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The Association Between Physiologic Sources of Pain and Sleep Quality in Older Adults and People with Dementia

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THE ASSOCIATION BETWEEN PHYSIOLOGIC SOURCES OF PAIN AND SLEEP
QUALITY IN OLDER ADULTS AND PEOPLE WITH DEMENTIA

by

Crystal-Rae Evans

A Dissertation Submitted in
Partial Fulfillment of the
Requirements for the Degree of

Doctor of Philosophy

in Nursing

at

The University of Wisconsin-Milwaukee

May 2018

ABSTRACT

THE ASSOCIATION BETWEEN PHYSIOLOGIC SOURCES OF PAIN AND SLEEP QUALITY IN OLDER ADULTS AND PEOPLE WITH DEMENTIA

by

Crystal-Rae Evans

The University of Wisconsin-Milwaukee, 2018
Under the Supervision of Professor Christine Kovach

The association between physiologic sources of pain and sleep quality in older adults and people with dementia was examined in this dissertation. Previous research illustrates multiple factors contribute to sleep quality outcomes. Musculoskeletal pain, respiratory distress, gastrointestinal discomfort, and genitourinary pain were examined in relation to sleep quality in older adults and people with dementia. No theory currently exists to guide this nursing research, therefore an illustration of pain and sleep quality in older adults and people with dementia was utilized. Descriptive data analysis and logistic regression were used to address the study aims. The findings from this research illustrate dementia, gender, pillow use, respiratory distress, and urinary retention were factors statistically significantly associated with nighttime sleep quality in older adults and people with dementia. Results from this study suggest comprehensive assessments of pain and sleep for older adults and PWD are needed. Future studies may include larger sample sizes with multiple different long-term care organizations using different payer sources. Research exploring factors associated with poor sleep and developing and testing of interventions that address these contributing factors may also improve sleep outcomes.

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Dedication Page

To family who are friends
and friends that are family,
you know who you are!

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CHAPTER 1

Introduction to the Chapter

This chapter presents a review of the current state of knowledge surrounding the factors associated with sleep quality in persons living with dementia (PWD). Several studies are examined that explore factors related to sleep quality in older adults and PWD. The term pain will be used synonymously with discomfort. Moreover, definitions of concept of sleep quality and pain will be presented in Chapter 2. Prevalence and significance of sleep problems as well as an introduction to the potential risk factors associated with poor sleep quality among older adults are described. Gaps in the literature are elucidated. The purpose of the proposed study is to a) describe diurnal characteristics of musculoskeletal, respiratory, gastrointestinal, and genitourinary discomfort in long-term care residents with dementia; and b) examine the association between physiologic sources of pain and sleep quality in older adults and a subset of PWD.

Factors Associated with Sleep Quality in People Living with Dementia: A Review of Literature

Introduction

Poor sleep quality is common in older adults and is particularly fragmented and impaired in people living with dementia (PWD), a major cause of reduced quality of life and a common reason for moving to a more restrictive living environment (Boeve, 2008; D'Aoust, Brewster, & Rowe, 2015; S. Kim, Oh, & Richards, 2014; Merrilees, Hubbard, Mastick, Miller, & Dowling, 2014; Rongve, Boeve, & Aarsland, 2010; Simpson & Carter, 2013). Although sleep changes are characteristic to the aging process, sleep dyssomnias are not considered a normal part of aging

(Zdanys & Steffens, 2015). Poor sleep quality affects anywhere from 25% to 80% of PWD and remains a problem even after moving to long-term care settings (Neikrug & Ancoli-Israel, 2010; Rongve et al., 2010; Roth, 2012). Normal aging changes include having a harder time falling asleep, nighttime awakenings due to physical function, as well as waking up earlier in the morning. According to the International Classification of Sleep Disorders, sleep dyssomnias include insomnias, sleep-related breathing disorders (obstructive sleep apnea), hypersomnias (narcolepsy), circadian rhythm sleep disorders (delayed sleep phase type and advanced sleep phase type), parasomnias, and sleep-related movement disorders (RLS and PLMD) (Thorpy, 2012). Older adults frequently have comorbid health conditions that can also effect sleep such as heart and lung disease, poor glucose tolerance, thyroid, gastrointestinal, and arthritis or pain related to health conditions (Figorilli, Puligheddu, & Ferri, 2015; Gitlin, Hodgson, Piersol, Hess, & Hauck, 2014; Monroe et al., 2014; Smolensky et al., 2015).

Disturbed and poor quality sleep can lead to significant negative health outcomes such as increased risk of falling and injury, physical and emotional distress, decreased quality of life, increased risk of placement in long-term care settings, and increased mortality (Greenblum & Rowe, 2012; Martin & Ancoli-Israel, 2008; Zdanys & Steffens, 2015). These negative outcomes are costly to the healthcare system (Alvarez Barbosa et al., 2016; Carroll, Slattum, & Cox, 2005; Stevens, Corso, Finkelstein, & Miller, 2006). Based on a review of fatal and non-fatal fall incidence rates, falls among all care settings were estimated to cost around \$34 billion per year in the United States (NCOA, 2017).

Causes of poor sleep quality are widespread, and include physical, psychiatric, cognitive, behavioral, environmental, and pharmacologic factors (Martin & Ancoli-Israel, 2008; Zdanys & Steffens, 2015). In particular, the medical factor of pain is associated with poor sleep quality

(Boeve, 2008; Q. Chen, Hayman, Shmerling, Bean, & Leveille, 2011; Martin & Ancoli-Israel, 2008; Neikrug & Ancoli-Israel, 2010; Roth, 2012). Pain has been associated with poor sleep quality in older PWD (Q. Chen et al., 2011; Flo, Gulla, & Husebo, 2014; Gitlin et al., 2014; Greenblum & Rowe, 2012; Harris, Richards, & Grando, 2012; Husebo, Ballard, Fritze, Sandvik, & Aarsland, 2014; Monroe et al., 2014). Specific sources of physical pain that relate to poor sleep quality in PWD have not been examined. In part, this may be related to the decreased cognitive ability to report pain or other needs in PWD (Flo et al., 2014).

Further investigation is warranted to understand the common sources of pain, such as pain stemming from the musculoskeletal, respiratory, genitourinary, and gastrointestinal systems, that relate to poor sleep quality. Understanding factors relating to physical comfort at night can lead to research on ways to improve sleep quality in older adults and PWD.

Prevalence and Significance

Evaluating poor sleep quality in older adults and those with dementia is imperative due to the inevitable nature of aging, increase in comorbid health conditions with age, and increase in PWD and negative consequences from poor sleep (CDC, 2006; Martin & Ancoli-Israel, 2008; Mazzotti, Guindalini, Sosa, Ferri, & Tufik, 2012; McPhee et al., 2016; Vitiello & Borson, 2001). Dementia is characterized by cerebral neurodegenerative changes. There are many forms of dementia such as Alzheimer's disease, vascular dementia, Dementia with Lewy Bodies (DLB), mixed, Parkinson's disease, frontotemporal, Creutzfeldt-Jakob disease, normal pressure hydrocephalus, Huntington's disease, and Wernicke-Korsakoff syndrome (Neef & Larson, 2008). In the United States the prevalence of Alzheimer's disease, the most common form of dementia, in older adults is expected to reach 7.1 million by 2025 and 11 to 16 million by 2050

(S. Kim et al., 2014). Dementia is a global health problem and currently affects an estimated 35.6 million people worldwide (Foltyn, 2015; Gitlin et al., 2014).

There is a high prevalence of pain in older adults. Nearly 40% of all older adults report that pain interferes with their activities of daily living (Monroe et al., 2014). Pain is recognized in 45-83% of long-term care residents including PWD (Monroe et al., 2014). In one study, 43% of older adults reported pain and 60% reported sleep problems at least once weekly (Gitlin et al., 2014). In a longitudinal study across multiple countries, 48.4% of people suffered from pain (range 19.8%-73%), whereas 45-80% (up to 83%) of long-term care residents had pain (Lukas, Mayer, et al., 2013). The existence of pain in PWD is not limited to the United States; pain is a global health problem.

Sources of pain in the literature are mainly identified as musculoskeletal pain, if any source is identified at all (Flo et al., 2014; Husebo et al., 2014). Only one study of community dwelling older adults was inclusive of other possible sources of pain such as, diabetes, neuropathy, peripheral artery disease, and lung disease (Q. Chen et al., 2011). As dementia progresses, the ability to verbally communicate pain is often compromised, complicating the task of recognizing and reporting pain (Flo et al., 2014; Monroe et al., 2014). Pain is under reported, under recognized, and consequently undertreated in PWD (Flo et al., 2014; Husebo et al., 2014; Lukas, Mayer, et al., 2013; Passmore & Cunningham, 2014). Specific sources of pain need to be recognized in order to treat and manage that pain and the associated sleep problems adequately.

Consequences of undermanaged pain in PWD may include exacerbations of neuropsychiatric symptoms such as agitation, aggression, negative mood, or depression (Flo et al., 2014; Gitlin et al., 2014; Husebo et al., 2014; Jaremka et al., 2014; Lukas, Mayer, et al., 2013; Passmore & Cunningham, 2014). Poorly managed pain may worsen sleep problems,

cognitive impairment, functional impairment, health conditions, immune system functioning, and quality of life (Q. Chen et al., 2011; Flo et al., 2014; Gitlin et al., 2014; Jaremka et al., 2014; Kovach et al., 2012; Lukas, Mayer, et al., 2013; Monroe et al., 2014; Passmore & Cunningham, 2014). Other consequences have been associated with increased risk of fractures, falls, pressure ulcers, number of drugs, and changes in appetite (Flo et al., 2014; Gitlin et al., 2014; Lukas, Mayer, et al., 2013). An estimated 40% of older adults have reported that pain extensively decreases their ability to perform activities of daily living and reduces quality of life (Jaremka et al., 2014; Lukas, Mayer, et al., 2013; Monroe et al., 2014). Covert implications for undermanaged pain may include health care costs to the person and healthcare system. Nursing research surrounding pain and sleep quality is limited, research in this area is mainly conducted by medicine, psychology, and psychiatry. The gap in understanding the sources of pain or discomfort that relate to sleep quality is impeding progress in developing nursing assessment and intervention protocols for people with dementia.

Albeit the concept of sleep quality remains poorly defined, the empirical evidence to date supports that good sleep quality is associated with positive health outcomes, less daytime sleepiness, and a greater well-being and psychological functioning (Hale et al., 2013; Ohayon et al., 2017). Understanding factors related to sleep are important to management of overall quality of life in older adults and PWD. Currently the literature supports many causes of poor sleep such as physiologic, cognitive, behavioral, environmental, and pharmacologic factors (Martin & Ancoli-Israel, 2008; Zdanys & Steffens, 2015). Pain is the physiologic factor most commonly associated with PWD experiencing poor sleep quality (Q. Chen et al., 2011; Neikrug & Ancoli-Israel, 2010; Roth, 2012). Unfortunately, specific types of physical pain that are associated with poor sleep quality in PWD have not been clearly elucidated in the literature. Limited information

on the specific types of physical pain may be related to deficits experienced by PWD, such as the decreased cognitive ability of PWD to report their experiences of pain (Flo et al., 2014).

