

DIFFERENCES IN PAIN EXPRESSION IN ELDERLY HIP FRACTURE
PATIENTS WITH AND WITHOUT DEMENTIA: A RETROSPECTIVE
REVIEW OF MEDICAL RECORDS

By

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To the millions who suffer from pain
While dementia ravages their brain
Without words to impart the suffering and hurt
We must learn to read pain that may seem covert

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LIST OF ABBREVIATIONS

AA	African American
ACC	Anterior Cingulate Cortex
AD	Alzheimer's disease
ANOVA	Analysis of variance
BMC	Baptist Medical Center
BP	Blood Pressure
CAD	Coronary Artery Disease
CAM	Confusion Assessment Method
CGA	Anterior cingulate gyrus
COPD	Chronic obstructive pulmonary disease
DemNOS	Dementia Non-specified
DM	Diabetes mellitus
ECG	Electrocardiogram
EEG	Electroencephalogram
fMRI	Functional magnetic resonance imaging
FTD	Frontotemporal dementia
FTLD	Frontotemporal lobar degeneration
HIPPA	Health Information Portability and Accountability Act
HR	Heart rate
HTN	Hypertension
ICD-9	International Classification of Diseases, Version 9
JCAHO	Joint Commission on Accreditation of Healthcare Organizations

MAR	Medication Administration Record
MDS	Minimum Data Set
MMSE	Mini Mental Status Exam
MOSES	Multidimensional Observational Scale of Elderly Subjects
MRI	Magnetic resonance imaging
PET	Positron emission tomography
PWD	Persons with dementia
PWOD	Persons without dementia
SD	Standard deviation
TIA	Transient ischemic attack
VaD	Vascular dementia
VPL	Ventral posterior lateral
WBFP-S	Wong Baker Faces Pain Scale

Abstract of Dissertation Presented to the Graduate School
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Pain is a common problem among older adults across many settings. Furthermore, acute pain is a significant problem in the hospitalized older adult. In the outpatient setting, research has consistently found persons with dementia to have pain that is under-recognized and under-treated compared to their cognitively intact counterparts, despite the fact that both persons with and without dementia share similar painful conditions. Research on this topic in the acute setting is sparse, however preliminary results share similar findings and are also revealing that nurses are not in compliance with the standards for pain assessment as established by the Joint Commissions for Health Care Accreditation in the year 2000, that pain be measured as the “fifth vital sign.” There are many possible explanations for the under-recognition and under-treatment of pain in persons with dementia. The purpose of this study was to investigate differences in pain expression, pain assessment, and pain management between persons with and without dementia who were hospitalized with acute hip fracture. The group of persons with dementia was further divided into subgroups of persons with Alzheimer’s disease and persons with dementia non-specified to investigate these differences between dementia subtypes. A descriptive, retrospective review of medical records, including a comparison group matched for age, gender, race and

location was conducted of persons admitted to one of four hospitals in the Jacksonville, Florida region during the years 2005 through 2009. Descriptive statistics as well as analysis of covariance and regression models were utilized for the analysis. Outcome measures for pain expression included verbal and non-verbal measures of pain intensity, and changes in heart rate and systolic blood pressure as measures of physiological signs of pain expression. Pain assessment was measured based on the number of nurse-based pain assessment recordings. Pain management was measured as the amount, based on equi-analgesic conversions, and type, opioid versus non-opioid, of pain medication *prescribed* and *administered*.

Findings of the current study support differences in verbal pain expression between persons with and without dementia, and suggest these differences may extend to the dementia subtypes. Further, these findings support emerging data that pain in persons with dementia is not only under-recognized and under-treated in the acute care setting, but that current clinical practice guidelines with regards to pain assessment are not being followed.

CHAPTER ONE

BACKGROUND AND SIGNIFICANCE AND THEORETICAL FRAMEWORK

Introduction

Pain is a common problem among older adults. It is estimated that, depending on residential status, the prevalence of pain in older adults ranges between 50 and 86% (Horgas, Elliott, & Marsiske, 2009). Furthermore, acute pain is a significant problem in the hospitalized older adult. The prevalence of surgeries on older adults was reported to be almost 9 million in the year 2000, with 1.25 million of those surgeries on the musculoskeletal system (Herr et al., 2004). The significance of this is exemplified by the negative consequences associated with pain. Pain has been shown to negatively affect the immune systems of elderly adults (Huffman & Kunik, 2000). Pain has also been associated with negative impacts on mood, sleep patterns and mobility, and leads to an increase in health care utilization (Horgas & Elliott, 2004). In the hospital setting, older adults suffering from acute pain have been reported to be at increased risk for thromboembolism, hospital acquired pneumonia, and functional decline (Herr & Titler, 2008). Complicating the current state of pain and its potentially negative consequences on older adults, especially if left untreated, is the increasing number of elderly persons, which prevalence is expected to double, from approximately 35 million in the year 2000, to approximately 70 million by 2030, thereby increasing the number of elderly persons with dementia (Plassman et al., 2007).

Despite the prevalence of pain and its consequences, the advancement of pain assessment measures in elderly persons has been slow over the last 2 decades (Smith, 2005). As a matter of fact, it has only been since around 1991, that the need to investigate differences in pain assessment and pain management in persons with dementia became a consideration (Epps, 2001). Initial studies to compare differences in analgesic consumption between persons with dementia and without dementia consistently revealed significantly lower amounts of consumed

analgesics among those with dementia despite the presence of similar painful diagnoses between the two groups (Epps, 2001). This finding, which has been robust across several studies, appears to persist, even despite the institution of pain as the “fifth vital sign” which mandated the assessment of pain in conjunction with the assessment of vital signs in the acute care setting. This mandate to measure pain as the fifth vital sign was instituted by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) in 2000.

Consistent findings that persons with dementia were found to consume lower amounts of analgesics compared to their cognitively intact counterparts sparked efforts to develop psychometrically sound observational pain assessment tools for use in persons who are unable to verbally express pain through self-report. Though self-report of pain is considered to be the gold standard in pain assessment across most populations (Bjoro & Herr, 2008), it is considered insufficient as a sole measure of pain in persons with dementia, and should be utilized in conjunction with observational measures of pain in this population (Horgas, Elliott, & Marsiske, 2009). Observational measures of pain are those that measure non-verbal expressions of pain, including facial grimacing, rubbing, posturing and guarding which are supported as behaviors indicative of pain (Horgas & Elliott, 2004), and physiological signs of pain, such as heart rate and blood pressure (Rainero, Vighetti, Bergamasco, Pinessi, & Benedetti, 2000). Work is ongoing in this area, and is now converging on some reliable and valid measures that will meet the needs of both researchers and clinicians. However, a consensus regarding which observational tools are appropriate for which populations and which settings has not been reached (Ersek, Herr, Neradile, Buck, & Black 2010).

Additionally, despite the attention devoted to the development of pain assessment measures, and recommendations to utilize more than just self report measures for pain

assessment in persons with dementia, the under-recognition and under-treatment of pain remains a problem among elderly persons with dementia. This reflects a discrepancy between the research that is occurring in this area and its translation to the clinical setting. Tait and Chibnall (2008) assert that failure to identify pain, “undoubtedly contributes to under treatment in this older [dementia] population.” Lack of knowledge as to what tools are available and which tools to apply to various settings and populations may be contributing factors. Additionally, inadequate skills necessary for the assessment of pain in persons with dementia is felt to be a major factor influencing pain management (Herr et al., 2004). Impairments in cognition also pose challenges for bedside nurses who must often assess pain in elderly persons with dementia. Herr and colleagues (2004) reported that up to 60% of elderly hip fracture patients were reported to be cognitively impaired. Pain assessment in these patients may be compromised due to a lack of education among health care providers who are unfamiliar with ways to assess pain in persons with impairments in cognition.

It must be considered that the difficulty in assessing pain in persons with dementia may also stem from the lack of knowledge that dementia is present. Research has shown that there is under-recognition of dementia in the private practice setting (Valcour, Masaki, Curb, & Blanchette, 2000). When the presence of dementia has been recognized, one study found that just slightly greater than half of the patients had an accurate diagnosis of dementia subtype (VanHout, Vernooij-Dassen, Poels, Hoefnagles, & Grol, 2000). Misclassification of dementia can complicate the recognition and treatment of pain, since different pathological processes in the brain may yield differences in pain expression, pain assessment, and pain management. Additionally, this practice can limit clarity and accuracy of research findings, thereby hindering progress in fully understanding the relationship between pain and dementia. Pursuing the

underlying cause for the under-recognition of dementia is beyond the scope of this dissertation however, knowledge of its presence is relevant.

In sum, pain in persons with dementia is strongly supported in the literature to be under-recognized and under-treated, despite a large amount of attention devoted to the development of tools to facilitate the assessment of pain in those whom pain expression is impaired.

Additionally, there are multiple forms of dementia, each with different pathologies that may differentially effect pain perception and expression. This issue, however, has not been systematically evaluated. Given that JCAHO has designated pain as the 5th vital sign, and mandated its regular assessment, and in light of the negative consequences associated with under-recognition and under-treatment of pain, the need to evaluate pain assessment and treatment approaches in hospitalized older adults in general, and those with and without dementia must be realized. Further, efforts need to be made to better understand potential differences in pain expression among persons with different types of dementia. Understanding current clinical practices in these areas can highlight current strengths and weakness in hospital settings, information that can be used to improve pain assessment and pain management in persons with dementia. This served as the premise for the current study in which current clinical practice relative to pain expression and the assessment and management of pain in the hospital setting in persons with and without dementia, and in the dementia subtypes, was investigated.

Background and Significance

Pain in Elderly Adults with and without Dementia

Pain, as defined by the International Association for the Study of Pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Loeser & Melzack, 1999). Acute pain is “the normal, predicted physiological response to an adverse chemical, thermal or mechanical stimulus...and is generally

associated with surgery, trauma, or acute illness” (Carr & Goudas, 1999). Pain is considered chronic when it persists for a period of time beyond that which would have been expected for healing (Schuler, Njoo, Hestermann, Oster, & Hauer, 2004). The experience of pain is subjective and requires a level of cognition that allows for the dissemination of information that arises from a noxious stimulus and is interpreted as a painful sensation. Dementia, which is characterized by a progressive decline in cognition, can ultimately impair one’s ability to recognize, remember and report the presence of pain (Horgas & Elliott, 2004). This may reflect an alteration in pain perception. Though pain perception is not directly being measured in this study, its components are relevant given the affect dementia may have on each. The inherent components of pain perception include sensory-discriminative, emotional-affective, cognitive-evaluative, and autonomic-neuro-endocrine aspects of pain – concepts that will be addressed. Each component involves distinct and interrelated pathways in the peripheral and central nervous systems that must work in concert in order for a person to be able to perceive and express pain, and ultimately have it assessed and treated.

It is estimated that the prevalence of pain among older adults is between 50% and 86% (Horgas, Elliott, & Marsiske, 2009). It is further estimated that up to approximately 50% of those persons with dementia experience daily pain (Horgas et al., 2009). In the hospital setting, acute pain is a significant problem, particularly among persons greater than age 65 (Herr & Titler et al., 2004). This will become increasingly important as more people with dementia are hospitalized. In a study reviewing the discharge data from computerized records of Johns Hopkins Hospital, it was found that the cumulative frequency of hospitalized persons with dementia rose as age increased beyond 65 years (Lyketsos, Sheppard, & Rabins, 2000). Furthermore, persons with dementia have a greater number of co-morbidities, and dementia, in

the context of other chronic conditions is independently linked to risk of hospitalization (Bynum et al., 2004). Additionally, it has been reported that cognitive decline over a three year period is an independent risk factor for hospitalization among elderly individuals (Chodosh et al., 2004). There are multiple reasons for an increase in hospitalizations among elderly adults with dementia including high rates of trauma, falls, and pressure ulcers. These are often associated with pain. A study of 15,013 hospitalized persons with dementia, almost 80% of whom had a diagnosis of AD ($n = 11,555$) found fracture of the femur to be the most common co-morbidity in this population (Sanderson et al., 2002). This top ranked co-morbidity was also found to be ranked among the top ten co-morbidities for other types of dementia (Sanderson et al., 2002). Thus, it is apparent that persons with dementia have co-morbidities that include diagnoses typically associated with pain and that often require hospitalization.

In 2000, there were almost 9 million surgeries performed on persons 65 years of age or older (Herr et al., 2004). Since most surgeries are associated with pain, it is likely that acute pain is a significant problem among this population. With a substantial percentage of elderly persons having dementia, it can be inferred that hospitalizations of persons with dementia suffering from acute pain is also a significant problem. Since studies suggest that persons with dementia are at greater risk for having pain that is under-recognized (Horgas & Tsai, 1998), it can be anticipated that under-recognition and therefore under-treatment of acute pain in hospitalized older adults with dementia is also a problem.

As mentioned, studies have consistently found that persons with dementia are at greater risk of having pain that is under-recognized (Horgas & Tsai, 1998). Evidence has also consistently demonstrated that elderly persons, especially those with cognitive impairments, have pain that is under-treated. Scherder and colleagues (2005) reported that elderly persons ($>$ age

75) with cancer received fewer analgesic medications compared to their younger counterparts, and lower cognition scores was an independent predictor of receiving fewer analgesics. Evidence also suggests that underutilization of opioid medication in older adults contributes to poor pain management (Auret & Schug, 2005). Scherder and colleagues (2005) reported that those in the more advanced stages of dementia who had sustained hip fractures received significantly less opioid analgesics compared to their cognitively intact counterparts.

A contributing factor to the under-recognition and under-treatment of pain is likely evidenced by findings that elderly persons with dementia under-report pain compared to non-demented persons (Bjoro & Herr, 2008). Additionally, it has been reported that in the hospital setting cognitively impaired patients were less precise in describing the location of their pain compared to their cognitively intact counterparts (Schuler et al., 2004). Under-reporting pain is a consequence of the neuropathology of dementia, which leads to deficits in memory, language, and abstract thought (Snow et al., 2004). Difficulties in adapting knowledge of pain assessment and pain assessment skills to this population, also contributes to the consistent under-recognition and under-treatment of pain (Herr et al., 2004).

Pain in Persons with Different Types of Dementia

Memory loss, impaired judgment, and in the later stages, inability to communicate can lead to potential discrepancies between identifying and meeting needs of persons with dementia. There are several types of dementia (Plassman et al., 2007), which present differently and may impact communication abilities differently. As discussed, a diagnosis of dementia is often overlooked (Valcour et al., 2000). Additionally, regardless of underlying pathology, the various types of dementia are often categorized in the “catch-all” category of “dementia.” As criteria for accurate classification of dementia subtypes have emerged however, studies have provided staggering prevalence estimates of dementia, that include the dementia subtypes. According to

Plassman and colleagues (2007), the prevalence of persons with dementia in the United States is 3.4 million, with more than two thirds having a diagnosis of Alzheimer's disease. In their report of the Aging, Demographics, and Memory Study (ADAMS), Plassman and colleagues (2007) reported that Alzheimer's disease accounts for approximately 70% of all dementias and vascular dementia (VaD) accounts for approximately 17%. The remaining 13% are included in a subset called, "dementia, undetermined etiology," which includes Parkinson's dementia, normal pressure hydrocephalus, frontal lobe dementia, alcoholic dementia, traumatic brain injury and Lewy body dementia. Frontotemporal dementia (FTD) though is more prevalent than the other types, especially in those under the age of 70. According to Bird and colleagues (2003), the prevalence of AD is at least 6 per 100 of those over age 70. The prevalence of FTD has also been reported to be approximately 6 per 100 in the general population over age 70. Additionally, FTD is more prevalent than the other types of dementia in those younger than 70, and is estimated to account for 17% of dementia in younger people (Bird et al., 2003).

As the pursuit of more effective ways to assess and manage pain in elderly persons with dementia progresses, consideration will have to be given to developing tools that target the assessment of pain in persons with various types of dementia. The neurodegenerative processes can differ between the dementia subtypes degrading different topographic areas of the brain, which are responsible for various aspects of pain perception and expression. As of this time, there is little knowledge describing the current differences in pain expression in different types of dementia, or the state of pain assessment and management between different types of dementia. It is therefore important to begin to discern these potential differences in pain expression, assessment, and management, including analgesic prescribing and administration patterns, between the most common types of dementia.

Consequences of Unrelieved Pain

As previously discussed, unrelieved acute pain within the hospital setting can lead to complications, such as pneumonia and thromboembolism from lack of mobility, and functional decline (Herr et al., 2004). Untreated pain can also lead to depression, declines in cognition, sleep disturbances, isolation, a decline in quality of life, and increased healthcare utilization (Herr & Garand, 2001). The consequences of unrelieved acute pain have also been implicated in subsequent long-term pain. One prospective cohort study of persons 80 years of age and older reported an association between acute pain and persistent pain two months later among elderly hospitalized individuals (Desbiens et al., 1997). Desbiens and colleagues (1997) reported that those with level 2 pain (on a 1-5 scale) had an almost 3-fold increase in the risk of pain two months post-hospitalization. Those reporting a pain level of 5 had a 9-fold increase in risk of later pain. As a matter of fact, these authors found that hospital level of pain was the variable most associated with pain reported at post-hospitalization interviews.

The growing number of elderly persons with dementia hospitalized for acute pain, in combination with the evidence suggesting that this population often suffers from under-recognized and under-treated pain places this population at higher risk for the consequences of unrelieved pain.

The Current State of Pain Assessment and Management in Persons with Dementia

Despite the known consequences of unrelieved pain, current literature suggests that pain is not being assessed according to guidelines that were instituted by JCAHO in 2000 (Herr et al., 2004). Pain was introduced as the “fifth vital sign” with the intent that pain would be assessed simultaneously with routinely assessed vital signs. Additionally, EBP, or evidence based practice, recommendations for pain assessment for older adults in the acute care setting have been available and suggest that baseline pain assessment followed by routine follow-up

assessments occur every four hours (Herr & Titler, 2008). Additionally, clinical recommendations for the assessment of pain, such as The Hierarchy of Pain Assessment Technique, by McCaffery and Pasero (1999), as described by Herr and colleagues (2006), have been recommended for use in persons with limited capacity to self-report pain. Again, consistent findings that pain is under-recognized and under-treated suggest that use of the available guidelines is not occurring.

Briefly, The Hierarchy of Pain Assessment Technique begins with an attempt to obtain a self-report of pain. This is followed by a search for an underlying cause of pain, such as position changing, wound care and a history of persistent pain. Pain can be assumed to be present if there is a reason to suspect pain, and a trial of analgesics can be initiated. It is further suggested that pain behaviors be observed as part of the comprehensive assessment, especially in the absence of self-report (Herr et al., 2006). Observational techniques for pain assessment focus on behavioral, or non-verbal expressions of pain, such as grimacing, rubbing and guarding (Horgas & Elliott, 2004), and physiological expressions of pain. Physiological expressions of pain include tachycardia, elevated blood pressure and sweating (Kovach, Weissman, Griffie, Matson, & Muchka, 1999).

As previously noted, self-reported pain is considered the gold standard of pain assessment among persons without cognitive impairment (Pautex et al., 2006). Pain is typically assessed using a unidimensional scale, such as a 0-10 numerical rating scale, which assesses the presence and severity of pain (Scherder et al., 2005). There is a growing body of literature supporting the use of observational assessment tools in conjunction with self-report measures in cognitively impaired elderly adults (Herr et al., 2004). The need for this is further exemplified by Horgas and colleagues (2009) who reported that persons with dementia were less likely to

verbally report pain, but displayed the same number of non-verbal pain indicators as persons without dementia.

