assisted living to be part of her study.

This study will help nurses better understand what affects people who have memory changes and live in assisted living. She is interested in things such as how pain and illness affect people with memory changes. If it is OK with you, Julie will meet with you, explain her study, answer any questions, and have you sign a form agreeing to participate. If you agree to be in her study she will ask you some questions, talk to the staff about your care and look at your medical chart.

It is OK if you are part of the study, or if you don't want to be part of the study that is OK too. It is totally up to you. Are you interested in having Julie come and speak with you about being in her study?

Resident response _____

Resident name _____ Resident Room Number _____

APPENDIX F**Letter of Participation and Consent****Julie L. Ellis MS RN C**


Date

Dear (Insert name of CBRF) Resident,

You are invited to participate in a research study that will look at issues that affect people with memory changes that live in assisted living facilities. You are being asked to be part of the study because you have some memory changes. My name is Julie L. Ellis. I am a geriatric nurse and a doctoral candidate at the University of Wisconsin – Milwaukee College of Nursing.

The purpose of the study is to better understand things that may affect persons with memory loss who live in assisted living such as pain, depression and the number of diseases a person has.

If you agree to participate, I will meet with you on one day for a short while. You will be asked to spend about 30 minutes with me answering some questions. I will also look at your medical record and talk to the staff about your care.

There is little risk to you if you agree to be in this study. If you decide that you do not want to answer questions you may stop being part of the study at any time. If you report pain when questions are asked, I will let your nurse know. There is no direct benefit to you if you agree to be in the study. It is possible that the study will help nurses learn more about things that affect people with memory changes who live in assisted living facilities.

The records of this study will be kept private. Your name will not be used in any reports.

Whether or not you agree to be in this study will not affect your relationship with (Insert name of CBRF) in any way. If you do decide to participate you are free to refuse to answer any of the questions or to stop being in the study at any time.

You may ask me any questions that you have about the study. If you have questions later, after the study is over, you may call me at . If you have any complaints about your treatment as a participant in this study, please write or call:

Chris Furness
Human Protections Administrator

University of Wisconsin – Milwaukee
 Graduate School-IRB Office

██████████
 Milwaukee, WI ██████████
 ██████████

Although Chris Furness will ask your name, all complaints are kept in confidence.

I have been informed regarding the study “Factors associated with behavioral symptoms in persons with dementia residing in assisted living” conducted by Julie L. Ellis MS RNC at (Insert CBRF name) assisted living facility in December of 2005 and Winter/Spring of 2006.

I have had an opportunity to have my questions answered and understand that signing below indicates consent to participate in the study. I understand that participation in this study is completely voluntary.

I understand that by signing below I give my permission for:

☐ Julie Ellis to ask me questions that will take 20-30 minutes

☐ Julie Ellis to ask the staff questions about me

☐ Julie Ellis to look at my medical record

Name

Date

This research project has been approved by the University of Wisconsin – Milwaukee Institutional Review Board for Protection of Human Subjects for a one-year period.

APPENDIX G**Script for Researcher to use when obtaining informed consent for participation in the main study.**

My name is Julie Ellis. I am a nurse and a doctoral candidate at the University of Wisconsin – Milwaukee. I am conducting a study about people who live in assisted living and I would like you to participate. You are free to say yes or no, either way is fine with the staff here at (name of facility). If you agree to participate I will ask you some questions to test your memory, and some questions about how you are feeling and whether you have pain. If you do not want to answer any of the questions you are free not to at any time. You are also free to stop being in the study at any time. It will take about 30 minutes of your time to participate. In addition, if you agree to be in the study I will look at your medical chart and talk briefly to the staff about your care.

Are you interested in being part of this study? Would you like me to read this letter to you?