Because 50 to 75% of people living in long-term care have some form of dementia ("2015 Alzheimer's disease facts and figures," 2015) and sleep problems are associated with many negative sequelae in long-term care, there is a particular interest in understanding factors associated with sleep quality in PWD. The systematic review presented in this chapter examined broadly the factors associated with sleep quality in older adults with dementia.

Methods

A comprehensive search was completed using two electronic databases. A combination of terms included were “sleep quality,” “nighttime sleep,” “sleep,” and “dementia.” Studies published within the past 10 years (inclusive of 2007), ages 65+ years, and humans yielded 218 results. Duplicates were removed yielding 200 articles. Initial exclusion criteria included studies focusing on caregivers, effects of medical conditions, pharmacological treatments, sleep as an antecedent to cognitive decline, non-English, symptoms of dementia, epidemiology of sleep, daytime sleepiness, systematic review, insomnia, and focus of study did not include sleep. Upon further evaluation of abstracts, articles were retrieved as full text and hand reviewed to ensure proper inclusion for the evidence table. Articles were initially categorized between four categories: genetic (5), psychological/behavioral (13), social support/environment (6), and clinical presentation/comorbid conditions (17). Because the central focus was on clinical/comorbid conditions, only these articles were used for this review. Comorbid conditions categorized were: respiratory disorders, nocturia, pain, movement disorders, and other health conditions. Between PubMed and Google Scholar a total of 17 articles were used for this review of the literature. See Figure 1.1 for a detailed display of literature search.

Figure 1.1

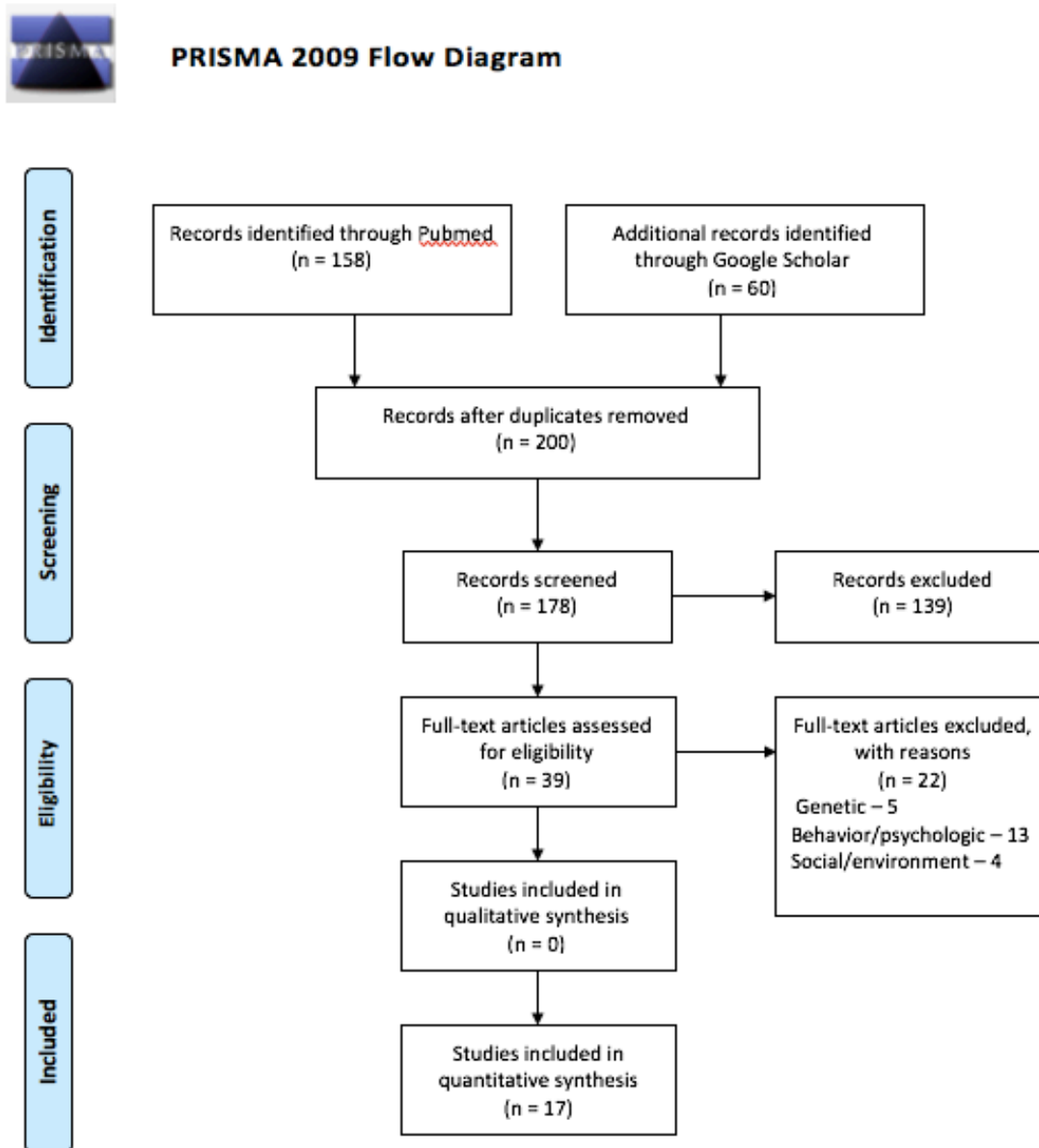


Figure 1.1

Emerging themes will be evaluated from the analysis of factors and their effect on sleep in PWD. Seventeen articles will be analyzed by design and strength of evidence. Additionally, measures used to assess sleep are of particular interest due to decreased reliability of self-report in PWD. See Appendix A for evidence table with supported studies.

Synthesis

Respiratory conditions, nocturia, pain, movement disorders, and other health conditions were common themes that emerged from the literature review. Sleep was not always the dependent variable, but was minimally an independent measure within the studies. Respiratory conditions like sleep apnea or sleep disordered breathing were prevalent in this literature review (Cooke et al., 2009; Esbensen, 2016; S. J. Kim, Lee, Lee, Jhoo, & Woo, 2011; Onen et al., 2010; Pao et al., 2013; Piano et al., 2015; Terpening et al., 2015). Improvement of respiratory conditions supported improvement in subjective sleep quality, improvement in daytime fatigue and sleepiness, less cognitive decline, as well as improvement of depression and anxiety symptoms (Cooke et al., 2009; Onen et al., 2010; Terpening et al., 2015). Whereas, when respiratory conditions remained unmanaged, sleep disturbances were associated with poorer health, more medical visits, heart and thyroid problems, worsening of mental health conditions, increases in daytime behaviors, and worsening cognition (Esbensen, 2016; S. Kim et al., 2014; Pao et al., 2013; Piano et al., 2015).

Only one study identified an association with nocturia, pain, and sleep (Bliwise et al., 2009). Interestingly, 53% of participants reported nocturia that interfered with nighttime sleep which can be identified as another source of discomfort. Pain was broadly acknowledged as a source of disrupted sleep, but no specific sources were identified through measurement (Gitlin et al., 2014; Hodgson, Gitlin, & Huang, 2014; Vitiello et al., 2014). In one study, 55% of participants reported pain as well as 49% of the sample also reported at least one sleep problem occurring once during the week (Hodgson et al., 2014).

Movement disorders were identified as restless legs syndrome (RLS) and periodic limb movements (PLM) (Bhalsing, Suresh, Muthane, & Pal, 2013; Cuellar, Strumpf, & Ratcliffe,

2007; Hibi et al., 2012). Evidence supports movement disorders are disruptive to sleep quality, social and daily functioning, emotional well-being, and quality of life. Health conditions like idiopathic REM sleep behavior disorder (Fernandez-Arcos, Iranzo, Serradell, Gaig, & Santamaria, 2016) and other comorbidities (Gitlin et al., 2014; Mazzotti et al., 2012; Zuurbier et al., 2015) had relationships with sleep problems, mental health, pain, fall risk, and functional challenges.

Summary and Quality of Evidence

The studies retrieved did not produce the results intended, which was to assess if current literature supports identification of specific factors of pain associated with sleep in PWD. This literature review revealed a lack of studying discomfort during the nighttime. While urinary retention was captured at one time point, nocturia may be caused by factors other than urinary retention. In addition, the timing of the measures did not allow measurement of restless legs or periodic limb movement disorders which are also known to contribute to sleep quality.

The studies retrieved had the largest influence from psychiatry, psychology, neurology, and medicine with only two articles from nursing (Cuellar et al., 2007; Hodgson et al., 2014). Thirteen studies had weak levels of evidence using descriptive, correlational designs (Bhalsing et al., 2013; Bliwise et al., 2009; Cooke et al., 2009; Cuellar et al., 2007; Fernandez-Arcos et al., 2016; Gitlin et al., 2014; Hibi et al., 2012; Hodgson et al., 2014; S. J. Kim et al., 2011; Mazzotti et al., 2012; Pao et al., 2013; Piano et al., 2015; Terpening et al., 2015; Vitiello et al., 2014) and small sample sizes (Cooke et al., 2009; Cuellar et al., 2007; Hibi et al., 2012; Onen et al., 2010; Piano et al., 2015). Only one study was longitudinal (Fernandez-Arcos et al., 2016) and six studies had a large sample size (Bhalsing et al., 2013; Bliwise et al., 2009; Fernandez-Arcos et al., 2016; Mazzotti et al., 2012; Vitiello et al., 2014; Zuurbier et al., 2015). Only one study was a

double-blind, randomized controlled trial with level II evidence rating (Fineout-Overholt et al., 2010). The remaining studies (n = 16) were exploratory and descriptive with small sample sizes.

Methodological issues were present which may have contributed to some of the studies overall findings and significance of results. This review did not include any qualitative articles. Measurement of sleep was primarily captured by chart review, Epworth Sleep Scale (ESS), Pittsburgh Sleep Quality Index (PSQI), Sleep Disorders Inventory (SDI), and polysomnography (PSG). Only one study utilized actigraphy to objectively measure sleep in the community setting (Zuurbier et al., 2015).

Discussion

Limitations

The current synthesis of the literature may have multiple limitations including an incomplete retrieval of the available literature. There is the possibility that new research findings are not available and thus not included in the review. The literature did not show temporal sequencing of discomfort among the participants, rather captured discomfort during one time point. Discomfort measures were not captured during nighttime sleep. Measurement of discomfort immediately prior to or during nighttime sleep period would demonstrate an increase of validity of causes related to disturbed or poor nighttime sleep. Additionally, the inclusion criteria only addressed the past 10 years, seminal works have not been included in this synthesis. Also, this review is limited to a single reviewer conducting the search and interpretation.