Not only is pain assessment not occurring according to guidelines, pain management has been reported to also be sub-optimal. Morrison and Siu (2000) reported that pain was undertreated in elderly hip fracture patients both with and without dementia, though persons *with* dementia were substantially more undertreated compared to their cognitively intact counterparts. Current practices in pain management are largely based on a clinician's assessment of the patient and their pain, including the presence, severity, impact, and need for treatment. Morrison and Siu's findings (2000) strongly support Herr and colleagues' (2004) assertion that impairments in cognition continue to challenge providers' effective assessment and management of pain in this population.

Summary

Dementia is associated with neurodegenerative changes that can alter the various components of pain perception and pain expression (Frampton, 2003). This makes pain assessment difficult in persons with dementia, and may partly explain the discrepancies in pain management in persons with dementia compared to persons without dementia. Further, it has yet to be demonstrated whether persons with different types of dementia express pain differently on existing tools, and whether or not differences exist in the frequency of pain assessment or how pain is managed between these dementia subtypes. In order to continue to validate existing pain assessment tools for use in persons with dementia, or to develop new tools for this population, it is imperative to continue to investigate differences in pain expression in persons with and without dementia, and to begin to gain a better understanding of these potential differences by dementia type. Exploring these differences by studying acute pain in hospitalized persons with

dementia, and by dementia subtype, may provide evidence supporting the need to develop and utilize dementia sub-type specific pain assessment tools.

Purpose of the Study

The purpose of this retrospective study was to investigate differences in pain expression (verbal, non-verbal, and physiological pain indicators), pain assessment (number of documented nurse-based assessments of verbal, non-verbal, and physiological indicators of pain), and pain management (type and amount of analgesics *prescribed* and *administered*) in hospitalized elderly persons with and without dementia. Hip fracture was the index diagnosis used in this study because it is known to be associated with significant pain. Further, this study investigated whether pain expression, pain assessment, and pain management differ between hospitalized elderly patients with different dementia subtypes, specifically comparing Alzheimer's disease to a diagnosis of dementia, non-specified. This study also examined pain expression and pain assessment as predictors of pain management, and how these relationships were influenced by (a) dementia status and (b) dementia subtype.

Research Questions and Hypotheses

The specific research questions and hypotheses are:

1. Among hospitalized older adults with hip fracture, does pain expression (e.g. verbal, non-verbal, and physiological pain intensity ratings) differ between persons (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified?
 - a. **H1a:** Statistically significant differences in verbal pain expression, as measured by pain intensity scores on the Wong-Baker Faces Pain Scale (W-BFPS), will be detected between hospitalized older adults with hip fracture (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified.
 - b. **H1b:** Statistically significant differences in non-verbal pain expression, as measured by pain intensity scores on an observational pain assessment tool, the Face, Legs Activity, Cry, Consolability (FLACC) will be detected between hospitalized older

- adults with hip fracture (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified.
- c. **H1c:** Statistically significant differences in physiological signs of pain expression as measured by changes in heart rate and systolic blood pressure will be detected between hospitalized older adults with hip fracture (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified.
2. Among hospitalized older adults with hip fracture, are there differences in pain assessment (e.g. the number of documented nurse-based assessments) between persons (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified (by dementia subtype)?
- a. **H2a:** Statistically significant differences in the number of documented nurse-based assessments will be detected between hospitalized older adults with hip fracture (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified.
3. Among hospitalized older adults with hip fracture, does pain management (e.g., the amount and type of analgesics *prescribed* and *administered*) differ between elderly persons (a) with and without dementia and (b) with Alzheimer's disease compared to dementia, non-specified?
- a. **H3a:** Persons with dementia will be *prescribed* and *administered* significantly less analgesic medications, measured in acetaminophen equivalents, than persons without dementia.
- b. **H3b:** Significant differences in analgesic *prescription* and *administration* will be detected between hospitalized older adults with hip fracture with Alzheimer's disease and with dementia non-specified.
4. Do pain expression and pain assessment predict pain management in older adults with hip fracture, and does (a) dementia status or (b) dementia subtype influence this relationship?
- a. **H4a:** The presence of dementia will negatively influence the relationship between pain expression and pain assessment, on pain management, in older adults with hip fracture.
- b. **H4b:** Dementia subtype will have an influence on the relationship between pain expression and pain assessment, on pain management, in older adults with hip fracture.

Theoretical Framework Introduction

This section will provide an overview of theories of pain. This is followed by a description of the theoretical model used to guide this study.

Overview of Pain Theories

Prior to the mid 1960's, there existed several ideologies regarding the concept of pain. Initially, the concept of pain was considered unidimensional, such that pain was a direct result, and in proportion to, the type and intensity of a painful stimulus. Pain was considered a response by specific pain nerve fibers secondary to a nociceptive, or painful, stimulus (Snow et al., 2004). In 1965, a multidimensional model of pain was introduced by Melzack and Wall that characterized pain as an outcome of complex bio-psycho-social interactions with physiologic, emotional, behavioral and cognitive influences on the pain experience. The Gate Control Theory of pain (Melzack & Wall, 1965; 2005) extended this bio-psycho-social model to explain neurological pathways for pain perception, thereby conceptualizing pain as a multidimensional construct. This model described how a pain stimulus travels afferently to the brain to generate the perception of pain, how descending pathways inhibit the pain response, and how pain is perceived via the different sensory-discriminative, motivational-affective, and cognitive-evaluative components of the neural processing system (Snow et al., 2004). The Gate Control Theory revolutionized the understanding of pain processing and was the prevailing theory of pain processing for several decades. When applied to the study of older adults, the cognitive aspect of this model is often conceptualized as cognitive status (i.e., dementia status). As such, the Gate Control Theory is used to posit that intact cognition is needed for persons to recognize and respond to pain stimuli. Empirically, however, there is no evidence to suggest that cognitively impaired persons experience less pain (Horgas et al., 2009), but rather they are unable to recognize, remember, or report the presence of pain, likely contributing to the

aforementioned findings that persons with dementia have pain that is undertreated. For this reason, alternative models of pain are needed that articulate pain processing and pain assessment in persons with dementia or other cognitive impairments.

The Pain Assessment Model

The Pain Assessment Model (Snow et al., 2004), which incorporates many of the concepts of the gate control theory, extends the experience of pain to factors that affect its assessment. The model serves as a guide to optimize pain assessment for persons with dementia. The original model is illustrated in Appendix A. The model has six main constructs: pain stimulus, pain sensation, pain perception, pain expression, and pain assessment. This model begins with the concept of a nociceptive stimulus, or the physiological basis for pain. The stimulus is the painful event which leads to the sensation of pain, which is characterized by factors that affect sensation, including the location, quality, intensity, frequency and duration of a the painful event, or nociceptive stimulus. The model posits that the pain stimulus leads to the pain sensation, and that a number of personal factors (e.g., gender, physical status, emotional status, cognitive status, and pain history), directly affect both pain sensation and pain perception. Pain perception, according to Snow and colleagues (2004), incorporates the sensory, behavioral, emotional, and cognitive components of pain described in the Gate Control model. There is a direct relationship between pain perception and external signs of pain including verbal, non-verbal, and physiological signs of pain.

According to the Pain Assessment Model (Snow et al., 2004), the external signs of pain provide a means for measuring pain based on rater observation, and leads to the outcome of the model, pain assessment. A number of factors are hypothesized to influence the rater observations of pain expression, including method factors such as construct characteristics, rater type, data collection method, and assessment instruments. Rater factors, including demographic

characteristics, pain history, knowledge and beliefs about pain, relationships between raters and patients, and secondary gain are hypothesized to influence the interpretation of pain expression, which ultimately results in pain assessment.

Adapted Pain Assessment Model – The Pain Management Model

Based on the Pain Assessment model described above, a model was adapted by the investigator of this study to guide this study of pain expression, pain assessment, and pain management in hospitalized adults with and without dementia. This adapted model is depicted in Figure 1-1 below.

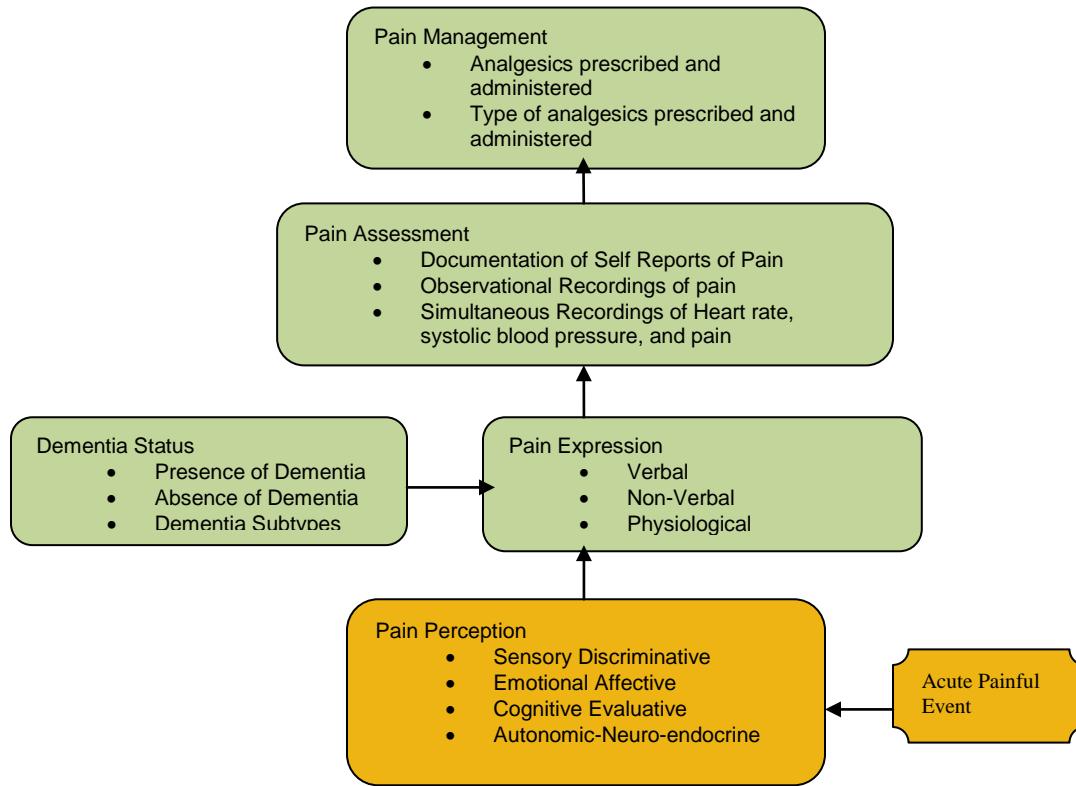


Figure 1-1: Adapted Pain Management Model

The purpose of the adapted model was to explicate (a) the role of dementia status and subtype on pain expression and (b) to differentiate factors such as pain assessment that are

involved in the pain management process, specifically factors that influence the *prescription* of pain treatment and those that influence the *administration* of pain treatment.

The adapted Pain Assessment Model consists of four main constructs: dementia status, pain expression, pain assessment, and pain management. It is hypothesized that dementia status (operationalized as dementia status and dementia subtype) has a direct effect on pain expression (operationalized as verbal, non-verbal, and physiological pain indicators). Pain expression is hypothesized to lead to pain assessment, (operationalized as frequency of recording pain expression) which, in turn, directly effects pain management (operationalized as amounts of analgesics prescribed and administered). Because this model was used to investigate the pain assessment and management process in hospitalized older adults with acute hip fracture, pain nociception was assumed and not directly measured. Pain perception was also assumed given that hip fracture is known to cause pain, and was also not measured in this study, though it is a key concept and was relevant to the current study.

Both the current model and the adapted model include a nociceptive stimulus. Variables of a nociceptive stimulus include stimulus location, duration, quality, intensity, and frequency. These variables may determine pain sensation and ultimately pain perception and expression. The current Pain Assessment Model expresses the outcome variable as the external rater's pain assessment based on observational signs. The adapted model, though inclusive of pain assessment scores by external raters, assigns pain management as the outcome. As stated, the adapted model is based purely on the presence of acute pain and the assumption that an index event, or nociceptive stimulus has occurred and pain has been perceived. Chronic pain may be present as an underlying condition.

As noted, the key constructs of the adapted model include dementia status, pain expression, pain assessment and pain management. Each construct was defined and operationalized to measurement tools that were available and being utilized in the facility where the study was conducted. Figure 1-2 below illustrates each construct (or concept as depicted in the table), the theoretical definition, and empirical means of measurement.

Though the measurement tools are discussed in detail in the Methods Chapter, a brief review of how each construct was operationalized and empirically measured is provided as further explanation of how the adapted theoretical model was utilized.

Operationalizing dementia status was achieved through the use the 9th version of the International Classifications of Diagnoses to identify medical records reflecting a diagnosis of Alzheimer's disease, or a diagnosis of dementia non-specified. In order to verify the classification, history and physical documents created by the admitting physicians were also utilized.

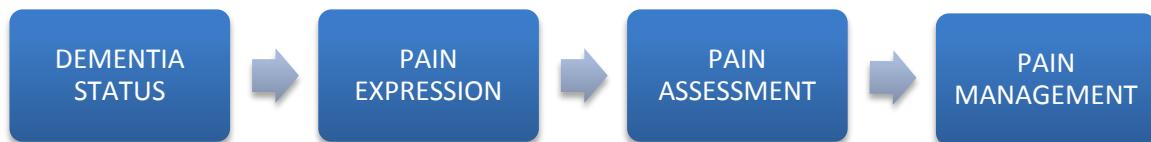
Pain expression was operationalized based on documentation in nurses' notes of pain intensity scores on the WBFP-S, or scores on the FLACC, an observational measure of pain severity. Since the fight-or-flight response, which is often activated secondary to a pain stimulus, is characterized by sympathetic activation and results in elevated heart rate and elevated blood pressure (Benarroch, 2006), physiological indicators of pain were operationalized as changes in heart rate and systolic blood pressure associated with documentation of pain severity.

Given the reasonable expectation that pain expression would result in a recording of pain, especially given the JCAHO mandates of the assessment of pain as the fifth vital sign (Phillips, 2000), and the evidence based practice guidelines for frequency of assessing pain, pain assessment was operationalized as the number of times each component of pain expression, e.g.,

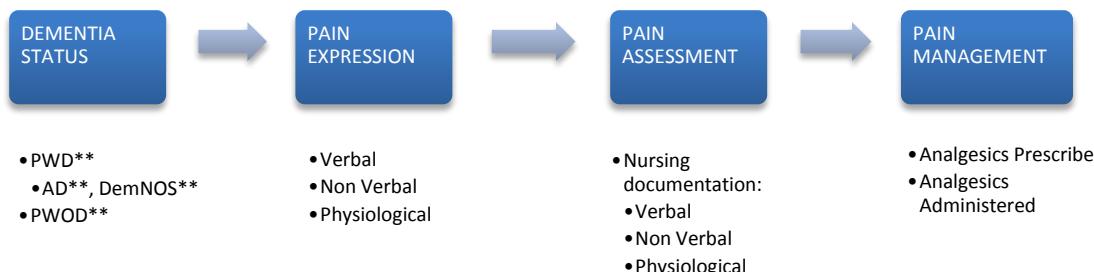
verbal, non-verbal, and physiological expressions of pain, was recorded in the nurses notes during the time period for the study.

The construct of pain management then, an outcome of pain assessment, was operationalized to type and amounts of analgesics *prescribed* and *administered*, and were captured on the Medication Administration Records.

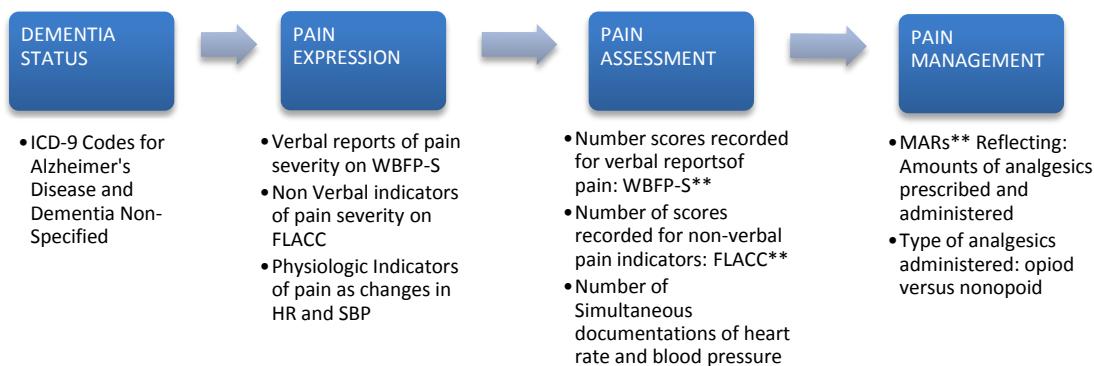
CONCEPTUAL



THEORETICAL



EMPIRICAL



**PWD: persons with dementia; PWOD: persons without dementia; AD: Alzheimer's Disease; DemNOS: Dementia non-specified; WBFP-S: Wong Baker Faces Pain-Scale; FLACC: Faces, Legs, Activity, Cry, Consolability; MAR: Medication Administration Record; HR: heart rate; SBP: systolic blood pressure

Figure 1-2: Conceptual, Theoretical, Empirical Model of Pain Management.

Though not directly measured in this study since pain perception is assumed, the components of pain perception are illustrated in the adapted model because the components of the concept of pain perception ultimately drive the three outcome variables in this study – pain expression, pain assessment and pain management. A description of these components is imperative in order to exemplify the potential influence of dementia status and dementia subtype on the outcome variables. The components of pain perception, described below, will be revisited throughout the discussion of the current study relative to the outcome variables.

Pain perception encompasses sensory-discriminative, motivational (emotional)-affective, cognitive-evaluative, and autonomic-neuro-endocrine components (Scherder, Sergeant, & Swaab, 2003). Sensory-discriminative aspects of pain are those that facilitate a person's ability to recognize pain and appreciate its quality and intensity. This component of pain is processed cortically through the somatosensory area of pain processing (Trout, 2004).

Emotional-affective components of pain can include behavioral responses to pain as well as facial expressions and result from the “suffering” and the “emotional arousal” that occurs as a result of pain (Treede, Kenshalo, Gracely, & Jones, 1999). The emotional-affective response to pain is processed through the limbic system (Trout, 2004). Cognitive-evaluative components include past experiences and memories related to pain which are expressed based on the ability to integrate these experiences through insight and knowledge. This component of pain is considered to be part of the thalamocortical pathway (Price, 2002). Finally, the autonomic-neuro-endocrine systems are inherent in the pain processing system by virtue of the stress-response system and immune system modulation (Trout, 2004). Together, the component parts of each operate to define pain further based on the perception of pain and ultimate expression, as illustrated by the adapted theoretical model.