APPENDIX H

Subject Code: _____

Date: ____/____/____

Score _____

The Mini-Mental State Examination

	Score	Points
Orientation		
1. What is the:		
Year?	_____	1
Season?	_____	1
Date?	_____	1
Day?	_____	1
Month	_____	1
2. Where are we?		
State?	_____	1
County?	_____	1
Town or City?	_____	1
Facility?	_____	1
Floor/unit?	_____	1
Registration		
3. Name three objects, taking one second to say each. Then ask the patient all three after you have said them. Give one point for each correct answer. Repeat the answers until the patient learns all three. (Tiger, green, book)	_____	3
Attention and calculation		
4. Serial sevens. Give one point for each correct answer. Stop after five answers. <i>Alternate: Spell WORLD backwards.</i>	_____	5
Recall		
5. Ask for names of three objects learned in question 3. Give one point for each correct answer.	_____	3
Language		
6. Point to a pencil and watch. Have the patient name them as you point.	_____	2

- | | | |
|--|-------|---|
| 7. Have the patient repeat “No ifs, ands, or buts.” | _____ | 1 |
| 8. Have the patient follow a three-stage command.
“Take the paper in your right hand. Fold the paper in half
Put the paper on the floor.” | _____ | 3 |
| 9. Have the patient read and obey the
following: “CLOSE YOUR EYES”.
Use printed sheet in large letters. | _____ | 1 |
| 10. Have the patient write a sentence of his or
her own choice. (The sentence should contain
a subject and a verb and should make sense.
Ignore spelling errors when scoring). | _____ | 1 |
| 11. Enlarge the design printed below to 1 inch
per side and have the patient copy it. (Give
one point if all sides and angles are preserved and
if the intersecting sides form a quadrangle). | _____ | 1 |

Total Points _____

≤ 23 = cognitive impairment

Reprinted from *Journal of Psychiatric Research* (1975) Vol 12 Folstein, MF, Folstein, SE & McHugh, PR., “Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician: 189-198.

CLOSE YOUR EYES

Instructions for Administration of Mini-Mental Status Examination

Orientation: Ask for the date. Then ask specifically for parts omitted e.g. “Can you also tell me what season it is?” One point for each correct answer. Ask in turn “Can you tell me the name of this place?” (assisted living facility). One point for each correct answer.

Registration: Ask the patient if you may test his memory. Then say the names of 3 unrelated objects, clearly and slowly, about once second for each. After you have said all 3, ask him to repeat all 3, up to 6 trials. If he does not eventually learn all 3 recall (see below) cannot be meaningfully tested.

Attention and Calculation: Ask the patient to begin with 100 and count backwards by 7. Stop after 5 subtractions (93,86,79,72,65). Score the total number of correct answers. If the patient cannot or will not perform this task; ask him to spell the word “world” backwards. The score is the number of letters in correct order. E.g. dlrow=5, dlorw=4.

Recall: Ask the patient if he can recall the 3 words you previously asked him to remember. Score 0-3.

Language: Naming: Show the patient a pencil and ask him what it is. Repeat for wrist watch. Score 0-2, one for each correct answer. 0 if none are named.

Repetition: Ask the patient to repeat the sentence after you. Allow only one trial. Score 0 or 1.

3-stage command: Give the patient a piece of plain blank paper and repeat the entire command. Score 1 point for each part correctly executed.

Reading: On a blank piece of paper print the sentence “Close your eyes” in letters large enough for the patient to see clearly. Ask him to read it and do what it says. Score 1 point only if he actually closes his eyes.

Writing: Give the patient a blank piece of paper and ask him to write a sentence for you. Do not dictate a sentence; it is to be written spontaneously. It must contain a subject and verb and be sensible. Correct grammar and punctuation are not necessary.

Copying: On a clean piece of paper, draw intersecting pentagons, each side about 1 inch, and ask him to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.

Reprinted from the *Journal of Psychiatric Research* Vol 12 Folstein, M.F., Folsten, M.F., McHugh, P.R. Mini-Mental State: A Practical method for grading the cognitive state of patients for the clinician. 189-198. 1975.