Considerations

Literature surrounding poor sleep quality infers relationship between sleep quality and musculoskeletal, respiratory, gastrointestinal, and genitourinary systems that has not been fully expounded. Moreover, it is important to account for multiple comorbidities among the older

adult population. Comorbid health conditions and physiologic systems do not operate singularly, instead are complex and effects between the systems intertwine. Since this search only included studies in PWD, it is possible pain may have been assessed in other samples that can accurately self-report pain. Sleep is already an ambiguous phenomenon and is difficult to capture comparably among various tools. The concept of pain is also abstract and is especially difficult to measure in a population with communication deficits. It is possible if the search was broadened, the specific association between pain and sleep may have been identified.

Gaps in Knowledge

In this review of the literature, it was clear that older adults with and without dementia experience poor sleep quality related to physiologic systems and comorbid health conditions. When physiologic systems remain under recognized and under managed, depression, anxiety, functional status, and quality of life are impacted. Requirement of a targeted comprehensive assessment in long-term care settings may be beneficial in managing symptoms associated with comorbid health conditions to improve sleep quality. Sleep patterns and quality of life may be improved through understanding factors associated with poor sleep and developing and testing interventions that address contributing factors.

Further research should be targeted at identifying physiological sources of pain associated with sleep in PWD. Comprehensive assessment strategies need to be targeted and implemented to evaluate effectiveness of identifying antecedents of poor sleep quality. Methods for understanding and measuring sleep quality in PWD are inadequate, which limits the ability to identify and effectively manage poor sleep and the associated negative outcomes (Gitlin, Hodgson, Piersol, Hess, & Hauck, 2014; Simpson & Carter, 2013). The proposed prospective study aims to comprehensively assess specific physiologic sources of pain and nighttime sleep

quality in PWD. Knowledge gained from this research will be used to stress the importance of further developing and conducting a more comprehensive pain assessment of PWD. Promoting routine sleep assessments of PWD and evaluating the long-term effects of poor sleep quality may be vital to achieving positive health outcomes for the patient within health care settings. This overall program of research is aimed at transforming the care delivered to PWD whose ability to communicate pain and sleep disturbances is compromised.

Purpose

The purpose of this study is to determine the relationship between sources of physical pain and sleep quality in older adults and PWD. This will be an exploratory study to understand if and to what degree relationships exist between sources of pain and sleep quality in older adults and PWD.

Research Questions and Hypotheses

The research questions that will be addressed in this study include:

1. What is the frequency of MS, respiratory, GI, and GU pain in long-term care residents and a subset with dementia?
2. What is the severity of MS, respiratory, GI, and GU pain?
3. What is the sleep quality (i.e. total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation) of older adults with and without dementia residing in long-term care?

The hypotheses for this study include:

1. Controlling for co-morbid problems including cognitive impairment, musculoskeletal (MS), respiratory, gastrointestinal (GI), and genitourinary (GU) pain will predict sleep quality (total sleep time, sleep efficiency, sleep latency, wake after sleep onset (WASO),

and sleep fragmentation). It is already known that higher pain levels will result in a decrease in sleep quality. This directional hypothesis is based on the gap in understanding of the types of pain that are more likely to predict sleep quality. Co-morbid problems and moderate to severe dementia may confound the relationship of pain on sleep quality.

2. Differences in the severity of MS, respiratory, GI, and GU pain will not be dependent on if the resident has moderate to severe dementia. This directional hypothesis is based on the premise that severity of pain may be interpreted differently for those with moderate to severe dementia.

Introduction to Theory

The premise of the study is based on the physiology of pain and Snow et al.'s (2004) model for pain assessment in PWD. These models are useful in explaining the relationship between specific sources of pain and sleep quality. Currently there is no model available in the literature that specifically describes the relationship between specific sources of pain and sleep quality in older adults. Therefore, in Chapter 2 an illustration of the antecedents of pain and sleep quality in PWD is presented.

Conclusion

In this chapter, literature surrounding factors associated with sleep quality in PWD was reviewed. Prevalence and significance of sleep problems as well as an introduction to the potential risk factors associated with poor sleep quality among older adults are described. Gaps in knowledge were emphasized. A proposed study is presented to address characteristics of MS, respiratory, GI, and GU discomfort in long-term care residents with and without dementia as well as to examine the association between physiologic sources of pain and sleep quality among the same population.

CHAPTER 2

In chapter 2 of this non-traditional dissertation, two manuscripts are presented. The first manuscript discusses theory surrounding pain and sleep quality in persons living with dementia. An illustration of the relationship between different sources pain and sleep quality in PWD is presented, conceptual definitions are provided, and the application of this theory to the study is discussed. The second manuscript discusses fundamental considerations when using actigraphy in research with older adults. Actigraphy is presented as a non-invasive yet sophisticated method to measure sleep in persons living in the community.

Section 2.2 – Manuscript 2

Manuscript 2: Nursing Theory on Pain and Sleep Quality in Persons Living with Dementia

Introduction to the Problem

Expanding the field of nursing research is imperative to the overall growth of nursing as a discipline (Polit & Beck, 2012). New knowledge acquired from high quality nursing research is needed to better care for patients in all circumstances. Cohesion between nursing theory, research, and practice are essential to moving nursing science forward. Nursing theory should foster growth in nursing research, while nursing research should inform clinical practice (Polit & Beck, 2012; Walker & Avant, 2010). Clinical practice should also guide nursing research and aide in the development of nursing theory. Nursing theory provides a foundation for scientific inquiry surrounding a concept or phenomenon related to nursing practice (Polit & Beck, 2012). Typically, nursing theory specifies a conceptual framework that guides research. Yet theory is not always available for a specific phenomenon and thus requires development through knowledge of clinical practice problems and exploration through nursing research.

Although several nursing theories and theories in other disciplines have been developed, there has been no specific theory available that explains the association between pain and sleep quality in people living with dementia (PWD). This paper will discuss the physiologic processes of circadian rhythms and pain perception that will guide this nursing research topic. Physiologic models from other disciplines will be combined and utilized to create an explanation of pain and sleep quality in PWD.

The Processes of Circadian Rhythms and Pain Perception

Circadian rhythms are important in the process of sleep and wake cycles. Pathways of pain perception is a principal concept to understanding the physiologic processes that occur as a response to a trigger or painful stimuli. Both circadian rhythms and pain perception become altered in PWD. This section will briefly discuss circadian rhythms and pain. Furthermore, the gap in the literature will be discussed.

Circadian Rhythm

Regulation of sleep, wakefulness, and arousal are managed through the suprachiasmatic nucleus (SCN). The SCN is the internal clock or mechanism that generates an entrained 24-hr day, also known as circadian rhythm. Many physiologic processes within the body are regulated by circadian rhythm. Many health conditions have day-night patterning many of which exacerbate at night time, leading to cascade of effects from disruption of sleep (Smolensky et al., 2015). Sleep-wake cycles associated with circadian rhythm are independent from other variables that can affect sleep such as the environment, social cues, or food. The pathophysiology of dementia results in degeneration of different pathways at pathologic and biochemical levels (Neef & Larson, 2008; Zuurbier et al., 2015). As a result, different aspects of

sleep and arousal can be affected depending on the type and severity of dementia (Zdanys & Steffens, 2015; Zuurbier et al., 2015).

Dementia related neurodegeneration to the brain has been identified in the cerebral cortex, hypothalamus, and thalamus (Musiek, Xiong, & Holtzman, 2015; Zelinski, Deibel, & McDonald, 2014). These areas of the brain are responsible for sleep-wake cycles and circadian rhythm. Once disrupted even through neurodegeneration because of dementia, sleep quality becomes affected. The cerebral cortex is responsible for learning, thinking, and organizing information. During wakefulness, the cerebral cortex is stimulated which inhibits the ventrolateral preoptic nucleus (VLPO). The VLPO is associated with the sleep promoting area of the brain the hypothalamus (Schwartz & Roth, 2008). VLPO neurons prevent activity to the brainstem that maintain wakefulness. Neurotransmitters identified in sleep-wake-arousal are Histamine, Dopamine, Norepinephrine, Serotonin, Glutamate, Orexin, and Acetylcholine (Schwartz & Roth, 2008). Serotonin is of particular interest as it produces melatonin, which is a regulator of the circadian cycle. Melatonin also feeds back to the SCN to regulate its own production. Production of melatonin is inhibited by light and the hormone cortisol, which also regulates sleep, wake, and arousal (Schwartz & Roth, 2008; Zdanys & Steffens, 2015).

The role of dopamine in regulating sleep and circadian rhythms has been implicated in the development of sleep disturbances in PWD. Sleep inhibiting neurotransmitters are classified as Ach inhibitors, B-blockers, pseudoephedrine, corticosteroids, antidepressants (tricyclic, SSRI, SNRIs) (Zdanys & Steffens, 2015). The body elicits a natural stress response with disruption of sleep associated with circadian rhythm, which in turn releases cortisol. Cortisol is a neurotransmitter associated with sleep inhibition and wake promotion. Cortisol also has a diurnal rhythm with an increase in production by the end of night to assist with waking. Cortisol

plays a role in the altered ability to maintain sleep when stress response, such as pain is elicited (Kovach, Woods, Logan, & Raff, 2011; Schwartz & Roth, 2008; Smolensky et al., 2015).

Pain

The relationship between the effects of uncontrolled pain and poor sleep quality is inferred in the literature (Monroe et al., 2014; Onen et al., 2010). Yet, the processes of pain and sleep are abstract and complex in nature, making it difficult to target the cause of disruption in either. Neurodegenerative damage to the pathways of pain signal conveyance result in altered sensory and affective reports of pain that require different assessment strategies for PWD.

The literature has identified four types of pain: nociceptive, neuropathic, mixed or unspecified, and psychological (Herr, 2011). In particular, this proposed study will investigate the nociceptive antecedents of pain that include musculoskeletal, gastrointestinal, genitourinary, and respiratory and their relationship with sleep quality. Nociception entails the sensory component and visceral organs such as the musculoskeletal, gastrointestinal, genitourinary, and respiratory systems. Neuropathic pain is caused by peripheral or central nervous system stimulation. Mixed or unspecified pain is the process of having mixed or unknown pain mechanisms. Whereas psychological pain or discomfort may due to psychological disorders or life circumstances such as grief or divorce.