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

This review of the literature focuses on pain and its expression, assessment and management in elderly adults with dementia, and different types of dementia. The importance of this study is supported by consistent findings in the literature that pain, in elderly adults with dementia, is under-recognized and under-treated. Explanations for these ongoing phenomena may include the nuances associated with recognizing pain in persons with dementia, which indicators may differ from familiar, and ordinary expressions of pain that are provided by persons who experience healthy cognitive aging. As will be demonstrated the relationship between the pathology of dementia and pain perception and expression are closely linked. Pain perception and expression, complex processes, rely heavily on intact pain pathways in order to be realized. The key constructs measured in this study, pain expression, pain assessment, and pain management, are discussed in detail. Though not measured in this study, pain perception is integrated into the discussion. Together these concepts may shed light on why pain is under-recognized and under-treated in older adults with dementia – a robust finding in the literature.

The review of this literature, then, focuses on pain processing and pain expression, and draws on what literature is available to explain potential differences in pain expression between different types of dementia. Though this research focuses specifically on Alzheimer's disease compared to a group of patients with non-specified dementia and persons without dementia, the review includes Alzheimer's disease and frontotemporal dementia. There are many different types of dementia however Alzheimer's disease and frontotemporal dementia (FTD) share a body of literature that supports their neuropathology. These two forms of dementia can easily be

used to exemplify potential differences in pain expression relative to differences in the neuropathology of each disease.

The structure of this literature review is as follows: An overview of the pathological differences between different types of dementia is provided. Pain is then defined followed by an overview of acute pain processing. Pain in dementia is then discussed from within the context of how the neuropathology of different types of dementia might affect pain processing and hence pain expression. This is followed by a brief synthesis which serves to describe the components of pain expression relative to the types of dementia, specifically AD and FTD. Finally, a review of pain assessment and pain management practices is briefly provided.

Neuropathological Differences between Alzheimer's Disease and Frontotemporal Dementia

Several studies have been conducted that establish pathological differences in the brains of persons with various types of dementia. Imaging studies to evaluate structural abnormalities in dementia have shown patterns of atrophy, for example, that distinguish AD from FTD (Rabinovici et al., 2007). In a study involving 11 adults with a criteria-based diagnosis of AD and 18 adults with a criteria based diagnosis of FTD, and who had undergone magnetic resonance imaging (MRI) prior to death, Rabinovici and colleagues (2008) compared atrophy patterns in autopsy-confirmed AD and FTD. These investigators reported that persons with AD showed greatest cerebral atrophy in the hippocampus, medial temporal lobe, and posterior temporoparietal cortices. This compared to persons with FTD who showed atrophy throughout the frontal lobes and anterior temporal lobes, with variations among several types of FTD.

In another study conducted by Varma and colleagues (2002), those with AD demonstrated mild or severe parietal cerebral atrophy based on magnetic resonance imaging (MRI), with a reduction of cerebral blood flow on single photon emission computed tomography (SPECT). These authors set out to examine the use of MRI and SPECT as diagnostic and

differentiating indicators of AD, FTD or vascular dementia (VaD) – the results pertaining to VaD are not reviewed. The sample of AD subjects consisted of 23 consecutively enrolled subjects who were referred for evaluation of dementia to a Cerebral Function Unit in the Manchester area. All AD subjects fulfilled the criteria for an AD diagnosis, according to the National Institute of Neurological and Communicative Disorders and Stroke. The sample of FTD subjects consisted of 21 consecutively enrolled subjects who met established criteria for diagnosis of FTD from the Brain Function Center in Manchester. Patients underwent both MRI and SPECT imaging. Subjective scales designed specifically for this study, and not previously validated for rating atrophy, were utilized. The use of non-validated tools was a weakness for this study and threatened the internal validity. Varma and colleagues (2002) reported that subjects with AD commonly demonstrated mild parietal atrophy. Medial temporal atrophy was seen in almost 80% of subjects, but was more severe for persons with AD compared to persons with FTD. Subjects with FTD had the most profound atrophic changes when compared to AD. They were also noted to demonstrate asymmetry of atrophy, which was a characteristic only seen in those subjects with FTD, compared to FTD and VaD. These subjects also demonstrated more severe atrophy in the frontal, lateral temporal, and parietal regions compared to AD subjects. Severe reductions in cerebral blood flow in the frontal and temporal regions of those suffering from FTD distinguished FTD from AD. The findings in this latter study were supported by findings in the aforementioned study by Rabinovici and colleagues (2008).

The Definition of Pain

Pain, according to the International Association for the Study of Pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Brooks & Tracey, 2005, p. 20). Melzack (1999), who utilizes this definition of pain, adds four broad categories that account for the existence of pain, including

nociception, perception of pain, suffering, and pain behaviors. Melzack asserts that each of these categories supports the existence of pain through anatomical, physiological and psychological components.

Pain as a perception has been defined as “a conscious experience, an interpretation of the nociceptive input influenced by memories, emotional, pathological, genetic, and cognitive factors” (Tracey & Mantyh, 2007, p. 377). Like Melzack, these authors agree that pain is not necessarily a direct result of a painful stimulus, but rather a highly subjective experience that integrates both intrinsic and extrinsic factors that result in a response to pain. Nociception is a term used specifically to describe the neural response to a noxious stimulus (Lange Anesthesiology, 2007).

Acute Pain

To provide a foundation for how brain pathology in persons with dementia might affect pain perception and expression, a brief review of pain transmission is provided. The purpose of nociceptive pain is to limit tissue damage, through detection and localization of a pain stimulus. At each level of the spinal cord there are primary afferent neurons that are located in the dorsal root ganglia, which lie in the vertebral foramina. Each neuron has an axon, which at one end innervates peripheral tissue and at the other end enters the dorsal horn (the back) of the spinal cord. Once a pain stimulus is transmitted from peripheral tissue, the primary afferent neuron synapses with a second-order neuron. Second order neurons also have axons that cross the midline in the spinal cord and travel on the contralateral side from where a stimulus enters the spinal cord. From here, the signal ascends in the spinothalamic tract to reach the thalamus. (An in depth review of the first and second-order neurons are beyond the scope of this paper since the goal is to gain an understanding of the physiology of pain as it relates to the function of the brain.) Once the signal has reached the thalamus, the second-order neurons synapse with third-

order neurons which send projections through several parts of the brain - the internal capsule, corona radiata and the postcentral gyrus - and ultimately reach the cerebral cortex (Lange Anesthesiology, 2007). This pathway is depicted in Figure 2-1 below.

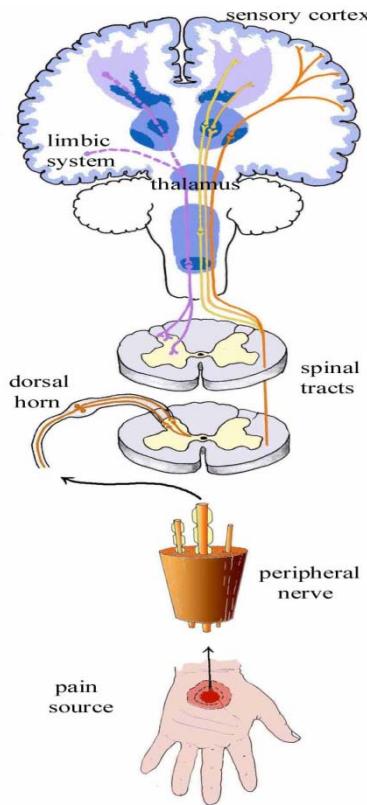


Figure 2-1: Anatomic Diagram of Pain Pathways

The ventral posterior lateral (VPL) nucleus of the thalamus is the end-point for the ascending neurons of the dorsal horn. From the VPL nucleus neurons are projected to the primary somatosensory cortex (Goetz, 2003). The regions of the brain that primarily become activated as a result of noxious stimuli, as demonstrated on positron emission tomography (PET) and functional magnetic resonance imaging (fMRI), include the limbic sensory cortex (insula) and the limbic motor cortex (anterior cingulate cortex) (Craig, 2002). These areas are directly associated with the emotional-affective components of pain perception and expression. Additional areas of the brain activated during painful events include the primary and secondary

somatosensory areas, the dorsolateral prefrontal cortex, striatum, cerebellum, hypothalamus, amygdala and periaqueductal gray. These structures are involved in the cerebral modulation of pain, and are depicted in Figure 2-2 below (Craig, 2002).

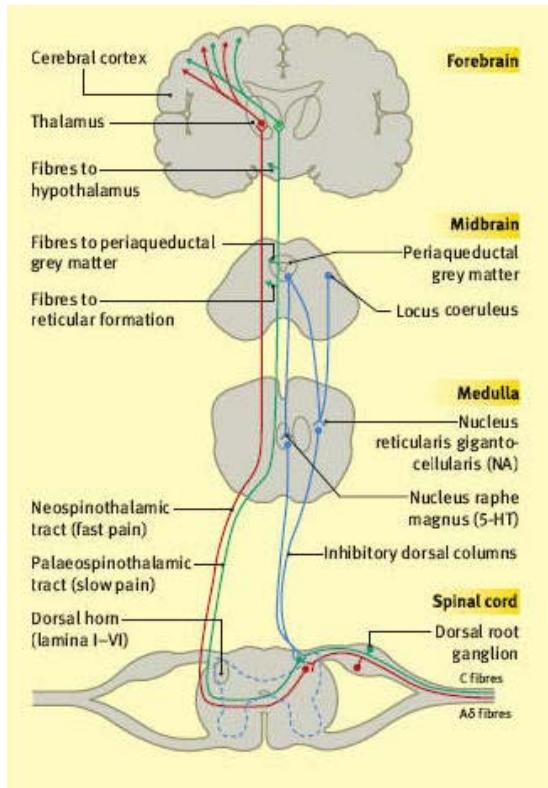


Figure 2-2: Cerebral structures involved in the modulation of pain

Though research has yet to substantiate with certainty how each of these areas in the brain are interconnected to modulate pain and pain perception, Craig (2002) suggests the following associations based on current research. The insula, or limbic sensory cortex, is associated with the ability to qualitatively differentiate pain sensation and to encode its memory. The insular cortex appears to be the primary region for sensations of pain and temperature as well as visceral sensation. The emotional-affective components of pain perception are associated with the anterior cingulate cortex. The anterior cingulate cortex appears to play a large role in noxious cutaneous stimuli and is reported to be selectively associated with pain perception. The

somatosensory areas are associated with the ability to discriminate the intensity of pain as well as the ability to integrate the sensation of pain into somatomotor components (Craig, 2002). This is directly related to sensory-discriminative components of pain perception and expression.

Though each of these areas appears to have specific functions, these areas of the forebrain are interconnected and therefore, stimulation to any one region may simultaneously affect the activation of other regions. Functional imaging studies have been utilized to explore regions of the brain that become activated during painful stimuli, and to attempt to identify locations in the brain that respond to pain from different locations in the body as well as different types of pain. Studies have found that various regions of the brain, including those that are responsible for emotion, cognition, sensation and motor response are often activated during a painful stimulus.

In a study by Henderson, Bandler, Gandevia, and Macefield (2006), in which the aim was to utilize fMRI to determine whether the same neural structures were utilized in deep versus superficial pain, these researchers found that distinct neural activity patterns occurred in different parts of the brain and resulted from pain evoked from different locations on the body. Henderson and colleagues (2006) recruited nineteen healthy participants who were administered either subcutaneous or intramuscular injections of hypertonic saline while undergoing functional imaging of the brain. Each participant received both superficial and deep stimuli, which procedures were separated by at least 20 minutes, or when the subject reported being pain free, and which orders were alternated between subjects. Participants rated their pain on a Likert-type scale with 0 representing the least amount of pain and 10 the most extreme pain. The authors reported significant differences in signal intensity on fMRI ($p < .01$) in various brain regions, when comparing deep versus superficial pain stimuli, especially those regions within the neuromatrix – the insular, somatosensory and cingulate cortices. Their findings indicate that

there are distinct perceptual and emotional responses to cutaneous and deep pain stimulation. Relevant findings suggest that within the cingulate cortex, in the mid and posterior insular cortex, fMRI changes were seen in both superficial and deep painful stimuli. These findings are consistent with other imaging studies of pain response in these brain regions. Additionally, the mid-cingulate and insular cortical regions contribute to many aspects of pain including detection, intensity, and duration (sensory-discriminative), regardless of whether the stimulus was superficial or deep (Henderson et al., 2006).

Henderson and colleagues (2006) also found perceptual differences by observing that superficial pain evoked changes in the primary somatosensory cortex which was localized to the dorsal aspect of the paracentral lobule. Deep pain, on the other hand, evoked changes to the entire paracentral lobule of the somatosensory cortex. The perceived differences were described as “perceived spread of the painful site.” Those who received superficial pain localized the pain to a small region surrounding the site of the stimulus, while the deep stimulus was described as painful sensation that radiated to the distal aspect of the limb injected.

In a review of imaging studies relevant to brain regions activated in the presence of a pain stimulus, Bromm (2001) suggests that fMRI studies of persons with persistent pain demonstrate involvement of the anterior cingulate cortex as playing a major role in pain transmission. The anterior cingulate gyrus (CGa) primarily receives input from the spinothalamic tract, which tract is believed to transmit all pain information. Additionally, the insula interacts with the CGa which further has reciprocal connections with the secondary somatosensory cortex in each cerebral hemisphere (Bromm, 2001). Interestingly, Bromm (2001) points to the involvement of both cerebral hemispheres as being necessary to allow for differentiation of where the pain is coming from. He describes somatotopy as the ability to localize pain, and suggests that stimulus response

characteristics contribute to the ability to rate pain from a qualitative perspective. He incorporates these definitions into the concept of the sensory-discriminative aspect of pain perception.

In a review of the literature describing pain affect and modulation relative to mechanisms in the brain, Rainville (2002), also describes the involvement of multiple areas in the brain working in concert to generate pain perception. He reports results of studies utilizing fMRI indicating that nociceptive information is represented in several areas of the brain and may have direct or indirect roles in the pain experience. Rainville (2002) further describes studies that have demonstrated positive correlations in self-reporting pain scales and fMRI results that demonstrate pain-associated activity in the anterior cingulate cortex (ACC). These results support the role of the ACC in the emotional-affective component of pain perception. Interestingly, studies further suggest that while the emotional-affective aspects of pain perception are correlated to the ACC, the ability to discriminate qualitative aspects of pain, or intensity of pain, as previously noted, is correlated with changes in the primary somatosensory cortex. Results of studies that support these findings are consistent with subjective findings that a lesion in the primary somatosensory cortex was associated with impaired pain sensation (Rainville, 2002). Several other studies reviewed by Rainville (2002), also support the involvement of subcortical structures in the brain, including the nucleus accumbens, amygdale, and periaqueductal gray, as playing contributing roles in the experience of pain.

Dementia and Pain

It is apparent based on the above discussion how the perception and expression of pain, might be affected by brain pathologies associated with dementia. Literature specific to pain in persons with Alzheimer's disease also supports this.

Pain Expression in Alzheimer's Disease

By applying the neuroanatomy of pain processing to the degeneration that occurs in AD, it would be expected that the emotional-affective components of pain perception would be affected. As described when discussing the pathology AD, pathologic changes have been seen in the thalamus, anterior cingulate cortex, insula, amygdala, and hippocampus. To obtain a better understanding of the effect of the progressive involvement of the thalamic components of the medial pain system in persons with AD, Rub, Tredici, Turco, and Braak (2002) studied the brains of 27 individuals from which blocks of tissue that included the thalamus were removed and cut into sections, equally between the 27 brains. Each thalamus was separated into sections and then put into four different groups where analyses would be conducted utilizing different staining techniques in each group. The authors found that all of the components of the thalamic intralaminar nuclei progress in relation to AD pathology simultaneously with the evolving pathology of the cerebral cortex. These regions, which contribute to the medial pain system, mediate the emotional-affective components of pain perception, such as altered reactions to painful stimuli, changes in pain tolerance levels and changes in pain affect.

Further support that the emotional-affective affective component of pain perception is affected in persons with AD is a study by Benedetti, Vighetti, and colleagues (1999) in which the investigators attempted to correlate pain thresholds and tolerance to electroencephalogram (EEG) changes to the severity of cognitive impairment. They recruited twenty-four AD patients from a dementia center in Italy who had not yet lost their ability to communicate. A group of twenty-four healthy subjects in the same age group were recruited as active controls in the study. Phasic pain was administered to the non-dominant wrist of each subject and consisted of timed, repeated electrical stimuli. For each pain stimulus, patients were asked to record their ability to detect the stimulus, to identify whether or not it was painful, and whether or not the pain was bearable.

Tonic pain was administered via the use of a tourniquet which was left in place while subjects performed isotonic exercises with the involved hand for up to 20 times or until pain was unbearable – whichever came first. The subjects reported the onset of mild pain and when the pain became unbearable. Pain threshold was defined as the time to onset of mild pain, and pain tolerance was defined as the point at which pain became unbearable. The study group was split into two groups, each receiving either the phasic pain stimulus or the tonic pain stimulus. The entire control group was exposed to both types of stimuli. In addition to recording the pain threshold and tolerance data, electroencephalogram recordings were obtained prior to the assessments of threshold and tolerance in order to assess severity of AD. A student's t-test and linear regression were performed for analysis of the data. This study revealed that though pain threshold was similar between AD subjects and normal controls, tolerance to pain was significantly higher among those with AD ($t(34) = -4.68, p < .001$), such that those subjects who were cognitively intact did not tolerate pain for as long a period of time as those who were cognitively impaired. Further, the authors reported that pain tolerance increased relative to the severity of AD. Based on this and other studies, according to Benedetti, Vighetti, and colleagues (1999), it appears that there is maintenance of the sensory-discriminative aspects of pain while there is an impaired cognitive response to pain in patients with AD. Additionally, the authors reported that the slowing down of EEG waves was correlated only to an increase in pain tolerance, not to the sensory-discriminative function of those with AD. Patients with lower tolerances for pain showed faster EEG waves in the parietal and occipital regions, which were opposite to those who had high tolerances to pain. This decrease in the EEG waves of those with a high tolerance for pain was present in all brain regions tested, including frontal, temporal, parietal and occipital regions.

With specific regards to physiological expressions of pain relative to heart rate and systolic blood pressure, studies have demonstrated differences in physiological expressions of pain in persons with AD compared to persons without dementia. Benedetti, Arduino, and colleagues (2004) conducted a study to determine if there is a relationship between cognitive impairment in AD, brain electrical activity changes, pain perception and autonomic responses to pain. A sample of thirty subjects was recruited from a dementia center in Italy who had a probable or possible diagnosis of AD. A pain stimulus in the form of an electrical shock was administered to the wrists of non-dominant arms in order to evaluate self-reported pain thresholds after timed repeated administrations of the stimulus. Additionally, subjects were warned of an upcoming stimulus in order to capture anticipatory pain responses. Heart rates were recorded using electrocardiogram (ECG) tracings. The authors found highly significant positive correlations between Mini Mental Status Exam (MMSE) score and heart rate increase during the anticipatory phase of a painful stimulation ($r = .86, p < .001$). A significantly positive correlation was also seen between MMSE score and heart rate after induction of a painful stimulus ($r = .85, p < .001$). Interestingly, neither stimulus detection nor pain threshold was dependent on MMSE score. These findings suggest a decreasing physiological signs of pain expression in response to anticipatory pain and painful stimuli with progression of AD.