Demographic Data Form

Date: _____
Investigator: _____
Data collected from: _____
Date of birth ____ / ____ / ____

-
1. **Age** _____
 2. **Gender** _____
 3. **Marital Status** _____
 4. **Length of time in facility** _____
1= 1 mo -12 months
2= 13 mo-36 months
3= 37 mo or greater
 5. **Ethnicity** Caucasian _____ Other _____
 6. **Medications:**

Total # of Medications _____
of Scheduled Medications _____
of PRN Medications _____

of Psychotropic medications _____
of Analgesic medications _____

(Used in Pilot Study)

Subject Code _____

Date _____

The Geriatric Depression Scale – Short Form

(Choose the best answer for how you felt over the past week)

- | | |
|---|--------|
| 1. Are you basically satisfied with your life? | yes/no |
| 2. Have you dropped many of your activities and interests? | yes/no |
| 3. Do you feel that your life is empty? | yes/no |
| 4. Do you often get bored? | yes/no |
| 5. Are you in good spirits most of the time? | yes/no |
| 6. Are you afraid that something bad is going to happen to you? | yes/no |
| 7. Do you feel happy most of the time? | yes/no |
| 8. Do you often feel helpless? | yes/no |
| 9. Do you prefer to stay at home, rather than going out and doing new things? | yes/no |
| 10. Do you feel you have more problems with memory than most? | yes/no |
| 11. Do you think it is wonderful to be alive now? | yes/no |
| 12. Do you feel pretty worthless the way you are now? | yes/no |
| 13. Do you feel full of energy? | yes/no |
| 14. Do you feel that your situation is helpless? | yes/no |
| 15. Do you think that most people are better off than you are? | yes/no |

Score _____Scoring Instructions Score 1 for “yes” response for questions 2-4, 6, 8-10, 12, 14-15.

Score 1 point for “no” response to questions 1, 5, 7, 11, 13. Add the scores for each question. Total SGDS scores can range from 0-15. The higher the score the more likely the individual is experiencing depression. For the purposes of this protocol, a score of 8 or greater should prompt further evaluation of the patient for depression.

Subject Code _____

Date _____

Geriatric Depression Scale

- | | |
|--|--------|
| 1. Are you basically satisfied with your life | Yes/No |
| 2. Have you dropped many of your activities and interests? | Yes/No |
| 3. Do you feel that your life is empty? | Yes/No |
| 4. Do you often get bored? | Yes/No |
| 5. Are you hopeful about the future? | Yes/No |
| 6. Are you bothered by thoughts you can't get out of your head? | Yes/No |
| 7. Are you in good spirits most of the time? | Yes/No |
| 8. Are you afraid that something bad is going to happen to you? | Yes/No |
| 9. Do you feel happy most of the time? | Yes/No |
| 10. Do you often feel helpless? | Yes/No |
| 11. Do you often get restless and fidgety? | Yes/No |
| 12. Do you prefer to stay at home, rather than going out and doing new things? | Yes/No |
| 13. Do you frequently worry about the future? | Yes/No |
| 14. Do you feel you have more problems with memory than most? | Yes/No |
| 15. Do you think it is wonderful to be alive now? | Yes/No |
| 16. Do you often feel downhearted and blue? | Yes/No |
| 17. Do you feel pretty worthless the way you are now? | Yes/No |
| 18. Do you worry a lot about the past? | Yes/No |
| 19. Do you find life very exciting? | Yes/No |
| 20. Is it hard for you to get started on new projects? | Yes/No |
| 21. Do you feel full of energy? | Yes/No |

Subject Code _____

Date _____

Cumulative Illness Rating Scale - Geriatric

Each system is rated as follows: 1=NONE: No impairment to that organ/system
 2=MILD: Impairment does not interfere with normal activity; treatment may or may not be required; prognosis is excellent.(Examples could be skin lesions, hernias, or hemorrhoids 3=MODERATE: Impairment interferes with normal activity; treatment is needed; prognosis is good. (Examples could be gallstones, diabetes or fractures) 4=SEVERE: Impairment is disabling; treatment is urgently needed; prognosis is guarded. (examples could be resectable carcinoma, pulmonary emphysema, or congestive heart failure) 5=EXTREMELY SEVERE: Impairment is life threatening; treatment is urgent or of no avail; prognosis is grave. (Examples could be myocardial infarction, cerebrovascular accident, gastrointestinal bleeding, or embolus). Compute comorbidity index by counting the number of items for which moderate to severe pathology (3,4,5) is reported.