Overall, undermanaged pain in PWD is a significant problem and is associated with multiple negative consequences including exacerbations of neuropsychiatric symptoms such as agitation, aggression, negative mood, or depression (Flo et al., 2014; Gitlin et al., 2014; Husebo et al., 2014; Jaremka et al., 2014; Lukas, Mayer, et al., 2013; Passmore & Cunningham, 2014). Poorly managed pain may also worsen sleep problems, cognitive impairment, functional impairment, health conditions, immune system functioning, and quality of life (Q. Chen et al.,

2011; Flo et al., 2014; Gitlin et al., 2014; Jaremka et al., 2014; Kovach et al., 2012; Lukas, Mayer, et al., 2013; Monroe et al., 2014; Passmore & Cunningham, 2014). Management of pain has been reported to significantly improve nighttime behaviors that may also be translatable to improved sleep (Husebo et al., 2014). Several studies describe musculoskeletal pain and sleep quality, but not the relationship between constructs (Q. Chen et al., 2011; Flo et al., 2014; S. Kim et al., 2014). Nurses have conducted limited nursing research, with most studies conducted by medicine or psychiatry. The gap in understanding the sources of pain or discomfort that relate to sleep quality is impeding progress in developing nursing assessment and intervention protocols for people with dementia. The next section will provide a proposed theoretical foundation to study the association between pain and poor sleep.

Proposed theoretical foundation

Since this study focuses on nociceptive physical pain as an antecedent of sleep quality, the path of signal conveyance from the dorsal horn of the spinal cord to the cerebral cortex will be described. In addition, evidence regarding pain perception in persons with cognitive impairment will be explicated. The physiology of pain and Snow et al.'s (2004) model for pain assessment in PWD is useful in explaining the relationship between specific sources of pain and sleep quality. The pain assessment model (Figure 2.2) recognizes pain as multidimensional and includes components of sensory, behavior, emotion, and cognition (Snow et al., 2004).

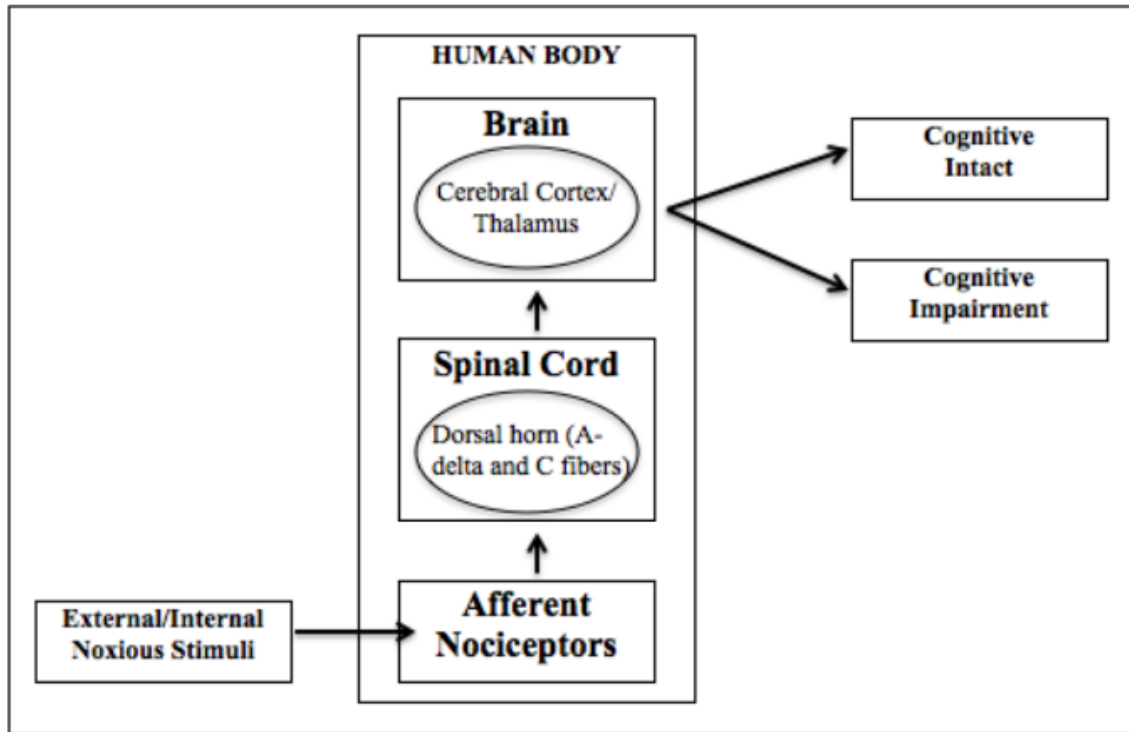


Figure 2.1 Path of Pain Signal Conveyance

Figure 2.1 illustrates the path of pain signal conveyance from a noxious stimulus to the visceral organ system. Primary afferent nociceptors are specific free nerve endings of primary afferent nerves identified as A-delta and C fibers. Generally, the primary afferent nerves are the first structures to be involved in the nociceptive process and are detected in various body tissues including skin, muscle, connective tissue, blood vessels and thoracic and abdominal viscera. A-delta and C-nociceptors/fibers are present in the skin. Muscles, joints, fasciae and other deep somatic structures are supplied mainly by C-fibers but also some A-delta nociceptors. First, activation of the primary afferent nociceptors occurs in the dorsal horn of the spinal cord. A-delta fibers and C fibers are primary afferent nerves located in the dorsal horn. A-delta are myelinated fibers that rapidly carry messages to the cerebral cortex. C fibers are unmyelinated and typically transmit pain slowly and long-term (Helme & Gibson, 2001). The pain signal

ascends the spinal tract to the brain where the pain perception is typically experienced in the thalamus and cerebral cortex ("The Anatomy and Physiology of Pain," 2000).

There are few references in the literature to the ways in which nociceptive pain stimuli affect sleep ("The Anatomy and Physiology of Pain," 2000; Roehrs & Roth, 2005; Rub, Del Tredici, Del Turco, & Braak, 2002). The basic notion is that nociceptive pain stimuli detection in the cerebral cortex triggers a stress response that affects sleep. In acute and chronic pain responses, literature suggests that the hypothalamic-pituitary-adrenal axis (HPA) of the central stress system is activated releasing cortisol and norepinephrine hormones. These hormones have adverse affects on sleep, reproductive health, bone growth and muscle strength, and immune system health (Roehrs & Roth, 2005). Sleep disturbance associated with pain is experienced through reduced total sleep time, fragmentation, and diminished amounts of slow wave and REM sleep (Roehrs & Roth, 2005).

Research on pain perception in persons with cognitive impairment is inconclusive and at times contradictory. Some literature suggests pain perception may be altered in some older adults due to the decrease in density of myelinated and unmyelinated nerve fibers (Helme & Gibson, 2001). Neurodegeneration related to dementia includes involvement of the medial temporal cortex and the prefrontal cortex components of the cerebral cortex. The medial-temporal cortex is accountable for the affective-motivational dimension of pain processing, whereas the prefrontal cortex is involved in executive functioning and descending pain inhibitory systems (Kunz, Mylius, Schepelmann, & Lautenbacher, 2015). The degeneration process not only results in reduced executive functioning but also a loss of pain inhibitory potency, which may render the person more susceptible to pain (Kunz et al., 2015).

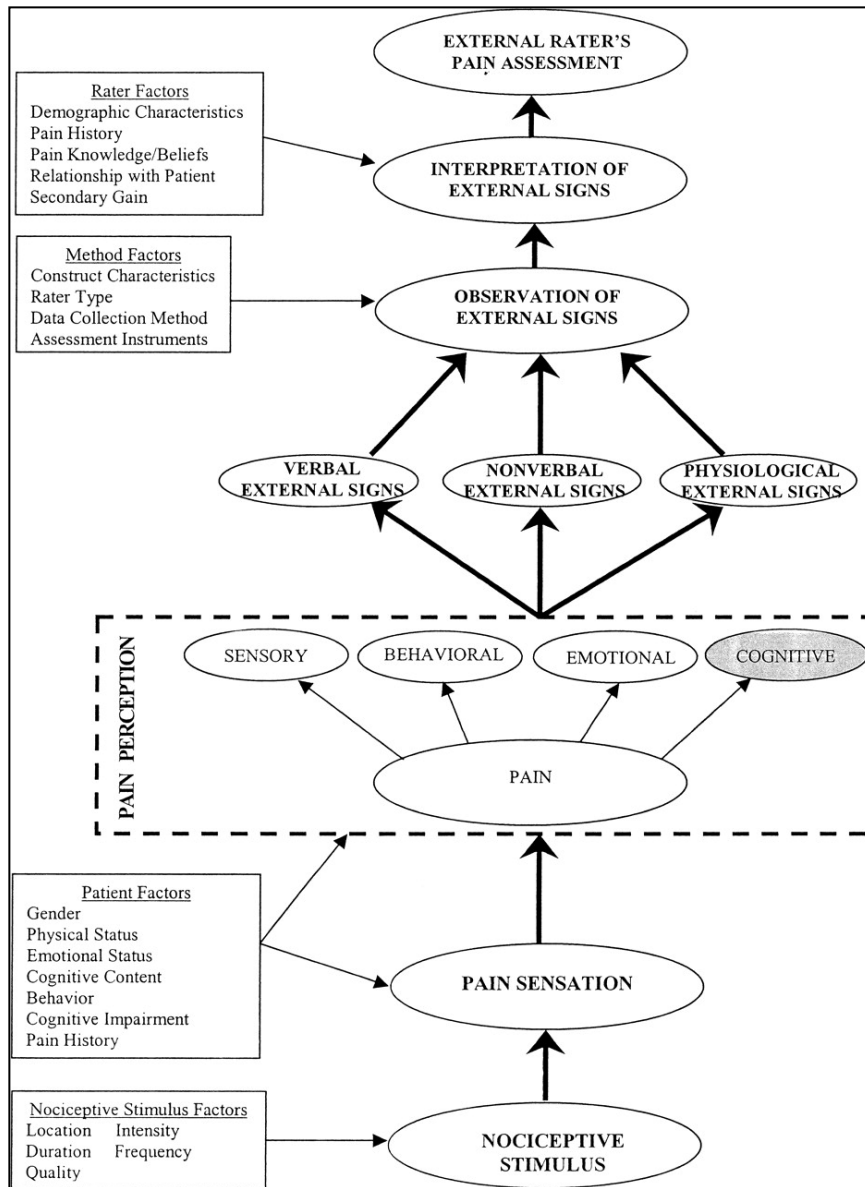


Figure 2.2 Pain assessment model. (Snow et al., 2004)

Illustration of pain and sleep quality in PWD

Pain has been identified as a single construct without fully examining specific sources of physical pain and their relationship to sleep quality in PWD (Flo et al., 2014; Gitlin et al., 2014; Harris et al., 2012; Husebo et al., 2014; Jaremka et al., 2014; Lukas, Barber, Johnson, & Gibson, 2013). However, the relationship between specific sources of pain and sleep quality in older

adults cannot be reasonably implied from existing literature. Therefore, an illustration of the antecedents of pain and sleep quality in PWD is depicted in Figure 2.3 below.