Rainero and colleagues (2000) studied autonomic responses and pain perception in Alzheimer's disease. The purpose of their study was to analyze autonomic responses and pain perception following the administration of a pain stimulus. Their sample consisted of twenty communicative patients with a probable or possible diagnosis of AD all of whom were recruited from a dementia center in Italy. A control group of 20 healthy subjects were also recruited to serve as controls. Both samples were conveniently selected. Subjects were given a pain

stimulus, which consisted of an electrical stimulus delivered through the wrists of the non-dominant arms of all participants. Autonomic measures including heart rate and systolic blood pressure were gathered at baseline, followed by a timed series of pain stimulus administration and subsequent recording of autonomic measurements. Additionally, subjects were asked to report their perception of pain after the administration of each pain stimulus. Statistical analysis was performed utilizing analysis of variance (ANOVA) and linear regression analysis with differences reported as statistically significant at $p < .05$. These authors reported that in AD, the administration of a mild pain stimulus was followed by blunting of autonomic responses despite the presence of an apparently normal pain experience, as demonstrated by self-report pain severity scores. On the other hand, a strong pain stimulus resulted in an increase in autonomic response similar to that of normal subjects, however the pain experience appeared to be blunted, as evidenced by self-reports of pain intensity. These results suggested that the threshold for autonomic activation with a pain stimulus is increased in patients with AD compared to persons without AD, and that these patients also have an increased pain tolerance. An additional finding was with regard to anticipation of a pain stimulus. Patients with AD did not have the increase in autonomic response when anticipating a pain stimulus as was seen in control subjects. This finding is consistent with the findings in the study described by Benedetti and colleagues (2004), in which persons with higher MMSE scores had stronger physiological pain expression responses (e.g. heart rate) to anticipatory pain. One would expect based on the neuropathology of AD that this response is due to a diminished limbic system response to pain thereby not generating a proper “fight or flight” response. This might be justified based on the fact that the sensory-discriminative components of pain are fairly spared in AD, yet the emotional-affective and autonomic components are impaired. This again supports the likelihood that alterations in

non-verbal and physiological signs of pain expression are present in persons with Alzheimer's disease. It should be noted that as Alzheimer's disease progresses in severity, and language becomes increasingly impaired, persons with AD may exhibit alterations in all components of pain expression.

Pain Expression in Frontotemporal Dementia

An extensive review of the literature did not reveal studies that are directly related to pain processing and FTD. However, based on what is known regarding the pathology of FTD and the physiology of pain, inferences can be made. The cerebral atrophy in persons with FTD, which tends to be primarily in the orbital frontal and the anterior temporal cortices, and can include the frontal lobes to the extent of involving the dorsolateral frontal cortex have strong implications for pain expression. These regions of the brain mediate higher executive functions, such as socially appropriate behavior, overall decision making, and decisions based on rewards and punishment (Rabinovici et al., 2007). Language is affected when the language dominant hemisphere is more severely impaired, especially with regards to temporal lobe atrophy. Hence, in addition to language impairments, there would be an expectation that the cognitive-evaluative component of pain perception would be impaired. These impairments would be reflected by alterations in verbal and non-verbal signs pain expression.

Differences in Pain Expression by Dementia Subtype: A Brief Synthesis.

The above findings are briefly synthesized to clarify expectations of differences in pain expression based on the pathology of each disease. Whereas emotional-affective components of pain are affected in AD, sensory-discriminative components are spared. Therefore, in persons with AD, while non-verbal signs of pain expression such as guarding and rubbing might be preserved and easily recognized as signs of pain, other non-verbal signs of pain expression, such as isolation, rocking movements, or decreased appetite, may not be recognized as signs of pain.

Additionally, the decreased autonomic response to pain, or the physiological expression of pain, may be a barrier to utilizing physiological signs of pain expression in this population. Persons with FTD, on the other hand, in whom there is extensive neurodegeneration in the frontal lobes affecting the cognitive evaluative components of pain perception, may not be forthcoming with verbal reports of pain. This would likely represent a lack of insight as to the need to impart pain. Additionally, verbally expressed pain might be affected due to loss of language skills, with ongoing damage to the temporal lobes, especially in the language-dominant hemisphere. Non-verbal signs of pain and physiological signs of pain, then, may be the cornerstone for identifying pain in persons with FTD.

Pain Assessment in Persons with Dementia

Much of the research with regards to pain assessment in persons with dementia has focused on defining behavioral indicators of pain in persons with dementia for use in conjunction with the gold standard for pain assessment - verbal reports of pain. The impairments in communication of individuals with moderate to severe dementia lead to the inability to adequately report the presence of pain (Buffum, Hutt, Chang, Craine, & Snow, 2007). This phenomenon has resulted in the development of multiple observational measures of pain. Yet despite the availability of multiple observational measures of pain, studies suggest that no single tool can be recommended for broad use across different populations, and across multiple settings (Ersek et al., 2010).

It is important to note that though the selection of pain assessment tools for various populations and settings remains an area of uncertainty, tools *are* available and their use has been mandated at the bedside in the acute care setting. Additionally, specific pain behaviors have been identified that can be utilized to facilitate pain assessment (Horgas & Elliott, 2004), many of which are incorporated into currently available pain assessment tools. For example, verbal

observations of pain can include verbalizations of pain, as in self-report, as well as vocalizations, such as moaning and crying (Smith, 2005). Non-verbal behaviors associated with pain which can be assessed include anxiety, agitation, restlessness, hypersensitivity to touch, guarding of a painful region, facial grimacing, and alterations in sleep habits (Smith, 2005). Additionally, monitoring vital signs to assess for changes in physiological expressions of pain has also been found to be useful given heart rate and systolic blood pressure responses to pain (Rainero et al., 2000).

Despite the availability of mandates, guidelines, and recommendations to utilize observational tools, as discussed in Chapter One, pain among elderly adults, and presumptively in elderly adults with dementia, in the acute care setting remains under-assessed. Evidence strongly suggests that the institution of pain as the “fifth vital sign” by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) in 2000 has not yielded better recognition of pain or better management in persons with dementia (Scherder et al., 2005). To date, specific studies investigating the impact of the JCAHO pain assessment guidelines on elderly hospitalized persons with and without dementia have not been readily forthcoming.

In one study, however, Herr and colleagues (2004) did investigate current nursing practices relative to pain assessment in older adults. Though this study occurred just a couple of years after the institution of the JCAHO mandates, these researchers found that pain assessment in the acute care setting was not being assessed, or reassessed in compliance with the current those standards. The investigators reviewed the medical records of elderly adults with hip fracture admitted to 12 acute care hospitals. Pain history assessments during the first 72 hours of hospitalization were evaluated for the presence of verbally reported pain. For the first 24 hours following admission 37.2 % of the sample had their pain assessed every 4 hours. For the 72

hours following hospitalization, only 5.5% of their sample ($n = 709$) had their pain assessed every 4-hours during the 72 hours investigated. Interestingly, those with dementia had a significantly higher ($p = .003$) percentage of pain assessed every 4 hours compared to persons without dementia. With regards to verbal recordings of pain assessments based on a numeric rating scale, the investigators found that among the 520 patients without a diagnosis of dementia, 86.4% had at least one recording of pain on the numeric rating scale during the 72 hours studied. This compared to only 13.6% of patients with a diagnosis of dementia having at least one pain assessment during the same time frame.

The current study of hospitalized older adults with hip fracture and with and without dementia may provide insight into more current pain assessment and management practices at the hospital bedside now that a decade has gone by since the institution of the JCAHO guidelines. It is also important to begin to investigate the persistence of the problem in a dementia-specific manner, considering that the various neurodegenerative processes that affect different parts of the brain in different types of dementia may provide clues as to why these problems persist. The findings by Herr and colleagues (2004) exemplify the importance of pursuing further knowledge regarding differences in pain expression, in an effort to clarify current clinical practices as they relate to pain assessment in the acute care setting, as well as to help delineate what types of tools may be more suited to various unique populations, such as persons with dementia.

Pain Management in Persons with Dementia

Like pain assessment, efforts to improve pain management in persons with dementia in the outpatient and the inpatient setting have not yet been shown to be effective. These findings are supported by several studies. In a study to evaluate variations in pain management by cognitive ability, utilizing chart abstraction, data were collected on 551 residents from six North

Carolina nursing homes (Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008).

Pertinent data were abstracted by trained data abstractors from the Minimum Data Set (MDS) of a random sample of nursing home residents' charts regarding cognitive decision-making abilities, and frequency and intensity of pain. Abstractors also collected data pertaining to physician orders, nursing documentation and resident care plans along with daily medication administration documents. Medication administration data included which pain medications residents received and whether the pain medication was a regularly scheduled or "as needed" medication. Non-pharmacological modes of pain management were also gathered from the resident's medical records. Using Chi-Square tests, the relationship between cognition and pain management practices was analyzed. These researchers found that cognitive impairment among nursing home residents was strongly associated with less treatment of pain ($p < .001$) (Chi Square statistics were utilized but not reported). In fact, they reported an inverse relationship between cognitive status and treatment for pain that was statistically significant, such that the higher the degree of cognitive impairment, the less likely they were to receive treatment for pain ($p < .001$). Interestingly, and supported by previous studies, these researchers found no differences in painful diagnoses of nursing home residents, regardless of cognitive status.

In another study designed to examine the relationship between cognitive impairment and pain medication use in nursing home residents, Hargas and Tsai (1998) analyzed a convenience sample of 339 nursing home residents to determine if residents with cognitive impairments were *prescribed* and *administered* less pain medications than their cognitively intact counterparts. Hargas & Tsai (1998) measured three separate domains, including cognition, painful diagnoses and medication use. Medical records were reviewed as sources to gather data pertaining to diagnoses, medications, and cognition. Cognition was determined based on behavioral indicators,

as evaluated by nursing assistants and medical diagnoses of cognitive impairments. The Multidimensional Observation Scale for Elderly Subjects (MOSES) was the tool utilized by the nursing assistants to document several dimensions of behavioral functioning, including self-care limitations, disorientation, depression, irritability, and withdrawal. This tool was utilized in order to evaluate the effect of cognition on analgesic prescribing practices and validate the MOSES tool as a congruent measurement with those documented diagnoses of cognitive impairment gathered from medical records. They found that nursing home residents who were cognitively impaired were less likely to be prescribed and administered analgesic medications. Following t-test analyses, Hargas & Tsai (1998) found that cognitively impaired individuals were *prescribed* significantly less pain medications than their cognitively intact counterparts ($t(336.9) = 3.7, p < .001$). Additionally, compared to cognitively intact subjects, those subjects in the study with cognitive impairments also *received* significantly less pain medication ($t(333.5) = 3.8, p < .001$). Analgesic dosages, which were analyzed based on acetaminophen equivalents, were also *prescribed* ($t(325.6) = 2.7, p < .01$) and *administered* ($t(273.7) = 2.9, p < 0.01$) in statistically significant lower amounts for persons with cognitive impairments.

In the hospital setting, there is some evidence that pain is also undertreated in persons with dementia. In one study, Morrison & Siu (2000) compared analgesic prescription patterns for persons with advanced dementia who had a hip fracture ($n = 38$) to cognitively intact elderly individuals with hip fracture ($n = 59$). These authors prospectively evaluated the two groups for pain severity and analgesic use for three days following surgery for hip fracture repair. Subjects were enrolled into the cognitively intact group if they had a score of 18 or higher out of 24 on the telephone version of Mini Mental Status Exam (MMSE). The dementia group consisted of persons considered to have severe dementia based on a Reisberg Global Deterioration Score of 6

or 7. All participants had their charts reviewed for data pertaining to analgesic prescribing and use. Additionally, those cognitively intact participants who underwent surgical repair of their fracture were also evaluated pre- and post-operatively for pain severity and adequacy of analgesic prescribing. Pain severity was evaluated in the cognitively intact group based on a 5-point numeric rating scale, where 0 represented no pain and 4 represented very severe pain. The pain rating scores collected for the cognitively intact group were used as approximations for the severity of pain experienced by the subjects with dementia since they were unable to self-report pain. Rationale for this methodology was not provided by the investigator.

The data were analyzed using t-tests and chi-square statistics to compare participant characteristics, including age, gender, ethnicity, type of hip fracture, and length of hospital stay. Analgesic use was converted to morphine sulfate equivalents so that drugs could be compared based on standardized metric. The results indicated that the cognitively intact group received statistically significantly higher morphine sulfate equivalents than their cognitively impaired counterparts through post-operative day 3 ($p = .002$). In addition, it was noted that 75% of the dementia group and almost 85% of the cognitively intact group did not have standing orders for analgesic medications. Instead, analgesic medications were ordered on an “as needed” basis. These results indicate that the under-treatment of pain in persons with dementia exists in the hospital setting.

Taken together, the literature supports the fact that pain is under-recognized and under-treated in elderly persons with cognitive impairments in the outpatient setting, primarily in nursing homes. Though there remains a paucity of research supporting these findings in the hospital setting, preliminary studies demonstrating similar pain assessment and pain management

discrepancies in the acute care setting support the need for further investigation, and hence for this study.

Confounding Variables

The study of elderly persons with dementia can be complicated by multiple variables that potentially affect pain expression, assessment, and management. The following is a brief review supporting the selection of gender, race, age, and location as confounding variables, which were controlled for in the matching process.

Gender Effects on Dementia, and Pain Outcomes

Though the incidence of dementia has been found to be similar in men and women under the age of 90, data from the Rotterdam Study, a large prospective cohort study in the Netherlands of more than 7,000 persons over the age of 55, found that the incidence of Alzheimer's disease was higher among women who were 90 or older compared to men (Ruitenberg, Ott, Swieten, Hofman, & Breteler, 2000). Additionally, men across all age groups had a higher incidence of vascular dementia compared to women (Ruitenberg et al., 2000).

Gender differences with respect to pain have been extensively studied. Findings have suggested differences in pain perception mediated by multiple factors including psychological, hormonal and molecular-based factors (Greenspan et al., 2007) - a detailed explanation of these factors is beyond the scope of this paper. These factors could be expected to affect pain expression, pain assessment and pain management. Additionally, pain management has been found to differ between the genders such that compared to males, when undergoing the same procedures, females have been reported to receive lower amounts of pain medications (Weisse, Sorum, Kafi, Sanders, & Syat, 2001).

Racial Effects on Dementia and Pain Outcomes

The current study is represented by Caucasians and African Americans only, though this was not an intended consequence. Studies have demonstrated higher frequencies of dementia across various ethnicities. Further, there is a growing body of literature suggesting that the prevalence of dementia is higher among elderly non-whites (Mehta et al., 2008). Based on a study of a random sample of Medicare beneficiaries in the State of Tennessee ($n = 33,688$), the prevalence of dementia was higher among African American men and women (Husaini et al., 2003).

With regards to pain, when undergoing similar procedures, lower amounts of pain medications have been reportedly received by minority races compared to non-minorities (Weisse et al., 2001). Green and colleagues (2003) performed an extensive review of the literature looking at racial and ethnic differences in pain and what factors contribute to disparities in pain management. The findings of their review were consistent with a report by the Institute of Medicine, in which disparities among racial minorities compared to non-minorities, in all aspects of pain, including perception, assessment and management were found across multiple settings, including emergency rooms and post-surgical units.

Age Effects on Dementia and Pain Outcomes

The growing prevalence of persons with dementia is a reflection of the demographic trends of an aging population (Rice et al., 2001). Dementia affects persons in the later years of life, though not all elderly individuals will develop dementia.

Age disparities in pain assessment and pain management have been well documented in the literature with findings demonstrating increasing age to be associated with lower amounts of pain medications being prescribed and administered. These disparities have been attributed to many factors, including both the population of older individuals and their healthcare providers

(Allock et al., 2002). These authors reported barriers to pain management as including provider misconceptions regarding pain in elderly adults, and concerns for pain medication side effects that can be exaggerated in older individuals. Additional barriers to pain assessment and management were due to elderly patients, including possible hesitation to report pain and its severity, and an expectation that pain is a part of aging, and therefore will be present regardless of reporting it to healthcare providers. Allen and colleagues (2003) reported that nursing home residents who were greater than 85 years of age, demonstrated low cognitive performance, and were on multiple medications, were especially at risk for not receiving pain medications.

Location

There were four locations utilized for this study which crossed both inner city, urban, and rural areas surrounding Jacksonville, Florida. The Institute of Medicine has reported that the quality of healthcare in the United States is disproportionately less than what would be expected given the extent of healthcare available and the costs associated with it (Lutfiyya et al., 2007). Despite the availability of the latest scientific knowledge, efforts to improve quality through widespread assessments of the current healthcare system, there remains a paucity of data reflecting comparisons between hospitals. This is of concern, especially for hospitals in rural areas where there are fewer resources, fewer specialists, and less funding. Complicating this, populations in rural areas tend to have more co-morbidities compared to populations in urban areas, and often have poorer health habits (Lutfiyya et al., (2007). The consideration that these factors would affect the outcomes of the study served as the rationale to include location in the matching process.

Summary

This review of the literature exemplifies the importance of investigating differences in pain expression, pain assessment, and pain management in persons with and without dementia,

and by dementia subtype. The need to investigate these differences in the hospital setting is supported by the paucity of research describing pain in persons with dementia in this setting – an area of increasing importance given the demographic trends. Additionally, the under-recognition and under-treatment of pain in persons with dementia underscores the possibility that differences in pain expression may be at the core of this problem.

Neurodegenerative processes differ by dementia type, and therefore may lead to differences in pain expression by dementia subtype. As described, the distributions of cortical atrophy vary by dementia type, such that persons with AD have been shown to have the greatest cerebral atrophy in the hippocampus, medial temporal lobe, and posterior temporoparietal cortices. This is compared to persons with FTD who have been demonstrated to have atrophy throughout the frontal lobes and anterior temporal lobes and often in the parietal lobes. A distinguishing feature between persons with FTD compared to persons with AD is the presence of profound and asymmetric atrophic changes in the regions described. Severe reduction in cerebral blood flow in the frontal and temporal regions of those suffering from FTD is also a distinguishing feature between FTD and AD. Autonomic differences, which have been tested between persons with AD compared to persons without dementia, have also been found. Persons with AD have heart rate responses to pain that are disproportionate to the anticipated pain stimulus and the experience of pain compared to those who are cognitively intact. These differences may explain differences in pain perception, and their effect on potential differences in pain expression (e.g. verbal, non-verbal, and physiological) between different types of dementia.

The literature review also provided support for the current study given consistent findings that pain in elderly persons with dementia is under-recognized and under-treated. Additionally,

limited research supports that nurses are not in compliance with current guidelines for pain assessment in the acute care setting, an area that requires further investigation, especially given that the JCAHO mandates for pain assessment are now a decade old.

CHAPTER 3

METHODS

Purpose

The purpose of this study was to investigate differences in pain expression (verbal, non-verbal, and physiological pain intensity ratings), pain assessment (number of documented nurse-based assessments of verbal, non-verbal, and physiological indicators of pain), and pain management (type and amounts of analgesics *prescribed* and *administered*) in hospitalized elderly persons with and without dementia. Hip fracture was the index diagnosis used in this study because it is known to be associated with significant pain. Further, this study investigated whether pain expression, pain assessment, and pain management differ between hospitalized elderly patients with different dementia subtypes, specifically comparing Alzheimer's disease to a diagnosis of dementia, non-specified. This study also examined pain expression and pain assessment as predictors of pain management, and how these relationships were influenced by (a) dementia status and (b) dementia subtype.