1. **Cardiac** (heart only) _____
 2. **Hypertension** (rating is based on severity; affected systems are rated separately)

 3. **Vascular** (blood, blood vessels and cells, marrow, spleen, lymphatics)_____
 4. **Respiratory** (lungs, bronchi, trachea below the larynx)_____
 5. **EENT** (eye, ear, nose, throat, larynx)_____
 6. **Upper GI** (esophagus, stomach, duodenum, biliary and pancreatic trees; do not include diabetes)_____
 7. **Lower GI** (intestines, hernias)_____
 8. **Hepatic** (liver only)_____
 9. **Renal** (kidneys only)_____
 10. **Other GU** (ureters, bladder, urethra, prostate, genitals)_____
 11. **Musculo-Skeletal-Integumentary** (muscles, bone, skin)_____
 12. **Neurological** (brain, spinal cord, nerves; do not include dementia)_____
 13. **Endocrine-Metabolic** (includes diabetes, diffuse infections, infections, toxicity)_____
 14. **Psychiatric/Behavioral** (includes dementia, depression, anxiety, agitation, psychosis)_____
- Total Score** _____

Subject Code _____

Date _____

Numerical Rating Scale

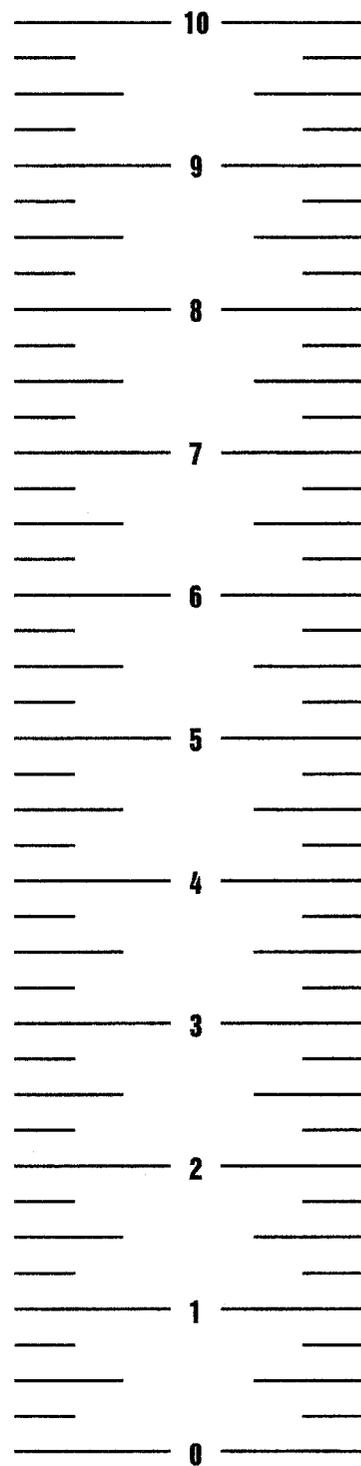
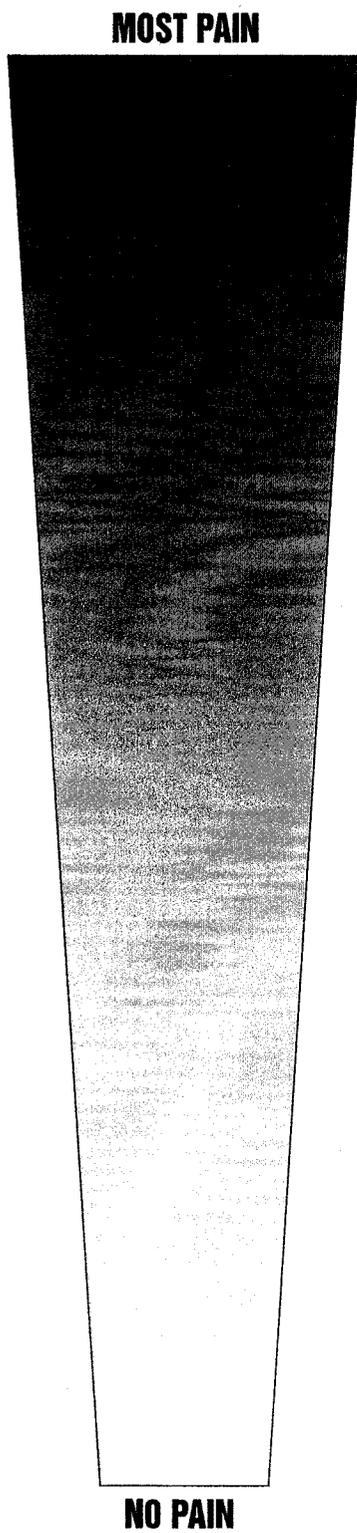
Verbal self-report pain scale