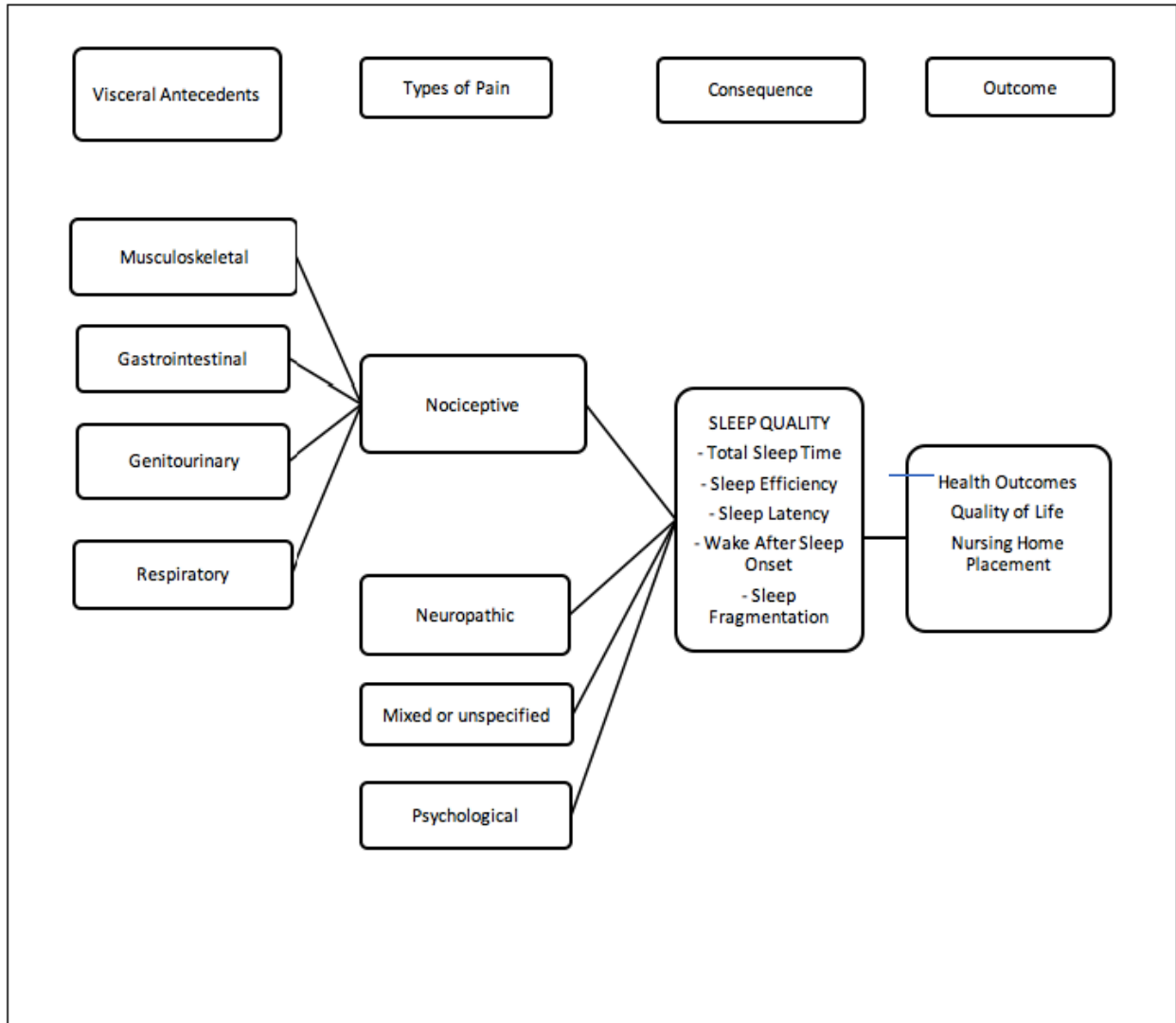


Figure 2.3 An Illustration of Pain and Sleep Quality in Persons with Dementia

Definition of Concepts and Empirical Evidence

Pain

Pain has been defined as an “unpleasant sensory or emotional experience associated with actual or potential tissue damage” (Ferrell & Coyle, 2010). Pain is a subjective experience and

usually occurs along a continuous duration of time. In PWD, pain can be theoretically difficult to objectively measure but is essential in order to manage the health needs of PWD.

Pain is typically classified as acute and chronic. Acute pain is “associated with tissue damage, inflammation, a disease process that is relatively brief, or surgical procedure” (Ferrell & Coyle, 2010). Chronic pain has been described as “persistent, worsens and intensifies with the passage of time, lasts for an extended period of time (months, years, or a lifetime), and adversely affects the patient’s function or well-being. Chronic pain may accompany disease processes like cancer, HIV, heart failure, diabetes, COPD, degenerative joint disease, osteoporosis, cystic fibrosis, fibromyalgia, or sickle cell disease or injuries that haven’t resolved within an expected period of time like low back pain, trauma, or spinal cord injury” (Ferrell & Coyle, 2010). This study will not differentiate between acute and chronic pain due to limited ability to distinguish between the types with objective observation. The targeted systems of study will include musculoskeletal, respiratory, gastrointestinal, and genitourinary.

The **musculoskeletal** system includes bones, muscles, cartilage, tendons, ligaments, joints, and other connective tissue that support and bind tissues and organs together. Musculoskeletal pain/discomfort measured by PAINAD (Warden, Hurley, & Volicer, 2003). The PAINAD primarily targets assessment of musculoskeletal pain during activities. Assessments of pain in the morning after sleep and at nighttime prior to sleep are the most logical times to assess pain surrounding sleep quality assessment.

The **respiratory** system includes the lungs that are responsible for taking in oxygen and expelling carbon dioxide. Respiratory discomfort measured by RDOS (Campbell, 2008; Campbell, Templin, & Walch, 2010) and oxygen saturation during morning and evening cares. This tool has been utilized in older adults that are unable to self-report and has been

psychometrically tested. The reliability of this 8-item scale using Cronbach α is 0.64. Perfect interrater reliability across data collectors was achieved (Campbell et al., 2010).

The mouth, esophagus, stomach, small intestine, large intestine, and anus are hollow organs of the **gastrointestinal** tract that allow food to nutrition. The liver, pancreas, and gall bladder are solid organs of the digestive system. Gastrointestinal discomfort measured by chart review and staff report for diarrhea, constipation, nausea, vomiting, c/o GI discomfort, or decreased appetite. There is no known tool that specifically targets gastrointestinal pain, therefore multiple components will be obtained from chart review and staff reports as these are more reliable than self-report from the participant.

The reproductive organs and urinary system compromise the **genitourinary** system. Genitourinary discomfort measured by urinary retention using a bladder scanner at bedtime. Signs and symptoms of urinary discomfort will be measured by resident or staff report. Urinary retention is being used as a proxy for overall genitourinary discomfort. Staff report will be utilized in residents unable to accurately self-report signs and symptoms of genitourinary discomfort.

Sleep Quality

Sleep quality is an outcome variable frequently used in the literature with poor conceptual clarity (Buysse et al., 1991; Carskadon & Dement, 2011; Chiu & Chao, 2010; Harvey, Stinson, Whitaker, Moskovitz, & Virk, 2008; Hyypa & Kronholm, 1989; Iliescu et al., 2003; Krystal & Edinger, 2008; Landry, Best, & Liu-Ambrose, 2015; Orsal, Alparslan, Ozkaraman, & Sonmez, 2014; Pilcher, Ginter, & Sadowsky, 1997). More so, conceptual understanding of sleep quality in persons with dementia (PWD) is lacking and requires further

investigation (Landry et al., 2015; Orsal et al., 2014). Sleep quality is ambiguous in its definition, making it difficult to concretely describe. The concept of sleep quality will be deconstructed into current definitions of sleep and quality. A synthesis of literature surrounding measures of sleep quality will be evaluated in an effort to create a more comprehensive understanding of the concept of sleep quality as it applies to PWD.

Sleep is identified as a reversible behavioral state of perceptual disengagement from and unresponsiveness to the environment (Carskadon & Dement, 2011). Sleep is a complex mixture of physiologic and behavioral processes that include stages of rapid eye movement (REM) and non-rapid eye movement (non-REM). Typically, the process of sleep is accompanied by postural recumbence, behavioral stillness, and closed eyes (Carskadon & Dement, 2011). Quality, on the other hand, may entail how good or bad something is. Sleep quality may be understood as the process of obtaining good or bad sleep. Disrupted sleep cycles produce "bad" sleep. REM sleep is important in the ability to feel well-rested (Neef & Larson, 2008; Zdanys & Steffens, 2015). **Sleep quality** may be characterized by objective measurements of total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation.

Total sleep time is the duration in minutes of nighttime sleep (Moore et al., 2015). Typically, 420 to 540 minutes of nighttime sleep is considered adequate (Miaskowski et al., 2011). It is important to be aware of quiet wakefulness as it can be misinterpreted as sleep, thus overestimating total sleep time (Shambroom, Fabregas, & Johnstone, 2012; Zinkhan et al., 2014).

Sleep efficiency is the percentage of time spent sleeping (Enderlin et al., 2011). A value of 80-85% or greater is considered an acceptable sleep efficiency value (Johansson, Adamson,

Ejdeback, & Edell-Gustafsson, 2014; Miaskowski et al., 2011). Sleep efficiency is a particularly useful measure of overall sleep quality.

Sleep latency is the time in minutes to fall asleep or the first period of persistent inactivity (Moore, Schmiede, & Matthews, 2015). Sleep latency has been reported as one of the least accurate sleep measures in actigraphy, but has been recommended for use as an adjunct to other sleep variables (Enderlin et al., 2011; Lichstein et al., 2006; Littner et al., 2003). A normal value for sleep latency proposed by Miaskowski et al. (2011) is less than 20 minutes.

Wake after sleep onset (WASO) is the total minutes awake during nighttime from sleep onset to final awakening (Ancoli-Israel et al., 2003). Normal values can range for WASO, but typically 10% of total sleep minutes spent awake is acceptable (Miaskowski et al., 2011).

Sleep fragmentation refers to the brief arousals that occur during a period of sleep. The fragmentation index is manifested by the variability of body movements from hour to hour during sleep hours (Ancoli-Israel et al., 2003). A fragmentation index score of less than 20 indicates good sleep, whereas greater than 50 indicates poor sleep (Blackwell, Ancoli-Israel, Redline, Stone, & Osteoporotic Fractures in Men Study, 2011). This variable does not typically align well with reported polysomnography variables.

Illustration of Relevance to Nursing

The illustration of pain and sleep quality in PWD is based on the pathway of pain signal conveyance and the physiologic process of circadian rhythms (Helme & Gibson, 2001; Neef & Larson, 2008; Snow et al., 2004; Zuurbier et al., 2015). Given the goal of nursing theory is to define and predict nursing care and outcomes (Meleis, 2012), an illustration addressing the

contributing factors for sleep quality can serve as a guide for the development of future nursing interventions following exploration of proposed relationships among the variables.