Design

This descriptive study was a retrospective review of medical records of 135 elderly persons who were hospitalized in the Baptist Medical Healthcare System (Jacksonville, Florida) with acute hip fracture. The purposive sample was selected by entering diagnosis codes, based on the International Classification of Diseases, for persons greater than 65 years of age with acute hip fracture and AD or dementia non-specified, or without dementia. The main group of persons with dementia served as the source of medical records for that analysis of the dementia subtypes – AD and dementia non-specified.

Medical records of persons with and without dementia were matched on age, gender, and race to avoid the potential effects of these confounding variables on the outcome variables.

Records were also matched for location since the types of areas served by these hospitals varied and included inner city (BMC Downtown), suburban (BMC South and BMC Beaches) and, rural (BMC Nassau).

Rationale for Retrospective Design

A retrospective design was chosen for several reasons. Though knowledge gained from research regarding pain assessment and management is yielding more effective ways to assess pain in persons with dementia, discrepancies still exist when it comes to assessing and managing acute pain in hospitalized persons with dementia compared to persons who are cognitively intact (Herr et al., 2004). Questions still remain about what factors contribute to poor pain assessment and poor pain management. Is it that older people with dementia cannot express pain? Is it that nurses cannot recognize pain in persons with dementia and therefore pain is not getting assessed and treated? For these reasons an exploratory study was felt to be an appropriate way to begin to answer these questions. Retrospectively examining current practices in the clinical setting can help to unveil existing relationships between these variables that need further investigation. This retrospective design provided the means through which to investigate these phenomena, and was both logistically and financially feasible.

Sample Population

Of a total of 386 medical records reviewed, 135 were eligible for the study. Sample characteristics are displayed in Table 3-1. The majority of the sample (almost 2/3) consisted of persons in the 85 or greater age group. The average age for the entire sample was 86. Women comprised almost 90% of the total sample. The sample represented only two ethnicities, Caucasians (96%) and African Americans (4%). Almost 2/3 of the entire sample reflected persons who were widowed. Of the four sites selected for this study, 40% of the sample came from the largest of the Baptist Medical Centers in downtown Jacksonville, Florida. Chi-square

statistics revealed no statistically significant differences in the demographic characteristics between the groups.

The sample was broken down by dementia status to two main groups - persons with dementia (n = 72) and persons without dementia (n = 63). The average age of both groups was 86. The sample characteristics by dementia status are also demonstrated in Table 3-1. Women comprised 86% (n = 72) of the sample of persons with dementia, and 90% (n = 63) of the sample of persons without dementia. Almost half of those with dementia were widowed compared to 2/3 of those without dementia.

Table 3-1. Sample Characteristics of Persons with and without Dementia

	SAMPLE N=135(%)	PWD n=72(%)	PWOD n=63(%)	$\chi^2(df)$	P
Age Group				.42(4)	.981
65-69	2 (1.4)	1 (1.3)	1 (1.6)		
70-74	7 (5.3)	4 (5.5)	3 (.4.7)		
75-79	5 (3.7)	2 (2.7)	3 (4.8)		
80-84	37 (27.4)	20 (27.7)	17 (27.0)		
85 and >	84 (62.2)	45 (62.3)	39 (62.0)		
Gender				.61(1)	.434
Male	16 (11.9)	10 (13.9)	6 (9.5)		
Female	119 (88.1)	62 (86.1)	57 (90.5)		
Race				1.5(1)	.223
White	130 (96.2)	68 (94.4)	62 (98.4)		
AA	5 (3.8)	4 (5.6)	1 (1.6)		
Marital Status				3.5(4)	.470
Married	28 (20.7)	13(18.1)	15(23.8)		
Widowed	83 (61.4)	45(63)	38(60.4)		
Divorced	8 (5.9)	4(5.5)	4(6.3)		
Single	1 (.07)	0(0)	1(21.6)		
Not Reported	15 (11.1)	10 (13.8)	5 (7.9)		
BMC Location				1.4(3)	.712
Downtown	56 (41.5)	33 (45.8)	23 (36.5)		
South	39 (28.9)	20 (27.8)	19 (30.2)		
Beaches	26 (19.3)	12 (16.7)	14 (22.2)		
Nassau	14 (10.3)	7 (9.7)	7 (11.1)		

The group of persons with dementia was broken down by dementia subtype, and comprised two sub-groups – persons with Alzheimer’s disease (AD) (n = 49) and persons with

dementia non-specified (DemNOS) ($n = 23$). Sample characteristics of the dementia subtype groups are illustrated in Table 3-2. Both dementia subtypes were represented mostly by persons who were greater than 85. Persons with Alzheimer's disease had an average age of 85.2 ($SD = 6.1$), while those with dementia non-specified had an average age of 88.0 ($SD = 5.2$). Ninety percent of the AD group consisted of women, while 78% of the DemNOS group consisted of women. Almost 2/3 of the dementia subtype sample consisted persons who were widowed. Though only representing a small number, all of the African Americans ($n = 4$) belonged to the AD group.

Table 3-2. Sample Characteristics of Dementia Subtypes ($N = 72$)

	AD $n=49(\%)$	DemNOS $n=23(\%)$	$\chi^2(df)$	P
Age Group			4.2(4)	.386
65-69	1 (2)	0(0)		
70-74	3 (6)	1 (4)		
75-79	2 (4)	0 (0)		
80-84	16 (33)	4 (17)		
85 and >	27 (55)	18 (78)		
Gender			.61(1)	.434
Male	5 (10)	5 (22)		
Female	44 (90)	18 (78)		
Race			2.0 (1)	.160
White	45 (92)	23 (100)		
AA	4 (8)	0 (0)		
Marital Status			1.3 (3)	.728
Married	9 (18)	4 (17)		
Widowed	30 (61)	15 (65)		
Divorced	2 (4)	2 (9)		
Single	8 (16)	2 (9)		
BMC Location			3.2 (3)	.355
Downtown	26 (53)	7 (30)		
South	12 (24)	8 (35)		
Beaches	7 (14)	5 (22)		
Nassau	4 (8)	3 (13)		

Given that elderly persons are often more susceptible to chronic illnesses (Sanderson et al., 2002) co-morbidity data were collected from each medical record. The distribution of the most common co-morbidities for the two main study groups (PWD and PWOD) and the

subgroups of dementia subtypes (AD and DemNOS) are illustrated in Table 3-3 below.

Cardiovascular disease was the predominating co-morbidity for all study groups. The total number of co-morbidities was calculated and used as a covariate for the study. There were no significant differences in the sum of co-morbidities between persons with and without dementia ($t = .36, p > .05$), or between persons with Alzheimer's disease compared to dementia non-specified ($t = .64, p > .05$).

Table 3-3. Number and Percent Distribution of Co-morbidities by Dementia Type

	PWD n=72(%)	PWOD n=63(%)	P	AD n=49(%)	DemNOS n=23(%)	p
Cardiovascular	65(90.3)	55(87.3)	.586	46(93.9)	19(82.6)	.296
CAD	20(27.8)	15(23.8)		11(22.4)	4(17.4)	
HTN	56(77.8)	50(79.4)		39(79.6)	17(73.7)	
Cerebrovascular	18(25)	14(22.2)	.708	10(20.4)	8(34.8)	.173
Ischemic Stroke	11(15.3)	8(12.7)		6(12.2)	8(34.8)	
TIA	5(6.9)	4(6.3)		4(8.2)	1(4.3)	
Endocrine	43(59.7)	44(69.8)	.223	28(57.1)	15(65.2)	.933
DM	9(12.5)	11(17.5)		5(10.2)	4(17.4)	
Thyroid Disease	21(29.2)	17(27.0)		14(28.6)	7(30.4)	
Dyslipidemia	23(31.9)	22(34.9)		14(28.6)	9(39.1)	
Musculoskeletal	28(38.9)	29(46.0)	.406	17(34.7)	11(47.8)	.554
Osteoarthritis	11(15.3)	5(7.9)		8(16.3)	3(13.0)	
Osteoporosis	12(16.7)	14(22.2)		8(16.3)	4(17.4)	
Neuro NonVasc	30(41.7)	17(27.0)	.075	19(38.8)	11(47.8)	.153
Parkinson's Dis	3(4.2)	3(4.8)		3(6.1)	0(0)	
Depression	15(20.8)	7(11.1)		11(22.4)	4(17.4)	
Pulmonary	16(22.2)	13(20.6)	.824	12(24.5)	4(17.4)	.603
COPD	12(16.7)	13(20.6)		9(18.4)	3(13.0)	
Sum Co-morbid	3.2(1.4)	3.3(1.4)	.362	3.1(1.4)	3.3(1.4)	.638

Study Sites

Medical records for this study came from four sites within Baptist Health Care System (BMC) in Florida. The sites included Baptist Medical Center in downtown Jacksonville, Baptist

Medical Center South in a suburban area of Jacksonville, Baptist Medical Center Beaches, a suburban city, and Baptist Medical Center Nassau, a rurally based hospital.

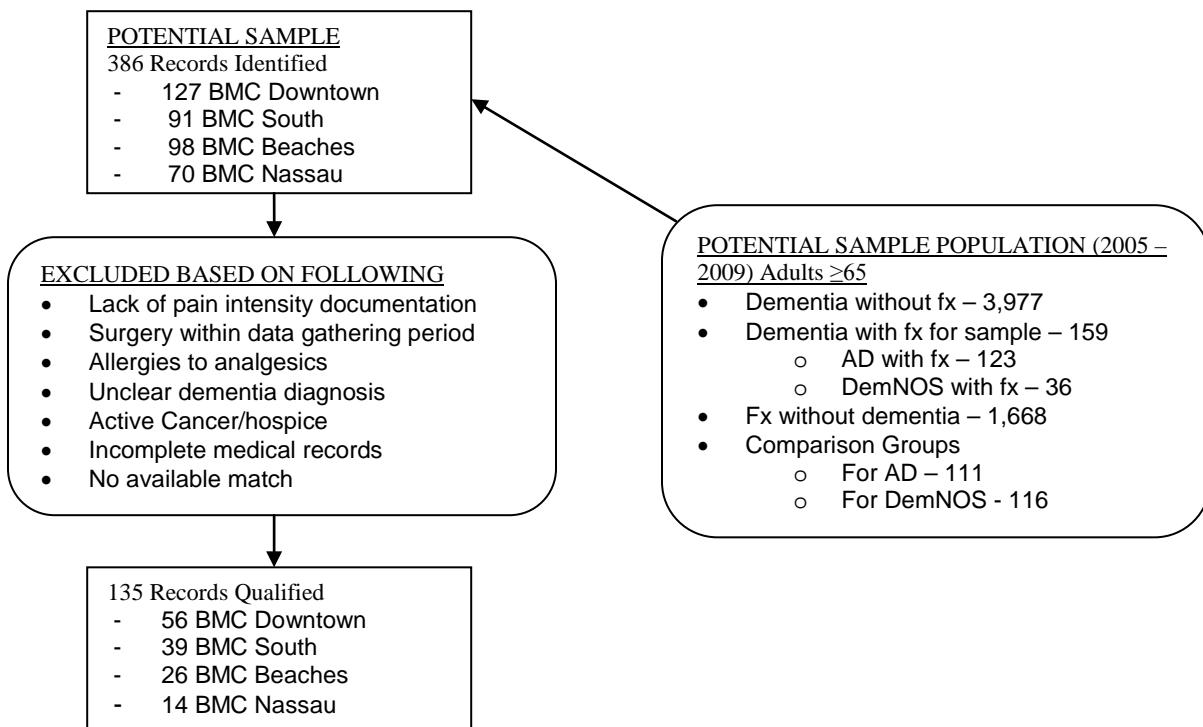
Chart Selection Methods and Inclusion Criteria

A purposive sample of medical records was identified through an electronic interrogation of discharge diagnosis codes for hospitalizations occurring within the Baptist Healthcare System between the years of 2005 and 2009. Medical records had to reflect the patient was 65 years or older at the time of admission. ICD-9 codes were entered with the assistance of the clinical effectiveness department at Baptist Medical Center in downtown Jacksonville. Included in the search were ICD9 codes for Alzheimer's disease and dementia non-specified, and hip fracture, including femoral neck fractures, pelvic fractures and trochanteric fractures. Hip fractures are often considered a homogeneous condition though they actually vary by anatomic location, including fractures of the femoral neck, pelvis and trochanter (Gnudi et al., 2002). Additionally, ICD 9 codes for hip fracture, selecting for age, gender, race, and location for persons without a diagnosis of dementia were selected for the comparison group. Based on this process, 386 charts were selected.

Chart Screening for Exclusion Criteria

The selected medical records were reviewed to screen out medical records based on the following criteria. Medical records were excluded if nurses' notes did not reflect at least one recording of a pain, on either the WBFP-S or the FLACC pain assessment tool. Additionally, charts were excluded if the patient was taken to surgery at any time during the time period covering the data collection. Charts were also excluded if on admission the record reflected that the patient was suffering from delirium or had an allergy to either opioid or non-opioid analgesic medications. Additionally, any medical record reflecting a diagnosis of cancer that was being actively treated, or that the patient had been admitted to hospice, was excluded from the study.

The chart selection process resulted in a purposeful sample of 135 medical records. The dominant reason for record exclusion was due to lack of pain assessment documentation. Figure 3-1 is an illustration of the chart screening process.



** **BMC: Baptist Medical Center; fx: fracture; AD: Alzheimer's Disease; DemNOS: dementia non-specified**

Figure 3-1. Chart Screening Process

Power Analysis

The sample size was calculated based on 80% power and a .05 level of significance to detect a small effect size (.25). The sample size was adequate to detect a small effect size.

Variables and Measurement Tools

A detailed description of the study constructs, and specific variables are provided below. Table 3-4 is an illustration of the constructs studied, as well as how they were operationally and empirically defined.

Independent Variables

There were two independent variables in this study: dementia status and dementia subtype. Dementia was operationalized as having either Alzheimer's disease or dementia non-specified as identified by discharge diagnosis codes from the 9th Version of the International Classification of Diseases (ICD-9). History and physical documentation was utilized to confirm the presence and type of dementia. History and physical documentation was also used to confirm the absence of dementia for those records identified as not having dementia based on the exclusion in the database search of ICD-9 codes for dementia. Dementia subtype was operationalized as the presence of Alzheimer's disease or dementia non-specified.

Dependent Variables

The dependent variables for this study were pain expression, pain assessment, and pain management. These are described in detail below. The measurement of pain expression was operationalized as verbal reports of pain severity, non-verbal indicators of pain severity, and changes in physiologic measures (e.g. heart rate and systolic blood pressure) of pain. Verbal and non-verbal reports of pain intensity were measured using average pain intensity, and average least (lowest) and worst (highest), pain intensity scores. Physiological measurements were based on changes in heart rate and systolic blood pressure, captured over time, based on simultaneous documentation of these measures with pain intensity recordings. Pain assessment was operationalized based on the *frequency* of nurses' recordings of pain in the nurses' notes for each of the empirical measurements of pain expression: Frequency of recording scores based on The Wong Baker Faces Pain-Scale (WBFP-S) for the assessment of verbal reports of pain, frequency of recording scores based on the Faces, Legs, Activity, Cry, Consolability scale (FLACC) for the assessment of non-verbal indicators of pain, and frequency of recording heart rate and systolic blood pressure simultaneously with verbal and non-verbal pain assessment scores for

physiological assessments of pain. It should be noted that this study followed the documentation of pain for a 24-hour period. The 24 hours began with the first recording of pain on either the WBFP-S or the FLACC, in nurses' notes following admission to the hospital for acute hip fracture. Since there had to be at least 24 hours of hospitalization following the first documentation of pain, there were 24 opportunities to assess and record pain. Pain management was operationalized as the amount and type of analgesic medications prescribed and administered as reflected on the Medication Administration Records.

Table 3-4. Study Variables, Operational Definitions, and Empirical Measurements

Variables	Operational Definition	Empirical Measurement
Independent Variables		
Dementia Status	Persons with dementia Alzheimer's disease Dementia non-specified Persons without dementia	ICD-9 Codes
Dependent Variables		
Pain Expression	Verbal Non-verbal Physiological	Verbal pain intensity scores on WBFPs Behavioral pain intensity Scores on the FLACC Changes in HR and SBP
Pain Assessment		
Verbal	Recording of verbal reports	Number of WBFP-S scores
Non-verbal	Recording of non-verbal indicators	Number of FLACC Scores
Physiological	Recordings of HR and SBP in conjunction with verbal and non-verbal pain assessments	Number of simultaneous HR and SBP recordings
Pain Management	Analgesics prescribed Analgesics administered	MARs reflecting amounts and types (opioids/non-opioids) of analgesics Prescribed and admin

** WBFP-S: Wong Baker Faces Pain-Scale; FLACC: Faces, Legs, Activity, Cry, Consolability; HR: heart rate; SBP: systolic blood pressure; MAR: Medication Administration Record

Measures

The measurement tools for pain expression are described below. Since pain assessment is measured based on the frequency of use of each of these measures, this section covers both constructs.

Pain expression

As noted, pain expression was operationally defined as the intensity of pain demonstrated through verbal, non-verbal, and physiological signs. The measurement tools utilized to capture pain expression within BMC health care system include the Wong-Baker Faces Pain Scale (WBFP-S) to capture verbal reports of pain, and the Faces, Legs, Activity, Cry, Consolability (FLACC) pain assessment tool as the observational measure to capture non-verbal indicators of pain. Heart rate and systolic blood pressure can be considered physiological measures of pain expression when they are recorded simultaneously with pain assessment.

For the purpose of the current study, verbal reports of pain intensity were captured based on nursing documentation of pain intensity scores, presumably reported by patients. Average pain intensity was calculated based on scores recorded during the 24 hours studied on the 10-point WBFP-S. Least pain intensity was measured as the average lowest WBFP-S score recorded during the 24 hours studied. Worst pain intensity was measured as the average highest score recorded.

Verbal measures of pain expression. The Wong-Baker Faces Pain Scale (WBFP-S) is a self-report ordinal scale designed to measure pain intensity in children. The original W-BFPS is a scale containing six hand-drawn faces with expressions ranging from smiling to crying. The faces are drawn over a horizontal numeric rating scale where zero is drawn under the smiling face (representing no pain) and 5 is drawn under the crying face (representing worst pain).

The Baptist Health Care System modified the WBFP-S to use as a 10-point scale (Figure 3-2). The first face is smiling and represents no pain (score = 0). Each of the following faces has a score that incrementally increases by 2 points, with 10 representing worst pain.

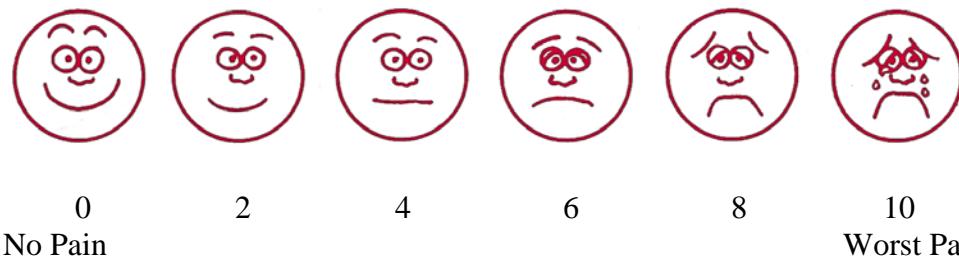


Figure 3-2: Wong Baker Faces Pain-Scale as modified by the Baptist Health Care System

The psychometric properties of the W-BFPS have been studied in pediatric populations. In a systematic review of the literature to examine pain intensity measures in children, Stinson, Kavanagh, Yamada, Gill, and Stevens (2006) found only a handful of articles describing psychometric properties, including content and construct validity of W-BFPS. Measures of reliability were also sparse, with test-retest reliability being the only measure of reliability reported. High stability of the W-BFPS has been demonstrated over 15 minutes and 8 hours in post-operative children with strong test-retest reliability ($r = .90$, Cronbach's $\alpha = .93$, and $r = .84$, respectively, though Cronbach's α was not reported for 8 hours). Concurrent validity was demonstrated between the W-BFPS and other established self-report measures of pain ($r = 0.74 - r = 0.78$) in children (Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006). The WBFP-S has been reported to be psychometrically sound in children and adolescents, and is extensively used in the clinical setting (Stinson et al., 2006).