First, ask the resident if they have any pain or aches?

0-5 Verbal Numeric Scale

“On a scale of 0-5, with 0 being no pain and 5 being the worst possible pain, what would you rate the severity or intensity of your pain right now?”

Rating: _____



McGrath, PA, Seifert, CE, Speechley, KN, Booth, JC, Stitt, L, & Gibson, MC (1996). A new analogue scale for assessing children's pain: an initial validation study. *Pain*, 64, 435-443.

Used with permission from the International Association for the Study of Pain (IASP).

Coloured Analogue Scale

Instructions for the CAS

See this scale it's like a thermometer. The bottom where it's small and there is hardly any color at all means "no pain". The top where it is large, very red and a long way from the bottom means "the most pain you can imagine". I want you to slide the marker up the scale to show me how much pain you have. Can you try it?

Checklist of Nonverbal Pain Indicators

Date: _____

Subject Code _____

(Researcher: observe for the presence or absence of the following pain behaviors during rest initially, then during the movement activity. Write a 0 if the behavior was not observed, and a 1 if the behavior occurred even briefly.)

I am going to change your position in bed from sitting to lying down.

(alternate : observe when the staff or the resident changes position, either goes from sitting to standing independently or with assistance, or if unable to stand, is transferred by staff)

	At Rest	With Movement
1. Vocal complaints: Non-verbal (Expression of pain, not in words, moans, groans, grunts, cries, gasps, sighs)	_____	_____
2. Facial Grimaces/Winces (Furrowed brow, narrowed eyes, tightened lips, jaw drop, clenched teeth, distorted expressions)	_____	_____
3. Bracing (Clutching or holding onto side rails, bed, tray table, or affected area of body during movement)	_____	_____
4. Rubbing (Massaging affected area)	_____	_____
5. Restlessness (Constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still)	_____	_____

In addition, record the presence or absence of these verbal indicators:

6. Vocal complaints: Verbal (Words expressing discomfort or pain, "ouch" "that hurts"; cursing during movement, or exclamations of protest 'stop', 'that's enough'.)	_____	_____
---	-------	-------

Feldt, K. (1996) Treatment of pain in cognitively impaired versus cognitively intact post hip fractured elders. Doctoral Dissertation. University of Minnesota, Minnesota.

FACILITY PROFILE

1. Name of facility _____ 2. Code # _____

3. Address of facility _____

4. State License Classification _____

5. Affiliated with nursing home yes _____ no _____

6. Year facility opened _____ 7. # of beds _____ 8. Average census _____

Description of Residents:

9. Gender _____ male _____ female 10. Average age _____

11. Minimum age _____ 12. % Private pay _____ 13% Family care _____

14. % Caucasian _____ % other _____

15. Dementia specific unit? yes _____ if yes, # of beds _____ no _____

16. Do residents with dementia reside in same unit as residents without
dementia? _____**Staffing:** 17. # of paid staff _____ 18. # of direct care staff _____ 19. # direct care
staff per shift: Day _____ Evening _____ Night _____

20. # of Registered Nurses (weekly hours per resident) _____

21. % of staff with training in behavior management _____

Subject Code _____

Date _____

Functional Behavior Profile

All of the questions relate to how the individual with impaired cognitive function performs in their daily activities. As a reference, the respondent should complete the instrument based on the impaired individual's behavior during the past week.