The illustration represents the relationship between antecedents of pain and their association to sleep quality and consequent health outcomes. The illustration shows that specific pain variables may contribute to sleep quality in older adults. It also reveals how these factors may influence health outcomes and quality of life older adults. Accordingly, the illustration represents a logical and dynamic design that could be useful to describe and explain the phenomenon of sleep quality and its associated risk factors in older adults. This illustration will also inform the research design, data collection and analysis, and discussion of the implications.

Section 2.2 – Manuscript 2

Manuscript 2: Fundamental Considerations When Using Actigraphy in Research with Older Adults

Abstract

Sleep quality is important to older adult health and well-being and can be a sensitive indicator of health outcomes. Actigraphy is a reliable and valid method to measure sleep quality compared to the gold standard polysomnography. This article provides fundamental considerations for the use of actigraphy in the older adult population. Feasibility of data collection with 33 long-term care residents with dementia is reported along with an examination of whether actigraphy light sensors reliably measured the night time-in-bed interval. There were statistically significant differences in the time-in-bed interval delineated by observation versus light measurements. Differences in sleep minutes, sleep efficiency, and sleep latency using the two procedures to delineate the time-in-bed interval were also evident. The use of actigraphy is feasible in clinical settings but requires thoughtful consideration of placement, sleep logs, care of device, sleep variables, features, epoch length, algorithms and modes.

Keywords: Actigraphy, older adults, sleep quality, measurement

Disclosure: The authors have reported no conflicts of interest

Introduction

There is increasing awareness that sleep quality, circadian rhythm, and rest-activity cycles are meaningful clinical indicators for research involving older adults. Sleep quality has been useful as an outcome variable and is associated with level of dementia, nighttime behaviors, and level physical activity in older adults (Ancoli-Israel, Martin, Kripke, Marler, & Klauber, 2002; Huang et al., 2002; J. Martin, Marler, Shochat, & Ancoli-Israel, 2000). Sleep quality has also been used as a measure of treatment response and can be a sensitive indicator of comfort, quality of life, diurnal rhythm, daytime sleepiness, and physiological functioning (Alessi et al., 2005; Ancoli-Israel et al., 2003; Harvey, Stinson, Whitaker, Moskovitz, & Virk, 2008; Neikrug & Ancoli-Israel, 2010). Circadian rhythm and rest-activity cycle problems are common in older adults (Blackwell et al., 2014; Walsh et al., 2014). The purpose of this article is to provide an introduction to actigraphy and to discuss 14 fundamental considerations when planning to use actigraphy in a research study with older adults. Actigraphy measures from 33 long-term care residents with dementia are used to illustrate the potential for measurement error when nighttime segments are determined using different techniques.

An actigraph is a small, non-invasive device typically worn on the wrist. Variations of physical activity are continuously captured using a piezoelectric accelerometer over a period of time and translated into numbers for a quantitative assessment of sleep (Boudebesse et al., 2014). The absence of movement over a specified time is considered a proxy for sleep and repetitive wrist activity is considered a proxy for wakefulness (Johansson, Adamson, Ejdeback, & Edell-Gustafsson, 2014).

Considerations

Polysomnography versus actigraph

While polysomnography has been considered the gold standard for assessing sleep, this testing has several disadvantages (Ancoli-Israel et al., 2003; Blackwell, Ancoli-Israel, Redline, Stone, & Osteoporotic Fractures in Men (MrOS) Study Group, 2011; Koch, Haesler, Tiziani, & Wilson, 2006; Shambroom, Fabregas, & Johnstone, 2012; van der Kooi et al., 2013; Zinkhan et al., 2014). An accurate assessment of sleep using polysomnography may not be feasible or realistic in older adults or people living with dementia (Blackwell et al., 2011; Hanisch et al., 2011; Shambroom et al., 2012; van der Kooi et al., 2013). Sleep evaluated by polysomnography is costly and usually recorded in a non-natural environment (Blackwell et al., 2011; van der Kooi et al., 2013). The multiple required sensors and wires attached to the body for polysomnography may lead to increased agitation and stress in older adults with dementia.

Actigraphy provides a practical and cost-effective way to measure rest-activity patterns (Morgenthaler et al., 2007). The device is easy to wear, non-invasive, portable, and allows for data collection in a natural environment. Costs of using an actigraph include the device and the software needed to interpret the data, which amounts to a fraction of the costs of using polysomnography. Actigraphy is especially valuable in long-term care settings to objectively measure sleep quality (Hanisch et al., 2011; Shambroom et al., 2012).

Actigraphy provides reliable results and is comparable to polysomnography in its sensitivity (89%) and specificity (95%) when evaluating patients with suspected sleep apnea (Morgenthaler et al., 2007). Yet, in the intensive care unit, actigraphy remained sensitive (>94%) but lacked specificity (<19%) (van der Kooi et al., 2013). Agreements between actigraphy and polysomnography for sleep and wake were 86.3% and 85.7% in healthy community dwelling adults, respectively (Shambroom et al., 2012). Correlations for total sleep

time (TST) were 0.81-0.91 and percent sleep were 0.61-0.78 (Ancoli-Israel et al., 2003; Dean et al., 2013).

Accelerometer versus actigraph.

While accelerometers are widely available to the public and very low-cost, these devices differ from traditional actigraphs in a number of ways (Tierney, Fraser, & Kennedy, 2015). Both accelerometer and actigraph devices are small, lightweight, and can be worn on the body easily like a watch. An accelerometer measures variability and intensity of activity such as gait patterns but does not have the ability to quantify sleep due to poor sensitivity and specificity distinguishing between periods of low activity and sleep (Fokkenrood et al., 2014; Saunders et al., 2015; Zinkhan et al., 2014). Accelerometers have frequently been used in research with young adults but have not been utilized widely among the elderly (Bento, Cortinhas, Leitao, & Mota, 2012; Kavanagh & Menz, 2008; Saunders et al., 2015).

Use in different populations.

Prior to assuming actigraphy is appropriate in evaluating sleep in special populations, there are a few potential barriers that need to be taken into consideration. Actigraphy data may be significantly compromised in people suffering from movement disorders, tremors, or insomnia (Ancoli-Israel et al., 2003; Kobayashi et al., 2014; Sadeh & Acebo, 2002). Polysomnography is needed to diagnose circadian rhythm disorders, insomnia, and some movement disorders (Kobayashi et al., 2014; Lichstein et al., 2006; Morgenthaler et al., 2007). The literature supports using actigraphy for research of people with bipolar disorder, coronary artery disease, stroke, peritoneal dialysis, cancer (lung, breast, prostate), sleep apnea, and heart failure (Bakken, Kim, Finset, & Lerdal, 2012; Bakken, Kim, Finset, & Lerdal, 2014; Boudebesse et al., 2014; Dean et al., 2013; Enderlin et al., 2011; Hanisch et al., 2011; Johansson et al., 2014;

Kawada, 2013; Koch et al., 2006; Miaskowski et al., 2011; Moore, Schmiege, & Matthews, 2015; Shambroom et al., 2012; van der Kooi et al., 2013; Wang, Hung, & Tsai, 2011).

Circadian rhythm.

While polysomnography is required for the diagnosis of circadian rhythm disorders, actigraphy is a sensible research method for gauging circadian rhythm since data can be collected over long periods of time (Ancoli-Israel et al., 2003; Zinkhan et al., 2014). Sleep onset and sleep offset times are used as circadian phase markers (Ancoli-Israel et al., 2003; Miaskowski et al., 2011). Computer programs are used to obtain twenty-four hour circadian rhythm parameters of mesor (mean), acrophase (time of peak activity), and amplitude (peak-to-nadir difference) using a cosinor analysis (Ancoli-Israel et al., 2003; Miaskowski et al., 2011; Youngstedt, Kripke, Elliott, & Klauber, 2001). Research has examined circadian rhythms disturbances occurring when people attempted to sleep outside of their endogenous rhythm, such as in shift workers, jet lag, and Alzheimer's disease (Ancoli-Israel et al., 2003; Satlin et al., 1991; van Someren et al., 1996; Youngstedt et al., 2001).

Sleep diary.

A sleep diary is important to use in combination with actigraphy. A sleep log can be useful to provide precise measurements of sleep and wake times. Although sleep diaries are subject to error and rely on accurate self-report, diaries can be used in conjunction with actigraphy data to validate exact times of events. Sleep diaries have been utilized in research to code actigraphy data and generally have good agreement in measuring changes in sleep patterns (Blackwell et al., 2014; Dean et al., 2013; Enderlin et al., 2011; Johansson et al., 2014). Total sleep time per night can be overestimated using actigraphy due to people lying awake but still in

their beds (Ancoli-Israel et al., 2003). Therefore, using sleep logs concurrently to validate the time the person went to bed for sleep is extremely important.

Actigraphy Placement.

There has been controversy as to the best placement of the actigraph. One study evaluated differences between concurrent actigraph placements on the non-dominant versus dominant wrists (Sadeh, Sharkey, & Carskadon, 1994). Results showed a 28% difference in sleep variation and implications were to use the non-dominant wrist to reduce the amount of artifact produced from breathing or lying on the dominant side (Sadeh et al., 1994). Another study reported no significant differences between placement on the dominant and non-dominant wrist or between the wrist and ankle (Jean-Louis et al., 1997). Recent literature has aligned with the use of non-dominant wrist placement and use of the dominant wrist or ankle in the case of paralysis or comfort (Blackwell et al., 2014; Boudebesse et al., 2014; Johansson et al., 2014; Kawada, 2013).

Special needs in clinical settings.

Since actigraphs look like a watch and tend to blend into the setting, it is important for all people involved with the actigraph to be educated on proper use and care of the device. It is possible for the actigraph to become lost, particularly during bathing and dressing. Utilizing a hospital wristband rather than watchband may minimize loss or theft. Although most actigraphs are considered waterproof and are marketed to withstand short periods of submersion in water, there is still the likelihood of damage. Submersion in water should be cautioned against and may be rectified by having research staff available to remove the watch during bathing.

Data and Sleep variables.

An important consideration is how much data is needed for valid and reliable interpretation of actigraphy data. While the amount of data needed is dependent on the purpose of the study, a minimum of continuous 72 hours of actigraphy data has been suggested to be useful (Alessi et al., 2005; Blackwell et al., 2005; J. L. Martin, Marler, Harker, Josephson, & Alessi, 2007). Actigraphy variables that have been validated to PSG include total sleep time, sleep efficiency, sleep latency, and wake after sleep onset (Johansson et al., 2014; Lichstein et al., 2006). Sleep latency, sleep efficiency, total sleep time, wake after sleep onset, and fragmentation index are the most commonly reported sleep variables in actigraphy (Blackwell et al., 2011; Kanady, Drummond, & Mednick, 2011; Miaskowski et al., 2011; Shambroom et al., 2012; Zinkhan et al., 2014).