Although the W-BFPS was developed for use in children, its visual approach has appeal for use in other clinical populations, such as those with cognitive impairments. However, its psychometric properties have not been well established in this population, and a review of the

literature did not reveal any studies testing the psychometric properties of the WBFP-S as a 10-point scale. Only one study using the WBFP-S as a 10-point scale was found in which the investigators sought to evaluate pain in nursing home residents. Wynn, Ling, and Rembsburg (2000) did not report psychometric properties of the WBFP-S, however they did report that residents with lower scores on the Mini Mental Status Exam (scores less than 15/30) had significantly lower response rates on all the instruments tested, including the WBFP-S.

Non-verbal measures of pain expression. The Faces, Legs, Activity, Cry, Consolability pain assessment tool [FLACC] is an objective scale used to quantify pain intensity according to behavioral indicators. There are five behavioral categories evaluated in this tool: Facial expression (grimacing), leg movement, activity, cry, and consolability. Nurses score behaviors in each of the five categories based on their observations. Scores range from 0-2, where 0 represents no pain behaviors and a score of 2 represents the most pain behaviors reflecting more pain severity. The scores for each of the five categories are summed to create a total FLACC score, ranging from 0 (no pain observed) to 10 (severe pain observed) (Manworren & Hynan, 2003). Figure 3-3 is an illustration of the FLACC pain assessment tool, as recreated for use within the Baptist Medical Healthcare System.

The FLACC was initially developed as a behavioral scale for use in the pediatric, post-operative population (Manworren & Hynan, 2003). The instrument has been validated in postoperative children aged 2 to 7, as well as in cognitively impaired children aged 4 to 18 (Voepel-Lewis, Malviya, Merkel, & Tait, 2003). In a sample of post-surgical children aged 2 months to 7 years, Merkel, Voepel-Lewis, Shayevitz, and Malviya (1997) found strong correlations between two observers ($r = .94$, $p < .001$), supporting inter-rater reliability. In another study of post operative pain in children and adolescents aged 4 – 18 who were

cognitively impaired, Voepel-Lewis, Malviya, Merkel, and Tait (2001) also found the FLACC to demonstrate inter-rater reliability based on the significant correlation between bedside nursing pre and post analgesia FLACC scores, and FLACC scores by nurses who watched videotapes and were blinded to whether or not analgesics had been administered ($r = .84, p < .001$). When the FLACC was compared to the Post Anesthesia Care Unit nurses' global ratings of pain in Merkel and colleagues' study of 2 to 7 year-olds, both tools were found to capture similar behaviors in the assessment of pain thereby supporting a high content validity ($r = .80, p < .001$). Both studies, by Merkel and colleagues (1997) and Voepel-Lewis and colleagues (2001) demonstrated significant decreases in FLACC scores following the administration of analgesic medications ($p = .005$ and $p < .001$ respectively) thereby supporting construct validity.

Faces, Legs, Activity, Cry, Consolability Scale			
Category	Score 0	Score 1	Score 2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No cry (wake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touch, hug, or being talked to; distractible	Difficult to console or comfort

Figure 3-3: FLACC Pain Assessment Tool

Though the FLACC has been shown to be a reliable and valid measure of pain in children, it has not been validated for use in older persons with dementia. A small study of six

cognitively impaired, long-term care residents was conducted to study the FLACC, and has been reported in several articles (Herr et al., 2006). Internal consistency data were not provided and inter-rater reliability was reported as low for the behaviors observed relative to pain ($\text{Kappa} \leq .40$). This limited data indicates poor reliability of the FLACC as a tool to measure pain in cognitively impaired nursing home residents. Despite the lack of data supporting the use of the FLACC for the assessment of pain in persons with dementia, the measure is widely used for this population in clinical practice (Herr, Bjoro, & Decker, 2006).

Physiological measures of pain expression. For the purpose of this study, heart rate and *systolic* blood pressure were the measurements for physiological signs of pain expression. It has been well documented that the autonomic nervous system is influenced by painful stimulation (Colloca, Benedetti, & Pollo, 2006). Colloca and colleagues (2006) reported that increases in heart rate have been investigated and used, especially in infants, as indicators for the presence of pain. In their study utilizing an electrical stimulus to elicit pain in healthy adults to investigate the reliability of the heart rate response to pain Colloca and colleagues (2006) found the heart rate response (e.g. heart rate increases) to have high re-test reliability since the painful stimulus induced similar heart rate changes across three painful sessions ($r = .678$ and $r = .598$, $p < .001$ respectively when session 1 was compared to 2, and session 2 to 3, and $r = .503$, $p < .005$ when session 1 was compared to session 3). In other words, the pain response across three separate sessions of painful stimuli resulted in accelerated heart rates. Li, Puntillo, and Miaskowski (2008) reported a study in which significant correlations were found between behavioral indicators of pain, physiological indicators of pain, including heart rate and blood pressure, and pain intensity measures as assessed by bedside nurses ($p < .05$). This supported convergent validity of physiological measures of pain intensity in conjunction with other measures of pain

intensity. These authors did not describe how blood pressure was measured. Though a review of the literature supports the use of changes in heart rate and blood pressure as sensitive and valid indicators of pain across several populations, healthy and critically ill (Li et al., 2008), it is unclear how “blood pressure” (e.g. systolic versus diastolic, versus pulse pressure) has consistently been defined.

Pain assessment

Pain assessment was operationalized as the *number* of nurse-based pain assessment recordings of WBFP-S scores, FLACC scores, and HR and SBP measurements during the 24 hour study period. These are the same tools that were used to measure the concept of pain expression, and have been described.

Pain management

Pain management was operationalized as the amount and types (e.g. opioid versus non-opioid) of analgesic medications *prescribed* and *administered* during the 24 hours following the first pain assessment recorded in the nurses’ notes following admission for acute hip fracture.

The Medication Administration Record (MAR) served as the document where medication prescription and administration is tracked during each patient’s hospitalization, and thus served as the tool from which to collect the analgesic medication data used for this study.

A medication form was designed for this study in order to capture detailed data regarding pain medication prescription and administration. This included the name of the medication, dosage, route, frequency, and whether or not the medication was ordered as a routine medication (to be given at pre-designated intervals), or on an “as needed” basis (to be given based on patient request). The study form was structured to capture the times the dosages were given on an hourly basis, for up to 24 hours. Additionally, analgesic medications were placed into categories based on opioid properties. In order to standardize the amount of analgesic medication prescribed and

administered, dosages were standardized to reflect equi-analgesic dosages by converting all analgesic medications to acetaminophen equivalents. The procedure for this is described in detail in the “procedures” section below.

Covariates

Age: Age was calculated based on number of years and months from the date of birth. This was captured from the face sheet in the medical record.

Sedation: For the current study, sedation was chosen as a covariate given the potential effects on the outcome variables. Sedation is well known to affect the ability to communicate and may be implicated in poor pain assessment and either over- or under-management of pain. The measurement tool within the Baptist System utilized to capture levels of sedation is the Modified Ramsay Scale of sedation. . The Modified Ramsay Scale (Figure 3-4) is the instrument utilized by the Baptist Health Care System to measure levels of sedation. A description of the tool is below.

The Modified Ramsay Sedation Scale (Ramsay Scale) is an ordinal scale of 1 to 6, where the lowest score represents agitation, and each increasing score represents varying degrees of cooperation and responsiveness. The highest score, 6, represents no response. The Ramsay scale has been utilized over several decades to rate level of sedation in the hospital setting. The Ramsay scale has been reported to demonstrate reliability ($r = .87, p < .0001$) and validity ($r = .091, p < .0001$) (De Jonghe et al., 2000). Measures of internal consistency were not found. Though the Ramsay Scale is a widely accepted scale for the evaluation of the extent of sedation, it should be noted that the presence of multiple reasons for altered level of consciousness, such as infection, fever, and encephalopathy, beyond sedating medications can adversely affect the interpretation of this scale.

Modified Ramsey Sedation Scale	
1	Patient is anxious and agitated or restless, or both
2	Patient is cooperative, oriented, and tranquil
3	Patient responds to commands only
4	Patient exhibits brisk response to light glabellar or loud auditory stimulus
5	Patient exhibits sluggish response to light glabellar or loud auditory stimulus
6	Patient exhibits no response

Figure 3-4: Modified Ramsay Scale

Co-morbidities: The sum of co-morbidities was utilized in the study analysis as a covariate in order to control for the effect of co-morbidities on the outcome variables. It has been estimated that the majority of elderly persons living in the community will have four or more coexisting medical conditions (Loeng, Farrell, Helme, & Gibson, 2007). Both dementia and the presence of multiple co-morbid medical conditions occur in increasing frequency with advancing age (Sanderson et al, 2002). The increase in chronic medical conditions in older adults is associated to the high prevalence of pain in this population (Horgas & Tsai, 1998). Loeng and colleagues (2007) reported an association between an increasing burden of co-morbid conditions and an increase in verbal reports of pain intensity ($p < .05$), based on their retrospective study of 565 community-dwelling elderly adults. Additionally, the presence of dementia which complicates medical management of diseases, and which complication extends to the acute care setting, may reduce the likelihood of receiving optimal medical management (Schubert et al., 2006). For the current study, a co-morbidity data collection form was designed and used to capture co-morbidities by body system.

Procedures

Institutional Review Board approval for this study was obtained from the University of Florida IRB 01 and the Baptist Medical Center Institutional Review Committee. This

retrospective chart review was granted expedited review since there were no human subjects enrolled, and all data gathered was de-identified. Because patients' medical records were being accessed, strict adherence to HIPAA regulations and University of Florida Health Science Center SPICE (Security Program for the Information and Computing Environment) requirements were followed. Data security procedures are described in the data collection section below.

Procedures for Matching the Comparison Group of Persons without Dementia

Matching for gender, race, age, and location was performed partly by the clinical effectiveness department through a database query and partly by the principal investigator of this study through manual efforts when reviewing medical records for inclusion into the study. The database query supplied a list of medical records for the study group as well as a list of records for the comparison group selected by diagnosis codes, as discussed, and by gender, race, age, and hospital location. Once a medical record was found to be eligible for the study group of persons with dementia, medical records from the list of those supplied for the comparison group were reviewed and matched to each of the confounding variables.

Procedures for Data Collection

Once IRB approval was obtained in February of 2010, data collection began and continued until April. All data were collected by the principal investigator of this study. Data collection forms were developed and prepared for coding prior to study initiation. Patient records that were identified by the clinical effectiveness department were supplied to the investigator once the IRB approval letter was provided to the department. The list of records was supplied to the investigator electronically through the Baptist System e-mail, which ensures privacy protection through HIPPA regulations.

Data gathering occurred via electronic medical records when available, or from hard copies supplied to this investigator by the medical records department once approval letters were

submitted. All records were reviewed on site at the appropriate Baptist facility. Data were gathered for a 24 hour period beginning with the initial documented pain assessment score on either the WBFP-S or the FLACC following admission for acute hip fracture.

Demographic data collected including age, gender, race, hospital location, and marital status were collected from hospital “face sheets.” Pain expression and pain assessment data were collected from the nursing records, and pain management data were collected from medication administration records. Sedation scores were collected from the nursing records. Co-morbidity data was gathered from history and physical documentation.

Missing Data

Missing data estimation procedures were not used in this study due to the potential for biasing data based on likelihood estimates, given the large amount of missing data. Instead, the actual data were used because the aim of the study was to examine actual clinical practice.

Procedures for Conversion of Analgesic Dosage Amounts to Acetaminophen Equivalents

Analgesics were classified as either opioid, or non-opioid based on the presence or absence of opioid receptor binding properties (e-Pocretes, n.d.). As adapted from a previous study by Hargas & Tsai (1998), analgesics were converted to acetaminophen equivalents in order to facilitate accurate comparisons between the groups studied. This method was previously utilized in a study of nursing home residents in which the researchers investigated the relationship between cognitive impairment and use of analgesic medications (Hargas & Tsai, 1998). Fisher and colleagues (2002) later adapted this method of converting analgesic medications to acetaminophen equivalents in their study of pain assessment in cognitively impaired nursing home residents.

For the purpose of this study, equi-analgesic conversion information was utilized to convert non-opioid and opioid analgesic medications to acetaminophen equivalents. In order to

account for those analgesic medications that could not be directly converted to acetaminophen equivalents, approximate equivalents between morphine and acetaminophen were calculated based on a codeine conversion mechanism used in prior studies (Hargas & Tsai, 1998). Where medication conversion data were not available due to the current study having a large number of intravenously administered medications, conversions were first made to an oral equivalent as outlined by the American Academy of Hospice and Palliative Medicine (2009) and the Family Practice Notebook (2010). Once converted to an oral equivalent dosage, the conversion to acetaminophen equivalents was possible utilizing the conversion table as described above. Although it is ordinarily used for disease management and prevention, Aspirin was included in the standardization due to its analgesic properties.

Procedures for Data Security

Subject medical records were assigned an identification number, and once the data were gathered, there was no way to associate data to a particular patient. No personal identification information was kept in paper format. Further protection of personal health information was done via the use of an encrypted computer that was password protected. In order to access computerized patient information, an additional password had to be utilized.

Ethical Considerations

This study population consisted of hospitalized elderly adults with and without dementia, a vulnerable population. This study conferred minimal risk to the subjects whose medical records were reviewed. Any risk would have pertained to the loss or exposure of personal identifying and personal health information. Data protection measures to protect this vulnerable population were described above.

Statistical Analysis

Data were coded and entered into an SPSS database as categorical and numeric variables based on appropriateness for each variable. Descriptive statistics were utilized to examine sample characteristics and categorical variables. For continuous variables, descriptive statistics included means, ranges, maximums, minimums and standard deviations. Results were considered statistically significant with a *p*-value of less than .05. The statistical analysis for each research question is described.

Research Question 1

Among hospitalized older adults with hip fracture, does pain expression (e.g. verbal, non-verbal, and physiological pain intensity ratings) differ between persons (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified?

Research Question 2

Among hospitalized older adults with hip fracture, are there differences in pain assessment (e.g. the number of documented nurse-based assessments) between persons (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified (by dementia subtype)?

To address research questions one and two, examining differences in pain expression between persons (a) with and without dementia, and (b) by dementia sub-type, analysis of variance controlling for mean age, and the sum of co-morbidities was performed.

Research Question 3

Among hospitalized older adults with hip fracture, does pain management (e.g., the amount and type of analgesics *prescribed* and *administered*) differ between elderly persons (a) with and without dementia and (b) with Alzheimer's disease compared to dementia, non-specified?

Analysis of variance controlling for mean age and the sum of co-morbidities was also utilized to address the hypotheses examining differences in pain medications *prescribed* and *administered* between (a) persons with and without dementia and (b) persons with Alzheimer's disease and dementia non-specified. To examine differences in the type of analgesics prescribed and administered between these groups, analgesic medications were classified into two categories – opioid and non-opioid medications for comparison. Pearson's chi-square was applied to examine differences in opioid medications *prescribed and administered*.

Research Question 4

Do pain expression and pain assessment predict pain management in older adults with hip fracture, and does (a) dementia status or (b) dementia subtype influence this relationship?

Multiple linear regression with covariates, mean age and sum of co-morbidities, was utilized by performing three separate models. The predictor variables were entered into the model based on forward selection. In the first model, pain expression and pain assessment were regressed on pain management. Then, the model was repeated with the addition of dementia status. Finally, pain expression, pain assessment, and dementia subtype were regressed on pain management.

CHAPTER 4

RESULTS

This study examined differences in pain expression (verbal, non-verbal, and physiological pain intensity ratings), pain assessment (number of documented nurse-based assessments), and pain management (analgesics *prescribed* and *administered*), in hospitalized elderly persons with and without dementia and by dementia subtype. This study also examined pain expression and pain assessment as predictors of pain management, and how these relationships were influenced by (a) dementia status and (b) dementia subtype.

Results

The questions and findings are reported below. In order to clearly report the results, the sections are separated by outcome variable, and discussed first, by dementia status, and second, by dementia subtype. The questions are restated for clarity of the findings. First, the distributional characteristics of the variables are briefly discussed.

Distributional Characteristics of Variables

Data were evaluated to examine the distributional characteristics of the variables. The dependent variables were found to be mildly asymmetrically distributed with a right skewed deviation. The ANOVA statistic is a robust test in the presence of non-normally distributed data. The assumption of homogeneity of variance revealed non-significant results across the sample, with the exception of worst pain intensity measures (Levene's statistic $p < .05$). Examining the data for regression analyses revealed that multicollinearity was not detected between the predictor variables. The assumption of independent errors was also met.

Pain Expression, Assessment, and Management

The measurement tools for the verbal, non-verbal, and physiological measures of pain expression included the WBFP-S, as a measure of verbal pain expression, the FLACC as a

measure of non-verbal pain expression, and HR and SBP, as physiological indicators of pain.

The data revealed that the only useful measurement of pain expression was the WBFP-S, which measured verbal reports of pain intensity. The measures for non-verbal (e.g. FLACC) and physiological (e.g. HR and SBP) measures of pain expression were found not to be useful indicators of pain in this study.

As illustrated in Table 4-1, only 39 subjects had non-verbal pain expression scores recorded based on the FLACC pain assessment tool, and those records that did reflect FLACC scores had an average of less than one recording during the 24 hours studied. Additionally, based on the mandate by JCAHO that pain assessment be documented as the “fifth vital sign” (Phillips, 2000), and unit requirements that vital signs occur at baseline, and routinely thereafter (every 4 hours for most non-ICU units), it would have been expected that simultaneous recordings of pain, heart rate and blood pressure would have occurred approximately 6 times per 24 hours. This was not found to be the case. On average there were only 2.7 simultaneous recordings of heart rate and systolic blood pressure with pain intensity per medical record. Almost 40% of the medical records had only one or no simultaneous recordings.

The measurement tool for sedation, which was to be used as a covariate in the study, was also found to be an inadequate measurement tool for this study. Documentation reflecting use of the Ramsay Sedation Scale by bedside nurses was found in only 38% of the medical records, with an average of 1 recording per record during the time period studied (Table 4-1).

Table 4-1. Number of documented recordings for each measure during the 24 hours of the study (N = 135)

	M	n (%)	Range
WBFP-S	4.5	132(98)	0 – 12
FLACC	.63	39(29)	0 – 7
HR/SBP with WBFPs	2.7	116(86)	0 – 7
Ramsay	1.1	51(38)	0 – 7

Verbal Pain Expression. The first 24 hours following the initial recording of pain in the medical record was utilized for the analysis. Average, least, and worst pain intensity, based on nurses' recordings of verbal reports of pain based on WBFP-S scores represent verbal pain expression.