Participant Code _____ Information obtained from: _____

1. Is able to concentrate on a task for:

4	3	2	1	0	Score
More than 25 minutes	5 to 15 minutes	3 to 5 minutes	1 to 3 minutes	< 1 minute	T _____

2. Finishes the tasks that have been started.

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

3. Performs work that is neat (tidy).

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

4. Can use tools or instruments (e.g., razor) in performing tasks (e.g. in the kitchen, for a hobby)

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

5. Can manipulate small items (e.g. doing hand work, buttoning, applying making.

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

6. Activities are appropriate to the time of day (e.g. sleeps at night, alert during the day)

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

7. Performs work that is accomplished within a reasonable timeframe

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

8. Performs activities without frustration

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

9. Continues an activity when frustrated

4	3	2	1	0	T _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

10. Shows enjoyment in activities

4	3	2	1	0	S _____
Always (100%)	Usually (80%)	Sometimes (50%)	Rarely (20%)	Never (<10%)	

11. Participates in activities.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	S_____

12. Can identify familiar individuals.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	S_____

13. Initiates conversations with family.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	S_____

14. Socializes when others initiate the interactions.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	S_____

15. Expresses himself or herself appropriate to the situation.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	S_____

16. Makes simple decisions independently (e.g. what to wear, what to eat, what to do around the house).

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P_____

17. Is able to make a decision when presented with choices.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P_____

18. Can learn a simple activity without difficulty (e.g. stirring, wiping dishes)

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P_____

19. Can respond to a two-step command (e.g. directions to do two things in sequence like "open the door" and "get the newspaper")

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P_____

20. Can solve a problem when given repeated assistance

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P_____

21. Takes responsibility for tasks that previously have been theirs (e.g. responsibilities for cooking, cleaning, home maintenance)

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P_____

22. Can respond to a one-step command (e.g. directions to do only one thing like “sit here” or “take my hand”).

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P _____

23. Can respond to a three-step command (e.g. directions to do three things in sequence like “open the door,” “get the newspaper” and “if Mary is in the yard tell her to come in for dinner”)

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P _____

24. Can learn a complex activity without difficulty (e.g. new game, directions)

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P _____

25. Knows the day of the week and/or the date

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P _____

26. Independently makes complex decisions.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P _____

27. Can solve a problem without assistance.

4	3	2	1	0	
Always	Usually	Sometimes	Rarely	Never	
(100%)	(80%)	(50%)	(20%)	(<10%)	P _____

Scoring: Total those marked according to the key on the right-hand side (i.e. T,S,P) and divide by the number of items in the scale. You can use the Task Performance, Social Interaction and Problem Solving Scales separately or use a total score. Subtotal T ____/9, S ____/6,

(Baum, CM, Edwards, DF & Morrow-Howell, N (1993). Total P ____/12

Identification and measurement of productive behaviors in senile dementia of the Alzheimer type. Total Score _____

The Gerontologist 33, 403-408.)

Task Performance Score (T): _____

Social Interaction Score (S): _____

Problem Solving Score (P): _____

Participant Code _____

Subject code _____

Date _____

THE COHEN-MANSFIELD AGITATION INVENTORY

Please read each of the 29 agitated behaviors, and circle how often (from 1-7) each was manifested by the resident during the last 2 weeks:

	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
1. Pacing, aimless wandering	1	2	3	4	5	6	7
2. Inappropriate 1 dress or disrobing	1	2	3	4	5	6	7
3. Spitting (include at meals)	1	2	3	4	5	6	7
4. Cursing or aggression	1	2	3	4	5	6	7
5. Constant unwarranted request for attention or help	1	2	3	4	5	6	7
6. Repetitive sentences or questions	1	2	3	4	5	6	7
7. Hitting (including self)	1	2	3	4	5	6	7
8. Kicking	1	2	3	4	5	6	7
9. Grabbing onto people	1	2	3	4	5	6	7
10. Pushing	1	2	3	4	5	6	7
11. Throwing things	1	2	3	4	5	6	7
12. Strange noises (weird laughter or crying)	1	2	3	4	5	6	7