Total sleep time is the duration in minutes of nighttime sleep (Moore et al., 2015). Typically, 420 to 540 minutes of nighttime sleep is considered adequate (Miaskowski et al., 2011). It is important to be aware of quiet wakefulness as it can be misinterpreted as sleep, thus overestimating total sleep time (Shambroom et al., 2012; Zinkhan et al., 2014).

Sleep efficiency is the percentage of time spent sleeping (Enderlin et al., 2011). A value of 80-85% or greater is considered an acceptable sleep efficiency value (Johansson et al., 2014; Miaskowski et al., 2011). Sleep efficiency is a particularly useful measure of overall sleep quality.

Sleep latency is the time in minutes to fall asleep or the first period of persistent inactivity (Moore et al., 2015). Sleep latency has been reported as one of the least accurate sleep measures in actigraphy, but has been recommended for use as an adjunct to other sleep variables (Enderlin et al., 2011; Lichstein et al., 2006; Littner et al., 2003). A normal value for sleep latency proposed by Miaskowski et al. (2011) is less than 20 minutes.

Wake after sleep onset (WASO) is the total minutes awake during nighttime from sleep onset to final awakening (Ancoli-Israel et al., 2003). Normal values can range for WASO, but typically 10% of total sleep minutes spent awake is acceptable (Miaskowski et al., 2011).

Sleep fragmentation refers to the brief arousals that occur during a period of sleep. The fragmentation index is manifested by the variability of body movements from hour to during sleep hours (Ancoli-Israel et al., 2003). A fragmentation index score of less than 20 indicates good sleep, whereas greater than 50 indicates poor sleep (Blackwell et al., 2011). This variable does not typically align well with reported polysomnography variables.

Features and Feasibility Testing Results.

It is important to think about the features available in actigraphs that may facilitate accurate measurement for a specific study. Most actigraphs come equipped with an event button, which is useful in marking times throughout the day specific to the outcome. Similar to sleep diaries, utilizing the event button can be useful as an adjunct for more precise documentation of sleep and wake times (Blackwell et al., 2014; Dean et al., 2013; Enderlin et al., 2011; Johansson et al., 2014). The event button can be pressed when the actigraph needs to be removed for a period of time, such as when a person needs to immerse in water for a bath. Consideration to the population, geographic area (seasons), and the environment for data collection is also important. Options for a light meter, temperature, and sound sensors are available on many actigraphs.

The light meter may not be reliable in determining the time people went to bed and arose in the morning if event markers are not consistently pressed. Our team collected actigraphy data for 2 nights to examine feasibility of data collection and determine if the light sensor could be used to reliably measure the night time-in-bed interval or select sleep variables. The University Institutional Review Board approved the study and consents were mailed to the durable power of

attorney. A 26% consent rate yielded a sample size of 33 residents with dementia from two long-term care facilities. The majority of the sample was female (n=28, 85%), had graduated from high school (n = 26, 79%) and all were of non-Hispanic white racial ethnicity. The average age was 89 (SD = 7.5) and the average MMSE cognitive status score was 10.58 (SD = 8.6).

The actigraph with light sensor was placed on the non-dominant wrist at 3:00 pm. This provided a washout period for adjustment to wearing the device prior to the start of data collection at bedtime. Data collection began at bedtime on Day 1 and continued until 9:00 am on Day 3. Two trained research assistants did observations every 15 minutes to capture the time-in-bed interval. The evening time-to-bed was recorded as the time the person was put to bed following nighttime care and coincided approximately with the lights being turned off. To demarcate the end of the nighttime time-in-bed interval, the research assistant marked the time the resident awakened naturally or was aroused by the nursing assistant in the early morning.

The time-in-bed interval was demarcated for analyses using both the observation and light recordings. Differences in the time-in-bed interval delineated by observation versus light were analyzed using a paired t-test. Due to skew in measures of sleep variables, differences in sleep latency, sleep minutes, sleep efficiency and wake after sleep onset (WASO) were compared using the Friedman test.

The actigraph was well tolerated and provided very complete data regarding activity and sleep. No participant's refused to wear the actigraph. Of 33 participants in the study, one participant removed the actigraph from her wrist for 740 of the 2520 minutes of data collection (29% lost data). Another participant had the actigraph removed by a nursing assistant per our directives for 35 minutes (1% lost data) during a bath.

There were statistically significant differences in the time-in-bed interval delineated by observation versus light measurements ($t(32) = -2.338, p = .026$). The time-in-bed interval average was 692.45 minutes ($SD = 97.1$) by observation and was 724.03 ($SD = 125.96$) minutes by time lights went off at night and on in the morning. As seen in Table 1, there were statistically significant differences in sleep minutes, sleep efficiency, and sleep latency using the two procedures to delineate the time-in-bed interval. Even though not statistically significant, there was a 19 minute difference in the median scores for wake after sleep onset between the two methods of delineating the time-in-bed interval.

Algorithms and modes.

Algorithms are pre-set equations within a computer program that are used to automatically score actigraph data. Cole-Kripke, UCSD, and Sadeh are three algorithms used that can produce different counts for the same data (Ancoli-Israel et al., 2003). Modes capture how the analog signal is digitized and stored which include time above threshold, zero crossing, or proportional integrating measure (PIM) (Ancoli-Israel et al., 2003). Algorithms and modes to process actigraph data are important to consider as results can vary between certain populations (Ancoli-Israel et al., 2003; Jean-Louis, Kripke, Cole, Assmus, & Langer, 2001). The literature is equivocal regarding which algorithms and modes may be most appropriate for studying specified populations and prohibit recommendations in this article.

Epoch length.

An epoch is a set time interval where activity counts are collected and stored. It is important to choose appropriate epoch lengths to align with the purpose of the study. Epoch lengths reported in research studies vary from 15 seconds to 2 minutes (Blackwell et al., 2014;

Dean et al., 2013; Girschik, Fritschi, Heyworth, & Waters, 2012; Hanisch et al., 2011; Shambroom et al., 2012). One-minute epochs are most commonly used for sleep estimation.

Actigraph selection.

It is important to compare actigraph devices for sensitivity, specificity, validity, and reliability. Sensitivity for sleep is the proportion of sleep epochs correctly identified as sleep by actigraphy. Specificity is the correct identification of wake epochs identified by actigraphy (Ancoli-Israel et al., 2003). Many actigraph devices exist on the market and it is important to consider needs of population and intended purpose in order to find the best fit when purchasing a device.

Conclusion

In order to solve many of the problems facing older adults, researchers must be able to obtain precise measures that are clinically meaningful and sensitive to change. Actigraphy can be useful in measuring sleep, rest-activity patterns, and circadian rhythms in older adults. Actigraphy is feasible for use with long-term care residents with dementia. Thoughtful planning regarding the use of event buttons, light sensors, sleep diaries, algorithms, epoch length, and modes of operation is needed to yield high quality measures of variables of interest. Since data can be collected continuously over long periods of time using actigraphy, an examination of the temporal sequencing of events that come before or after patterns of sleep or activity can be researched.

Summary

In this chapter, two manuscripts were presented. The first manuscript examined theory surrounding pain and sleep quality in PWD. An illustration of the relationship between various physiologic sources of pain and sleep quality in PWD was presented. Conceptual definitions and

the application of theory to the study was discussed. The second manuscript describes fundamental considerations when using actigraphy in research with older adults. Actigraphy was presented as a non-invasive yet sophisticated method to measure sleep in persons living in the community and long-term care settings.

CHAPTER 3

Introduction

Poor sleep quality is associated with an increased risk for negative health outcomes, decreased functional status, decreased quality of life, and an increased risk for hospitalizations, morbidity, and mortality in older adults. The focus of this dissertation was a descriptive, correlational study examining the relationship between musculoskeletal, respiratory, gastrointestinal, and genitourinary discomfort and sleep quality in older adults and a subset of PWD. The population of older adults and those with dementia is steadily increasing. Understanding how to prevent negative health outcomes and costly hospitalizations in older adults and PWD is a national priority.

The purpose of this study was to determine the relationship between sources of physical pain and sleep quality in older adults and PWD. This was an exploratory study to understand if and to what degree relationships exist between sources of pain and sleep quality in older adults and PWD. Knowledge regarding the relationship of pain and sleep quality is extremely important to move the nursing science forward in developing targeted assessment skills and appropriate interventions for older adults and PWD to improve sleep quality and overall health outcomes.

Method

Research Design

This proposed study was a secondary data analysis using a descriptive, correlational design. The descriptive, correlational design is intended to describe the relationship between the dependent and independent variables as well as to provide information to generate future hypotheses and research. Data for this study was collected for a larger descriptive study to

explore the relationship between lung health and sleep in older adults. The primary study was approved by the Institutional Review Board at the University of Wisconsin-Milwaukee. The author of this study was the project manager for the primary study. She was responsible for all aspects of the study including recruitment, data collection, management, and data entry. The independent variables in this study are inherently not able to be assigned but represent states of discomfort/pain. This study explored the association between specific types of pain and sleep quality since most types of pain previously have not been identified in the literature.

Research Questions and Hypotheses

The research questions addressed in this study include:

- 1) What is the frequency of MS, respiratory, GI, and GU pain in long-term care residents and a subset with dementia?
- 2) What is the severity of MS, respiratory, GI, and GU pain?
- 3) What is the sleep quality (i.e. total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation) of older adults with and without dementia residing in long-term care?

The hypotheses for this study include:

- 1) Controlling for co-morbid problems including cognitive impairment, musculoskeletal (MS), respiratory, gastrointestinal (GI), and genitourinary (GU) pain will predict sleep quality (total sleep time, sleep efficiency, sleep latency, wake after sleep onset (WASO), and sleep fragmentation). It is already known that higher pain levels will result in a decrease in sleep quality. This directional hypothesis is based on the gap in understanding of the types of pain that are more likely to predict sleep quality. Co-morbid problems and moderate to severe dementia may confound the relationship of pain on sleep quality.

2) There will be no differences in the severity of MS, respiratory, GI, and GU pain in residents with no and mild cognitive impairment and those with moderate to severe dementia. This directional hypothesis is based on the premise that severity of pain may be interpreted differently for those with moderate to severe dementia.

Sample and Setting

The proposed study setting occurred at one long term care organization with three sites located in a Midwestern city. The city was chosen by convenience for geographic closeness to the PI. Use of the specific long-term care setting provides feasible access to older adults and PWD as the researcher already has a working relationship within the care setting. The setting provides a continuum of services and includes adult daycare, community outpatient memory care programs, independent apartments, assisted living, skilled care, and post-acute rehabilitation.

Consecutive sampling was used for recruitment for feasibility. Power analysis using effect sizes from previous studies in the literature was used to determine the appropriate sample size to protect against Type II error. After adjusting for multiple relationships, effect size of 0.2 (small-medium), power level of 0.8, and probability (alpha) level of 0.05, a minimum sample size of 83 is required per power analysis (Cohen, 1988).