Research Question One

Among hospitalized older adults with hip fracture, does pain expression (e.g. verbal, non-verbal, and physiological pain intensity ratings) differ between persons (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified?

Verbal pain expression in persons with dementia compared to persons without dementia

Differences in average, least, and worst pain intensity between persons with and without dementia were examined using Analysis of Variance. Least and worst pain intensity scores for persons with and without dementia ranged from 0, reflecting no pain, to 10, reflecting worst pain, for both groups. As demonstrated in Table 4-2, differences in worst pain intensity scores were statistically significant between persons with and without dementia [$F(1, 127) = 8.4, p = .004$]. Though the results reflect that there was no statistically significant difference in mean pain intensity, the trend reflected that persons without dementia, on average, had worse pain intensity compared to persons with dementia ($p = .058$). There were no significant differences in average [$F(1, 127) = 3.4, p > .05$] and least [$F(1, 127) = .004, p > .05$] pain intensity scores between persons with and without dementia.

Table 4-2. Analyses of Variance for Differences in Pain Expression Between Persons with and without Dementia Controlling for Mean Age and Sum of Co-morbidities

	PWD		PWOD		$F(1, 127)$	p
	M	SD	M	SD		
Mean Pain Intensity	3.9	2.4	4.6	2.1	3.7	.058
Least Pain Intensity	1.7	2.5	1.8	2.3	.004	.958
Worst Pain Intensity	6.4	3.2	7.8	2.4	8.3	.005

Verbal pain expression in persons with Alzheimer's disease compared to persons with dementia non-specified

Differences in average, least, and worst pain intensity between dementia subtypes were also examined using Analysis of Variance. The range of pain intensity scores for persons with AD was 0 to 8, while for persons with dementia non-specified had scores ranging from 0 to 10. Least pain intensity scores differed significantly between the dementia subtypes [$F(1, 65) = 4.38, p = .040$], with the group of dementia non-specified having lower least pain intensity scores compared to the group of AD (Table 4-3). Differences in average pain intensity between the dementia subtypes were not statistically significant [$F(1, 65) = 1.7, p > .05$] as were differences in worst pain intensity [$F(1, 65) = .046, p > .05$].

Table 4-3. Analyses of Variance for Differences in Pain Expression Between the Dementia Subtypes Controlling for Mean Age and Sum of Co-morbidities

	AD		DemNOS		$F(1, 65)$	<i>P</i>
	M	SD	M	SD		
Mean Pain Intensity	4.3	2.4	3.4	2.2	1.7	.201
Least Pain Intensity	2.2	2.7	0.9	1.7	4.38	.040
Worst Pain Intensity	6.4	3.0	6.3	3.6	.046	.830

Research Question Two

Pain Assessment. Among hospitalized older adults with hip fracture, are there differences in pain assessment (e.g. the number of documented nurse-based assessments) between persons (a) with dementia and without dementia and (b) with Alzheimer's disease compared to dementia non-specified (by dementia subtype)?

Pain assessment in persons with dementia compared to persons without dementia

Differences in pain assessment between persons with and without dementia were analyzed using Analysis of Variance. The maximum number of nurse-based documentations of verbal pain intensity during the 24 hours studied for the entire sample ($N = 135$) was 12 out of 24 potential recordings (Table 4-4). On average nurses recorded pain intensity five times during the

study period. Persons without dementia had more nurse-based assessments recorded ($M = 5.4$, $SD = 2.5$) compared to persons without dementia ($M = 3.7$, $SD = 2.2$) (Table 4-2), which was statistically significant ($F(1, 130) = 17.44, p = .000$).

Table 4-4. Analyses of Variance for Differences in Pain Assessment Between Persons with and without Dementia Controlling for Mean Age and Sum of Co-morbidities

	PWD (72)		PWOD(63)		$F(1, 130)$	p
	M	SD	M	SD		
Number of Nurse Based Pain Assessments	3.7	2.2	5.4	2.5	17.44	.000

Pain assessment in persons with Alzheimer's disease compared to persons with dementia non-specified

Differences in pain assessment between the dementia subtypes were analyzed using Analysis of Variance. Persons with dementia non-specified had, on average, more nurse-based pain assessment recordings than person with Alzheimer's disease (Table 4-5). However, this finding was not statistically significant between the groups.

Table 4-5. Analyses of Variance for Differences in Pain Assessment Between Dementia Subtypes Controlling for Mean Age and Sum of Co-morbidities

	AD(45)		DemNOS(23)		$F(1, 68)$	p
	M	SD	M	SD		
Number of Nurse Based Pain Assessments	3.5	2.1	4.2	2.4	1.32	.254

Research Question Three

Pain Management. Among hospitalized older adults with hip fracture, does pain management (e.g. the amount and type of analgesics *prescribed* and *administered*) differ between elderly persons (a) with and without dementia and (b) with Alzheimer's disease compared to dementia non-specified?

Pain management in persons with dementia compared to persons without dementia

Differences in the amount of pain medication prescribed and administered between persons with and without dementia were analyzed using Analysis of Variance. Ninety-nine

percent of the medical records examined reflected prescriptions for analgesic medications – 2 medical records did not reflect that any pain medications had been ordered. Additionally, the vast majority (94%) of patients were prescribed pain medications on an “as needed” basis (generally based on patient request) with only 8 patients having orders for regularly scheduled (routine) analgesics. Of those with regularly scheduled pain medications, half were for persons without dementia and half for persons with dementia.

Table 4-6 illustrates differences in mean acetaminophen equivalents *prescribed* and *administered* between persons with dementia, and persons without dementia. Overall, persons without dementia were *prescribed* and *administered* more pain medications compared to persons without dementia, though the difference for analgesics *prescribed* was not statistically significant [$F(1, 130) = 2.70, p > .05$]. There were significant differences between the two groups in the amount of acetaminophen equivalents *administered* [$F(1, 130) = 5.70, p = .018$].

Table 4-6. Analyses of Variance for Differences in Mean Acetaminophen Equivalents Prescribed and Administered Between Persons with and without Dementia Controlling for Mean Age and Sum of Co-morbidities

	PWD Mean (SD)	PWOD Mean (SD)	$F(1, 130)$	p
Aceta Prescribed	12331 (10595)	16863 (20077)	2.70	.246
Aceta Admin	2735 (3053)	4078 (3392)	5.70	.018

Examining the records for types of analgesic (opioid versus non-opioid) medications *prescribed* and *administered* revealed that almost all (96%, n = 130) of the medical records (n = 135) reflected prescriptions for only opioid analgesics. Only 16 (12%) medical records reflected prescriptions for *both* opioid and non-opioid medications, with the option for the nurse to choose which type to administer. Of the records reflecting that opioids had been prescribed, 88% (n=117) reflected that they were actually administered. Since most records reflected orders for

opioid medications, Pearson's chi-square was utilized to examine the difference in opioid medications *prescribed* and *administered* between the study groups.

As reflected in Table 4-7, there were no significant differences in opioid analgesic medications *prescribed* ($\chi^2(1) = 1.48, p > .05$) or *administered* ($\chi^2(1) = 1.9, p > .05$) and whether or not dementia was present.

Table 4-7. Differences in Opioids by Dementia Status

	PWD (n=72)		PWOD (n= 63)		$\chi^2(1)$	<i>p</i>
	<i>n</i>	%	<i>n</i>	%		
Prescribed						
Yes	68	94	62	98	1.48	.223
No	4	6	1	2		
Administered						
Yes	59	82	58	92	1.9	.169
No	13	18	5	8		

Pain management in persons with Alzheimer's disease compared to persons with dementia non-specified

Differences in the amount of pain medication prescribed and administered between the dementia subtypes were analyzed using Analysis of Variance. Table 4-8 illustrates differences in mean acetaminophen equivalents *prescribed* and *administered* between the dementia subtypes. No statistically significant differences were found in the mean amount of acetaminophen equivalents *prescribed* or *administered* between persons with Alzheimer's disease compared to persons with dementia non-specified.

Table 4-8. Analyses of Variance for Differences in Mean Acetaminophen Equivalents Prescribed and Administered Between Dementia Subtypes Controlling for Mean Age and Sum of Co-morbidities

	AD	DemNOS	<i>F</i> (1, 67)	<i>p</i>
	Mean (SD)	Mean (SD)		
Aceta Prescribed	12299 (10963)	12397 (10019)	.031	.861
Aceta Admin	2782 (3139)	2639 (2934)	.167	.684

Though 94% of the medical records of persons with dementia had opioid medications prescribed, only 82% actually reflected that they were administered. This was reflected in Table 4-7.

Table 4-9 reflects the results utilizing chi-square statistics to investigate differences in opioid medication *prescribed* and *administered* between the dementia subtypes. This analysis revealed no significant differences between the dementia subtypes in opioid medications *prescribed* ($\chi^2 = 3.6, p > .05$) or *administered* ($\chi^2 = 1.47, p > .05$), though people with dementia non-specified tended towards lower numbers of opioids prescribed compared to persons with AD ($p = .057$). Eleven medical records for the dementia subtype group reflected only the administration of non-opioid analgesics.

Table 4-9. Differences in Opioids by Dementia Subtype

	AD(49)		DemNOS(23)		$\chi^2(1)$	<i>p</i>
	<i>n</i>	%	<i>n</i>	%		
Prescribed						
Yes	48	98	20	87	3.6	.057
No	1	2	3	13		
Administered						
Yes	42	86	19	74	.11	.746
No	7	14	6	26		

Research Question Four

Do pain expression and pain assessment predict pain management in older adults with hip fracture, and does (a) dementia status or (b) dementia subtype influence this relationship?

A regression analysis was conducted to examine the influence of pain expression and pain assessment on pain management. In the first model, pain expression and pain assessment were regressed on pain management. There were no significant bivariate relationships for any of the variables included in the first model. The model was then repeated with the addition of dementia status. Examining bivariate relationships for the second model revealed a significant relationship between dementia status and pain assessment ($p < .001$), such that persons with

dementia had significantly fewer nurse-based recordings of pain. Finally, pain expression, pain assessment, and the subgroup of Alzheimer's disease and dementia non-specified were regressed on pain management ($n = 72$). There were no significant bivariate relationships between the predictor variables in this final model. The covariates, mean age and sum of co-morbidities, were added into each model – age was found to be significantly associated with pain assessment, such that as age increased, the frequency of nurse based assessments decreased.

The predictors in both the first and second models accounted for 25% of the variance in pain management, and the relationships between pain expression and pain assessment did not change when dementia status was added to the model. As reflected in Table 4-10, both pain expression and pain assessment significantly ($p = .001$ and $p = .000$, respectively) influenced pain management for the overall sample ($N = 135$).

Table 4-10. Regression Analysis Summary for Variables Influencing Pain Management Controlling for Mean Age and Sum of Co-morbidities ($N=135$)

Variable	B	SE B	B	t	p
Pain Intensity	401.73	114.66	.28	3.50	.001
Number of Nurse-Based Pain Assessments	421.33	106.90	.31	3.94	.000

Table 4-11 demonstrates that when dementia status was added as a predictor variable, pain expression and pain assessment still had a statistically significant influence on pain management ($p = .001$). Dementia status, on the other hand, did not influence these relationships and did no influence pain management ($p > .05$).

Table 4-11. Regression Analysis Summary for Variables Influencing Pain Management, Including Dementia Status, Controlling for Mean Age and Sum of Co-Morbidities

Variable	B	SE B	B	t	p
Pain Intensity	390.62	116.32	.27	3.36	.001
Number of Nurse Based Pain Assessments	399.21	112.91	.30	3.54	.001
Dementia Status	-337.52	542.73	-.051	-.62	.535

The model was run a third time to examine the influence of the subgroup of persons with Alzheimer's disease and dementia non-specified (dementia subtypes), on the relationship

between pain expression and pain assessment, on pain management. The results of this regression demonstrated that when the subset of dementia subtypes were added to the model, with pain expression and pain assessment, there was no longer a relationship between any of the predictor variables and pain management (Table 4-12). These predictor variables together accounted for only 10.6% of the variance in pain management.

Table 4-12. Regression Analysis Summary for Variables Influencing Pain Management, Including Dementia Subtypes, Controlling for Mean Age and Sum of Co-Morbidities(n = 72)

Variable	B	SE B	B	t	p
Pain Intensity	271.76	161.86	.21	1.68	.098
Number of Nurse Based Pain Assessments	160.25	183.01	.11	.88	.385
Dementia Subtype	-307.21	815.50	-.05	-.38	.708

CHAPTER 5 DISCUSSION

This study examined differences in pain expression, pain assessment, and pain management between persons with and without dementia, *and* between persons with Alzheimer's disease compared to persons with dementia non-specified (e.g. dementia subtypes). The results revealed several significant findings. Beginning with pain expression, as measured by self-reported pain intensity scores, persons with dementia had significantly lower worst pain intensity scores ($M = 6.4$) compared to persons without dementia ($M = 7.8$) ($p = .005$). Interestingly, there were no significant differences in least pain intensity scores. This reflects that when pain was at its worst for persons with dementia, it was lower than when pain was at its worst for persons without dementia, despite having experienced the same acute painful condition – e.g. acute hip fracture. In contrast, when their pain was at the lowest level of severity, it did not differ significantly from persons without dementia. Finally, though not statistically significant, the average pain intensity for persons without dementia, tended to be higher than persons with dementia ($p = .058$). It can be assumed that these pain intensity scores represent what patients reported to nurses. Therefore, this is a reflection of what has consistently been demonstrated in the literature – that persons with dementia report less pain than their cognitively intact counterparts (Horgas et al., 2009; Bjoro & Herr, 2008) and that this carries over from the outpatient settings where these findings have been robust, to the hospital setting.

With regards to pain expression in persons with Alzheimer's disease compared to dementia non-specified, the latter group reported significantly lower least pain intensity scores ($M = 0.9$) compared to persons with Alzheimer's disease ($M = 2.2$) ($p = .040$). This finding may reflect differences in the ability to report pain severity, or may reflect differences in the pain experience between persons with different types of dementia. Studying differences in pain

expression between persons with different types of the disease is an area that has not yet received much attention. Yet, given these differences, even though they only reflected differences in least pain intensity, consideration needs to be given to the possibility that dementia-specific damage to pain pathways leading to the perception and expression of pain may be an explanation for these differences.

With regards to pain assessment, reflected by the number of nurse-based documentations of pain, this study found a highly significant difference between persons with and without dementia ($p = 0.00$). Persons without dementia had their pain assessed significantly more often compared to those with dementia. There are several possible explanations for this finding. Persons with dementia may have difficulty expressing pain verbally, and may exhibit pain behaviors that are not recognized by the nurse as indicators of pain. Additionally, persons with dementia may experience pain differently, and therefore have difficulty discerning the type of discomfort they are feeling. However, regardless of the reasons for the discrepancy in the number of pain assessments between persons with and without dementia, this finding supports the growing body of literature that pain assessment in the hospital setting is inadequate (Herr et al., 2004). It should be noted that there was no significant difference in the number of nurse-based pain assessments between the dementia subtypes.

. Interestingly, analysis of pain management revealed no significant differences in the amount or type of analgesics *prescribed* between any of the groups. This finding reveals that healthcare providers did not significantly alter their prescribing patterns based on the presence or absence of dementia, or by dementia subtype. It should be noted, however, that although the difference in acetaminophen equivalents *prescribed* between persons with and without dementia was not statistically significant, there was a trend in the data such that persons without dementia

were *prescribed* more than 1/3 higher amounts of acetaminophen equivalents compared to persons with dementia. These findings of no significant differences in pain medications prescribed, however, are in contrast to previous findings that demonstrated significant differences in *both* the amounts of analgesics prescribed *and* administered (Horgas & Tsai, 1998).

It should also be noted, that although there were no significant differences in whether or not opioids were prescribed or administered between the groups, persons with dementia non-specified tended towards lower numbers of *prescribed* opioids compared to persons with Alzheimer's disease, though this was not statistically significant ($p = .057$). Though the reason for this is not clear, and the sample size of persons with dementia non-specified was small, it can be postulated that this was secondary to age, as this group of PWD had an average age of 88, which was higher than the average age of persons with AD ($M = 85.2$).

Pain management relative to the *administration* of analgesic medications revealed different results. Persons without dementia received almost 50% more pain medication compared to their demented counterparts following acute hip fracture. This difference was statistically significant [$F(1, 131)$, $p = .018$]. Given the lack of empirical evidence in the literature that persons with dementia experience less pain (Horgas et al., 2009), the findings in the current study support the prospect that there is a failure to recognize the presence of pain and/or its severity in persons with dementia, subsequently leading to its under-treatment in this population.

There were no significant differences in the amount of analgesics *administered* between the dementia subtypes. This is interesting given the differences in self-reported least pain intensity scores. So, persons in the dementia non-specified group were administered equivalent amounts of analgesics despite lower least pain intensity scores compared to persons with

Alzheimer's disease. Given that there were no significant differences in the number of times nurses recorded pain between these subtypes, this may reflect that pain medication is administered when pain is assessed regardless of the pain intensity reported by the patient.

Finally, the findings demonstrated that, both pain expression and pain assessment had a significantly positive influence on the administration of pain medications. This means that overall, when pain was expressed and assessed pain medication was administered. Interestingly, when dementia status was included as a predictor variable, pain expression and pain assessment still had a significant influence on pain management, however dementia status did not influence this relationship, nor did it influence pain management. This is interesting given the findings of statistically significant differences in the amount of pain medication administered between persons with and without dementia. Could this reflect that nurses *are* basing the administration of pain medication on pain intensity and the frequency of reporting pain, regardless of the presence of dementia? This is encouraging if in fact nurses are treating pain based on severity. However, these findings, together with the discrepancies in pain expression, assessment, and management, should caution that this actually reflects a lack of understanding of how to assess and treat pain in persons with dementia. It is important to note that these variables together only accounted for 25% of the variance in pain management. This reflects that there are underlying variables that account for a large portion of the variance in the administration of pain medication that were not captured in this analysis and which could provide further clarity to these findings.

When the subset of persons with different types of dementia was used as a predictor variable with pain expression and pain assessment, the results demonstrated that none of these variables influenced pain management. Importantly, these variables only accounted for 10.6% of the variance in pain management. These findings are important because pain expression and pain

assessment *should* have an influence on pain management, and these findings reflected that this was not the case when dementia subtype was included as a predictor variable.

Significance of Findings

The results of this study reveal that persons with dementia continue to report lower levels of pain, have their pain assessed less frequently, and receive lower amounts of pain medications compared to their cognitively intact counterparts - even when experiencing the same acute painful event. This is a disturbing finding because this is consistent with findings that were reported as early as 1998 (Hargas & Tsai, 1998) in which persons with dementia were prescribed and administered significantly less pain medication compared to their cognitively intact counterparts. Given the amount of attention that has been given to developing multiple modalities to assess pain, and providing recommendations to facilitate pain assessment, it would have been expected that these findings would no longer exist. Herein lays the core of the significance of the current study findings. Additionally these findings lend support to the growing body of literature that these discrepancies occur in the acute care setting (Morrison & Siu, 2000).

The results of this study further underscore the importance of addressing previous recommendations to continue the pursuit of validating pain assessment tools that combine measurement strategies to include the various components of pain expression (Herr & Coyne et al., 2006). Where some persons may have difficulty communicating pain via verbal modalities, others may have difficulty providing non-verbal cues of pain expression.