	Never	a week	Less than once a week	Once or twice a week	Several times a day	Once or twice a day	Several times an hour	Several times
	1	2	3	4	5	6	7	
13. Screaming	1	2	3	4	5	6	7	
14. Biting	1	2	3	4	5	6	7	
15. Scratching	1	2	3	4	5	6	7	
16. Trying to get to different place (e.g. out of the room, building)	1	2	3	4	5	6	7	
17. Intentional falling	1	2	3	4	5	6	7	
18. Complaining	1	2	3	4	5	6	7	
19. Negativism	1	2	3	4	5	6	7	
20. Eating/drinking inappropriate substances	1	2	3	4	5	6	7	
21. Hurt self or other (cigarette, hot water, etc)	1	2	3	4	5	6	7	
22. Handling things inappropriately	1	2	3	4	5	6	7	
23. Hiding things inappropriately	1	2	3	4	5	6	7	
24. Hoarding things	1	2	3	4	5	6	7	
25. Tearing things or destroying property	1	2	3	4	5	6	7	
26. Performing repetitious mannerisms	1	2	3	4	5	6	7	

	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
27. Making verbal sexual advances	1	2	3	4	5	6	7
28. Making physical sexual advances	1	2	3	4	5	6	7
29. General restlessness	1	2	3	4	5	6	7

Cohen-Mansfield, 1986.

Total Score _____

Accreditations	Certified Clinical Nurse Specialist in Gerontological Nursing American Nurses Credentialing Center	1996-present
Publications	<p>Piette, M., Ellis, J., St. Denis, P., & Sarauer, J. (2002). Integrating ethics and quality improvement: Practical implementation in the transitional/extended care setting. <u>Journal of Nursing Care Quarterly</u> 17 (1), 35-42.</p> <p>Ellis, J. (2005). Commentary. <u>Journal of Nursing Scholarship</u> 37 (2) p. 140.</p>	
Scholarships	Milton and Joan Morris Graduate Scholarship	2000
	Milwaukee District Nurses Association	2003
	American Association of Retired Persons (AARP) AARP Scholar	2005-2006
Professional Membership	Sigma Theta Tau International Honor Society of Nursing <i>Eta Nu Chapter</i>	1989-present
	Milwaukee District Nurses Association Vice President, President-Elect and President	1995-2000
	Milwaukee Aging Consortium Secretary, current President-Elect Past chair of Public Policy Committee	2004-present
Grants	<p>Elder Health Upholders Primary Investigator (Wheaton Healthcare and Medical College Wisconsin) April 2005-March 2006 A \$24,000 planning grant from The Healthier Wisconsin Partnership Program (HWPP)</p>	

Elder Health Upholders II

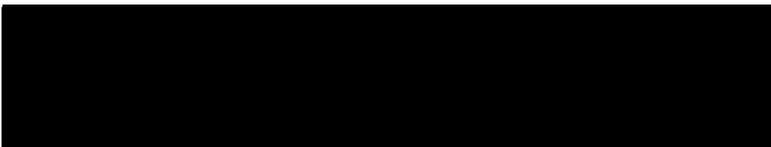
Primary Investigator (Wheaton Healthcare and Medical College of Wisconsin)

July 2006-June 2007

A \$50,000 development grant from The Healthier Wisconsin Partnership Program (HWPP)

A faith-based program to train volunteers to provide health education and advocacy in African American inner city churches for older adult church members

Presentations	Iatrogenesis Across the Health System Nursing Research Day Symposium Milwaukee, WI	2002
	The Hospital Elder Life Program: Translating Research into Practice Nursing Research Day Symposium Milwaukee, WI	2003
	Elder Health Upholder Project Research Symposium at the Medical College of Wisconsin 2006 Department of Family and Community Medicine Milwaukee WI	


Major Professor

12/4/06
Date