The following is a more detailed discussion of the significance of the findings, and incorporates the pathology of dementia, first from within the context of the main study group of persons with and without dementia, and then from within the context dementia subtypes. Finally, the significance of the findings relative to the adapted theoretical model will briefly be addressed.

Significance of the Findings Relative to Pain Expression, Pain Assessment and Pain Management in Persons with and without Dementia

The findings of significant differences in verbal pain expression, pain assessment and pain management between persons *with* and *without* dementia may have been attributable to several factors. Multiple areas in the brain must work in concert to create a perception of pain followed by an expression of pain (Rainville, 2000). This is a consequence of the neuropathology of dementia, which progresses to declines in memory, and impairments in both language and abstract thought (Snow et al., 2004). The alterations in pain expression are likely the results of impairments in pain perception, including the sensory-discriminative, cognitive-evaluative, emotional-affective, and autonomic-neuro-endocrine components. The results of the current study demonstrating significant differences in pain severity scores between persons with and without dementia, specifically that persons *without* dementia had significantly more intense pain than persons with dementia, may reflect deficits in the cognitive-evaluative components of pain perception leading to the inability to insightfully interpret the level of pain, or the proper way to verbally express its severity. If there is damage to the sensory-discriminative aspects of pain expression, then lower verbal pain severity scores may reflect alterations in the pain experience, including the inability to localize and qualify pain, making it difficult to translate the experience verbally to a level of severity.

Significantly fewer nurse-rated pain scores in persons with dementia compared to persons without dementia may be a direct reflection of impairments in language centers of the brain or perhaps the cognitive-evaluative components of pain. Cognitive-evaluative deficits may lead to the inability to understand or interpret pain, or judge it to be important enough to verbally address. Deficits in language centers may lead to the inability to draw on the vocabulary necessary to verbally express pain. These scenarios would explain fewer pain assessments.

Unfortunately, fewer pain assessments may also reflect a lack of knowledge and/or skills among bedside nurses that the absence of pain reporting does not necessarily translate to the absence of pain. Though not a focus of the current study, it is important to note that on several occasions nursing documentation reflected changes in behavior, such as “agitation,” which was immediately followed by the administration of psychotropic medications that are frequently utilized to manage agitation in persons with dementia in the acute care setting. It is plausible that “agitation” was actually an expression of pain, yet the behavior was not recognized as a sign of pain by the bedside nurse.

With regard to current clinical practices and pain assessment, an important finding that is of great significance was the discovery that nurses are not in compliance with JCAHO standards for assessing pain. This finding is consistent with findings from a previous study (Herr et al., 2004) in which the number of pain recordings during the 72 hours post hospitalizations for acute hip fracture for both older adults with and without dementia was not in compliance with the JCAHO standards. The significance of this finding however, as related to the aims of this study are such that had nurses documented pain assessments per the JCAHO mandate, discrepancies in frequency of pain assessment recordings between persons with and without dementia may have been eliminated, and differences in pain expression might have been better clarified. Additionally, the question regarding potential differences in physiological expressions would have been investigated, since following the guidelines would have meant the consistent and simultaneous documentation of vital signs and pain. The significance of these findings from a grander perspective, though not directly related to the aims of this study, cannot be ignored. As it becomes clearer that pain is not being adequately assessed in the hospital setting, the

consequences of untreated pain will become an increasing burden, for patients, families, healthcare providers and the healthcare system.

It should be noted however, that guidelines are not a panacea for pain assessment. In fact, following guidelines for clinical practice, such as the JCAHO guidelines for routine assessment of pain, may actually mask the genuine underlying problems associated with infrequent documentation of pain assessment by actually leading to pain assessments that do not reflect the actual severity or presence of pain. Essentially, this can lead to paper compliance which may contribute to the mismanagement of pain by either over- or under-medication.

With regard to pain management, the findings in the current study showed that elderly adults with dementia receive significantly lower amounts of pain medication compared to their cognitively intact counterparts, despite the fact that both groups had suffered the same acute painful event. Acute hip fracture is associated with high amounts of pain (Morrison & Siu, 2000). Despite this knowledge however, the current study, like Morrison and Siu (2000), found that elderly persons with dementia, hospitalized for acute hip fracture, consistently receive lower amounts of pain medications. This study did however illustrate progress relative to pain management, in that there were no significant differences in the amount of analgesics *prescribed* between any of the groups. The issue, then, appears to be largely at the patient bedside.

Additionally, the influence of pain expression and pain assessment were found to be significant predictors of pain management, regardless of the presence or absence of dementia. The significant influence of pain expression and pain assessment on pain management is *not* surprising given that one would expect pain intensity and the frequency of pain assessments to determine the amount of pain medication administered. However, the lack of contribution to the model by dementia status is a question that remains. Additionally, that pain expression and pain

assessment together, and with the addition of dementia status only accounted for 25% of the variance in pain management, reflects the presence of other underlying variables that influence the administration of pain medication. It is possible that level of sedation, time of day, or patient request or refusal, contributed to the variance however, these were not captured in the analysis. This does not minimize however, the findings that persons with dementia report less pain, are assessed less frequently, and receive lower amounts of pain medications than persons who are cognitively intact.

Though the following finding does not represent a difference in pain management between persons with and without dementia, it is a disturbing finding and its significance is worth mentioning. Current analgesic prescribing practices revealed that only 8 medical records reflected prescriptions for regularly scheduled pain medications (e.g. every four hours), excluding Aspirin. This phenomenon was previously demonstrated in Morrison and Siu's (2000) study in which they noted that of their sample of 98 hip fracture patients, ¾ of the dementia group ($n = 38$) and almost 85% of the cognitively intact group did not have standing orders for routine analgesic medications. Instead, analgesic medications were ordered on an "as needed" (e.g. per patient request) basis, much like the current study. This is a reflection of the need to continue to educate health-care providers about pain management.

Significance of the Findings Relative Pain Expression, Pain Assessment and Pain Management in Persons with Different Types of Dementia

The results of this study, that persons with dementia non-specified had significantly lower least pain intensity scores compared to persons with Alzheimer's disease, support the concept that there are differences in verbal pain expression between persons with different types of dementia. The various components of pain expression, though intermingled may be more easily teased out when the dementias are sorted by type. Studies have been conducted that

establish pathological differences in the brains of persons with various types of dementia (Rabinovici, 2008). These differences may lead to differences in pain expression between persons with different types of the disease. This may be explained for example, by the preservation in persons with earlier Alzheimer's disease in the sensory-discriminative components of pain perception, thereby allowing persons with Alzheimer's disease to localize pain more effectively, and to verbally describe its location and presence. If there were an overwhelming number of persons with frontotemporal dementia in the group of persons with dementia non-specified, then impairments in the cognitive-evaluative components of pain perception might have resulted in poor insight and judgment into the need to verbally express pain to others. Additionally, if the language areas of the brain were impaired in the group of persons with dementia non-specified, as occurs in persons with FTD, then verbally expressed pain may not have been possible.

The findings that pain management was not significantly influenced by pain expression or pain assessment in the presence of dementia subtype is disturbing, since pain expression and pain assessment *should* determine pain management. These findings, in combination with the findings of no significant differences in pain assessment and pain medication administration between the subtypes may exemplify the lack of understanding of how to treat pain in persons with dementia, especially when differences between the subtypes may complicate the interpretation of pain by bedside nurses.

The examination of pain in different types of dementia is a relatively new area of investigation. Therefore these findings must be considered cautiously, as there are many factors that could have affected these results, including the small and unequal sizes of the dementia subtype groups.

Significance of the Findings Relative to the Adapted Theoretical Model of Pain Management

The aim of this study was not to test the adapted model but rather to use it as a conceptual guide. However, it is important to address the findings relative to the theory. Briefly, the model posits that following an acute painful event, pain is perceived, which is followed by pain expression, pain assessment, and ultimately pain management. The model also posits that dementia status effects pain expression. This theory, though not directly tested in the current study, is suggested based on the findings that there were discrepancies between pain assessment and pain management between persons with and without dementia. The findings that pain expression and pain assessment continued to impact pain management with the addition of dementia status as a predictor variable, yet the latter predictor did not influence pain management, supports that overall, pain management was influenced by pain expression and pain assessment regardless of dementia status. However, the prospect that dementia status effects pain expression was supported by the lack of any significant influence on pain management by pain expression or pain assessment in the presence of dementia subtype. One could hypothesize that the discrepancies in pain assessment and pain management between people with and without dementia, and the lack of impact of pain expression and pain assessment on pain management in the presence of dementia subtype, were due to the effect that dementia status has on pain expression.

Implications for Nursing

There are several important findings that have substantial implications for nursing. These findings revealed that nurses are recording significantly fewer pain assessments, and administering significantly less analgesic medications to persons with dementia compared to persons without dementia, in the context of an acute hip fracture. These findings, coupled with

existing literature raises ongoing questions regarding current clinical practices at the bedside. Finally, regardless of the differences in verbal pain expression scores between the groups of persons with dementia compared to those without dementia, and which may partly account for infrequent pain assessments in persons with dementia, nurses were not in compliance with JCAHO's mandate to assess pain as the "fifth vital sign." This has implications for hospital accreditation in addition to implications for nurses.

It is apparent that there is a need for additional nursing education regarding pain assessment and pain management in persons with dementia. For example, perhaps the results of this study actually reflect a discrepancy in the number of times pain was recorded versus the number of times pain was expressed. Additionally, if assessing pain in persons with dementia is difficult due to nurses' inability to differentiate pain in persons with dementia, then perhaps pain is being expressed as frequently, but not recognized as pain. This then, reflects a need to educate nurses regarding pain expression, assessment, and management in older adults with dementia. Given the ongoing research focusing on this area and on the development of pain assessment tools, it will be imperative to provide education on an ongoing basis. Education is also necessary to re-introduce JCAHO guidelines, as well as to educate regarding the medical, legal, and ethical implications of not treating pain.

Implications for Future Research

The findings from the current study highlight several important areas for future research. Nursing research should continue focusing on the discovery of nursing factors that affect pain assessment and management including the effect that pain expression in persons with dementia has on nurses' abilities to assess pain. Exploring these issues will include gaining insight into current nursing attitudes, beliefs and knowledge about how pain manifests in elderly persons with and without dementia, and what that means with respect to pain management, or the

administration of pain medications at the bedside. This would help to shed light on other variables that influence pain management above and beyond those tested in this study. Reasons for poor adherence to the JCAHO guidelines should also be investigated.

Several other areas of research can be recommended based on the current study. First, it is worthwhile to continue to investigate differences in pain expression between persons with and without dementia. Imaging studies of persons with dementia implicate various parts of the brain as being associated to various types of dementia. Developing a keen understanding of how these areas affect pain perception and pain expression can contribute important information to the refinement and/or development of pain assessment tools. Given the growing number of elderly and associated increases in the prevalence of pain (Davis & Srivastava, 2003) and dementia (Plassman et al., 2007), research investigating differences in pain expression in persons with dementia will become increasingly important and should be pursued with a sense of urgency. Though the findings from the current study did not clearly elucidate differences in verbal pain expression between the dementia subtypes, given the differences in the pathology of the dementias, and a suggestion in the current study that differences may exist, investigation into these differences should continue.

Importantly, the pursuit of research studying differences in pain expression is fraught with challenges, which have implications for research. First and foremost, dementia is under-recognized in the private setting (Valcour et al., 2000), and therefore methods of identifying research subjects with dementia will require educating private clinical settings about dementia, and diagnostic resources.

Further, the fact that there are different types of dementia has not led to consistency in diagnosing the type of dementia appropriately. In one study, subtype of dementia was only

recognized in approximately half of persons with dementia (VanHout, et al., 2000). The under-recognition of dementia, complicated by the under-recognition of dementia sub-type, has likely led to the inclusion of multiple types of dementia into the category of Alzheimer's disease, and similarly the inclusion of many types of dementia, including Alzheimer's disease into the category of dementia non-specified. This may have clouded the outcomes of the current study. As there are existing diagnostic criteria for many types of dementia, future research on pain expression in dementia should include diagnostic evaluations of dementia subtypes in order to accurately categorize the dementias into appropriate study groups. There is evidence that Alzheimer's disease has become easier to classify based on criteria for diagnosis and more advanced means of detecting Alzheimer's disease pre-mortem.

Study Limitations

There were several threats to the internal and external validity of the study, and therefore the sample could not be generalized to groups outside of the current setting. The current study utilized a retrospective design, which precluded any control over the tools utilized as outcome measures, and the methods in which data were collected at the bedside. The primary pain assessment tool utilized in this study as a measure of pain in persons with and without dementia was the self-reporting WBFP-S, and was modified by the Baptist Healthcare System from a five-point to a ten-point scale. The WBFP-S has not been studied for its psychometric properties as a 10-point scale, or in elderly people with dementia. This reduced the validity and reliability of the results of this study relative to verbal pain expression. Additionally, a potential bias inherent in the use of the WBFP-S could have been introduced as a result of the way the instrument was administered by bedside nurses.

The other tools intended for use as measures of pain expression, including the FLACC, and heart rate and systolic blood pressure were either found to be poorly documented or, as

should have occurred with vital sign assessments, not recorded simultaneously with recordings of pain. The inability to utilize these other pain expression measures had significant implications for this study. The inclusion in this study of additional pain expression measures could have helped to confer the reliability and validity of the tools utilized, thereby strengthening the results of this study. The amount of missing data was considered another limitation of this study which could have biased the results.

Additional limitations included the inability to draw strong conclusions based on the retrospective nature of the study. The purposively selected and assigned sample, and the potential for misclassification of a dementia diagnosis, could have biased the sample. This could have led to relationships between the independent and dependent variables that were over or under represented, if the groups were not affected equally.

Summary

In sum, the current study can contribute several meaningful things to existing literature and the current state of clinical practice. The differences in verbal pain expression between persons with and without dementia, and between the dementia subtypes, reminds us that there is an ongoing need to investigate how dementia can affect the pain experience. It is becoming increasingly evident that we must pay more attention to understanding these differences in a dementia-specific manner. Additionally, ongoing efforts via research and education pertaining to pain assessment and pain management must forge on in order to close the gap in the disparity in how nurses assess and treat pain in persons with dementia compared to persons without dementia. The negative consequences associated with untreated pain in combination with the growing prevalence of the elderly population and subsequently, the population of persons with dementia leaves no doubt that these areas must be addressed with a sense of urgency. As a first follow-up to the current study, the current investigator hopes to design a prospective study

examining differences in pain expression in persons with different types of dementia while incorporating nursing factors that influence the assessment and management of pain in persons with dementia.

APPENDIX PAIN ASSESSMENT MODEL

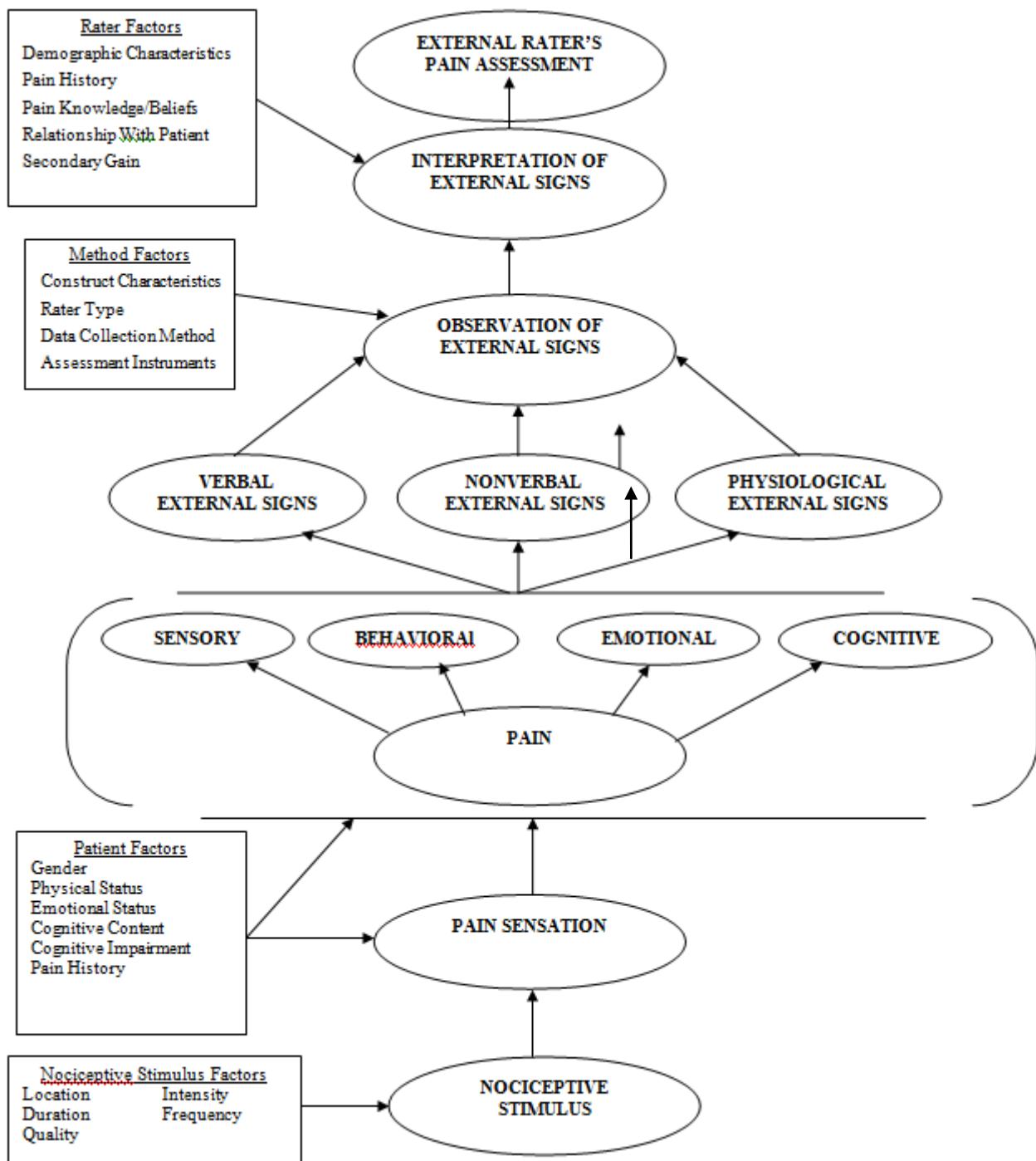


Figure A-1. Pain Assessment Model (Snow, et al., 2004)

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BIOGRAPHICAL SKETCH

Mindy Grall was employed in the pharmaceutical industry as a marketing research analyst for new investigational drugs until going on to pursue a degree in nursing. She graduated from the University of North Florida with her Bachelor of Science in nursing in 1997. She practiced as a registered nurse in a coronary care unit becoming a clinical research coordinator, for which she became professionally certified. As a clinical researcher, she coordinated clinical trials and monitored enrolled patients through each study. She went on to earn her Master of Science in nursing and her certification as an Advanced Registered Nurse Practitioner in 2004. Since that time, she has practiced in the field of neurology, both in the in-patient and out-patient settings, at Baptist Medical Center in Jacksonville, Florida. While earning her doctorate, she became increasingly involved in the neurological care of older adults, specifically those with cognitive impairments and dementia. Her minor course of study for her doctorate was gerontology.