Due to the heterogeneity in population of older adults and PWD residing in the long term care organization, powers for small to medium effect size was appropriate for expressing the proper strength of relationships among the sample (Polit & Beck, 2012, p. 285). Limiting the population to people residing in residential long-term care was feasible and controls for confounds from multiple settings. The population needed to remain very specific, as the problem of poor sleep quality in older adults and PWD is different than in infants, children, or younger adults. Residents were screened for eligibility criteria that included: a) current acute illness; b)

undergoing rehabilitation for a change in condition; and c) movement disorder(s) which would interfere with actigraphy.

Instruments

This section of the paper provides a description of the tools that were used in the original study to measure the dependent and independent variables. Observational measures, clinical assessment data, and bio-physiological measures are used in this dissertation. While the some of the clinical variables do not have sensitivity and specificity data, these are all commonly used parameters used in assessment of older adults in long-term care.

Dependent variable. Sleep has been defined as a complex combination of physiologic and behavioral processes that is typically evidenced by postural recumbence, behavioral stillness, and closed eyes. Quality of sleep is understood as a perception of how good or bad the process of sleep occurred. Sleep quality can be captured objectively and subjectively. For the purpose of this dissertation study, sleep quality was characterized objectively by total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation captured through actigraphy. Definitions of total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation is described below as well as acceptable ranges.

Actigraphy as measurement

The actigraph utilized for this study was the Micro Mini-Motionlogger® actigraph by Ambulatory Monitoring Inc. (Ardley, New York). This device is particularly feasible for use in older adults with dementia residing in long-term care settings due to its ease of use and low invasiveness (Shambroom et al., 2012). The actigraph is a biophysical tool typically worn on the non-dominant wrist for a minimum of 72 hours. Self-reported sleep logs were utilized as an adjunct to actigraphy for an accurate mark of the nighttime sleep period. Sleep logs have been

used in research to code actigraphy data and generally have good agreement in capturing changes in sleep patterns (Johansson et al., 2014). Variations of physical activity were continuously captured using a piezoelectric accelerometer over a period of time and translated into numbers for a quantitative assessment of sleep quality (Boudebesse et al., 2014). Absence of movement was considered a proxy for sleep as well as repetitive wrist activity is used as a proxy for wakefulness (Johansson et al., 2014). Actigraphy provides reliable results and is comparable to polysomnography in its sensitivity (89%) and specificity (95%) when evaluating patients with suspected sleep apnea (Morgenthaler et al., 2007). Agreements between actigraphy and polysomnography for sleep and wake were 86.3% and 85.7% in healthy community dwelling adults, respectively (Shambroom, Fabregas, & Johnstone, 2012).

Total sleep time. Total sleep time is the length in minutes of nighttime sleep (Moore et al., 2015). An acceptable range of nighttime sleep ranges from 420 to 540 minutes (Miaskowski et al., 2011). Periods of quiet wakefulness can be miscalculated as sleep, thus overestimating total sleep time (Shambroom et al., 2012; Zinkhan et al., 2014).

Sleep efficiency. The percentage of time spent asleep is characterized as sleep efficiency (Enderlin et al., 2011). As a particularly useful measure of overall sleep quality, a value of 80-85% or greater is considered an adequate sleep efficiency (Johansson et al., 2014; Miaskowski et al., 2011).

Sleep latency. Sleep latency is defined as the duration in minutes to fall asleep or the first period of persistent inactivity (Moore et al., 2015). A standard value for sleep latency offered by Miaskowski et al. (2011) is less than 20 minutes. Sleep latency has been stated as one of the least accurate sleep measures in actigraphy, but has been recommend for use as an adjunct to other sleep variables (Enderlin et al., 2011; Lichstein et al., 2006; Littner et al., 2003).

Wake after sleep onset. Wake after sleep onset (WASO) is the percent of minutes awake during nighttime from sleep onset to final awakening (Ancoli-Israel et al., 2003). Normal values can range for WASO, but typically 10% of total sleep minutes spent awake is adequate (Miaskowski et al., 2011).

Sleep fragmentation index. Sleep fragmentation refers to the brief arousals that occur during a period of sleep. The fragmentation index is demonstrated by the variability of body movements from hour to hour during sleep hours (Ancoli-Israel et al., 2003). A fragmentation index score of less than 20 signifies good sleep, whereas greater than 50 suggests poor sleep (Blackwell et al., 2011). This variable does not typically align well with reported polysomnography variables.

Independent variables. Pain has been portrayed as an unpleasant sensory or emotional occurrence associated with actual or potential tissue damage (Ferrell & Coyle, 2010). Pain is a highly subjective experience and usually varies along a continuous duration of time. In PWD, pain can theoretically be difficult to measure due to the questionable accuracy of self-report. Although self-report can be unreliable, the experience of pain in PWD needs to be acknowledged. Therefore, it is essential to attempt to target sources of pain through objective measurement in order to manage the health needs of PWD. Pain is typically classified as acute and chronic. For the purpose of this dissertation, this study did not attempt to differentiate between these classifications of pain. This study identified pain or discomfort in the musculoskeletal, respiratory, gastrointestinal, and genitourinary systems. Comorbid conditions and level of dementia were also measured. Conceptual definitions of each variable are provided as well as measurement and reliability and validity will be discussed.

Musculoskeletal pain. The musculoskeletal system includes bones, muscles, cartilage, tendons, ligaments, joints, and other connective tissue that support and bind tissues and organs

together. Musculoskeletal pain/discomfort assessment was measured using the PAINAD (Warden, Hurley, & Volicer, 2003). This five-item Likert-scale requires 5-minutes of observations with total scores ranging from 0 to 10. A higher score indicates more severe pain versus a lower score indicates mild pain. The PAINAD primarily targets assessment of musculoskeletal pain during activities. Assessments of pain in the morning after sleep and at nighttime prior to sleep were the most logical times to assess pain surrounding sleep quality assessment. According to Warden, Hurley, and Volicer (2003), internal consistency using Cronbach alpha was 0.70. Significant correlations were found among the DS-DAT (Discomfort Scale – Dementia of Alzheimer Type) and DS-VAS (Discomfort Scale – Visual Analog Scale) as well as between simultaneous ratings of pain during both presumed pleasant and unpleasant conditions as a way to support appropriate construct validity and reliability (Warden et al., 2003).

Respiratory discomfort. The respiratory system includes the lungs that are responsible for taking in oxygen and expelling carbon dioxide. Respiratory discomfort will be captured using the Respiratory Distress Observation Scale (RDOS) (Campbell, 2008; Campbell, Templin, & Walch, 2010) and oxygen saturation using a pulse oximeter at rest during morning and evening times. Number of pillows and elevation of head of bed were assessed. The RDOS is an 8-item Likert-scale with scores ranging from 0 to 16, with a higher score indicating severe respiratory distress. The RDOS is simple to use and scoring takes less than 5 minutes (Campbell et al., 2010). After psychometric testing, the RDOS has been utilized in older adults that are unable to self-report as an objective tool to evaluate measures of dyspnea. Internal consistency and convergent validity with dyspnea self-report and discriminant validity with pain and no dyspnea has been shown (Campbell et al., 2010). The reliability of this 8-item scale was supported with a Cronbach alpha

of 0.64. Perfect interrater reliability across data collectors was reported (Campbell et al., 2010). Assessments of discomfort in the morning and prior to nighttime sleep were reasonable times to evaluate the associations of pain as close to nighttime sleep as possible.

Oxygen saturation was assessed in conjunction with the RDOS as a proxy of respiratory discomfort. Pulse oximetry was a feasible, noninvasive method for monitoring indirect oxygen saturation through reading of peripheral oxygen saturation (Fahy, Lareau, & Sockrider, 2011). The Contec Portable Sports and Aviation Finger Pulse Oximeter OX Spo2 Fingertip Oxygen Digital OLED Monitor Display, CE FDA approved was used for this study. The pulse oximeter is a small device with a built-in finger/toe clip where beams of light pass through the blood in the finger (or toe) to measure oxygen. The beams of light are interpreted to calculate the percentage of blood that is carrying oxygen as well as calculation of heart rate. To ensure accuracy of the pulse oximeter, it was recommended to count the heart rate for one minute and compare to the recording on the device. If the numbers were the same, this was indicative a good signal (Fahy et al., 2011; O'Driscoll, Howard, Earis, & Mak, 2017). Normative values for oxygen saturation readings in healthcare settings range from 94-98% (O'Driscoll et al., 2017). The pulse oximeter is comparable to the gold standard of arterial blood gas to obtain oxygen level, with 2% variability in saturation readings. Accuracy of pulse oximetry is questionable with nail polish, artificial nails, cold hands, poor circulation, dark skin, or very low oxygen saturation levels (below 80%) (Fahy et al., 2011).

Gastrointestinal discomfort. The mouth, esophagus, stomach, small intestine, large intestine, and anus are hollow organs of the gastrointestinal tract allow for digestion of food. The liver, pancreas, and gall bladder are solid organs of the digestive system. Gastrointestinal (GI) discomfort was captured through identification of same day symptoms of diarrhea, constipation,

nausea, vomiting, GI discomfort, decreased appetite, or hiatal hernia. There is no known tool that specifically targets gastrointestinal pain, therefore multiple components were obtained from chart review and staff report. If participants were cognitively intact based on Mini-Mental Status Examination (MMSE), self-report was utilized. A scale was used to measure GI discomfort based on one point for each symptom that day: diarrhea, constipation, nausea, vomiting, c/o GI distress, decreased appetite ($\leq 50\%$ of diet eaten compared to the previous day or past 1 or 3 days $\leq 50\%$ of past 1 to 3 days), and current or history of hiatal hernia. The amount of time before dinner and bedtime as well as auscultation of bowel sounds (normoactive, hypoactive, hyperactive) was also be recorded as a potential source of discomfort. While no reliability or validity information was found for simple questions of gastrointestinal discomfort, patients are commonly questioned about these sources of discomfort as a part of routine physical assessments (Haws, 2015).

Genitourinary discomfort. The reproductive organs and urinary system comprise the genitourinary system. Genitourinary (GU) discomfort included assessment of urinary retention using a bladder scanner at bedtime with a proxy value of 100ml or more as an indication discomfort (AUA, 2016). The bladder scanner is a clinical device that uses ultrasound waves to determine volume of urine inside the bladder. Ultrasound (US) waves pass through the transducer and are converted to ratio level numbers displayed on the machine screen. Cubescan™ BioCon-700 is the bladder scanner device that will be utilized for this study. In a comparison study, this bladder scanner was compared computed tomography (CT) scan volumes and was shown to be an equivalent to the standard measure of bladder volume. Comparison of the ultrasound (US) and CT mean, the difference was 10 ± 49.92 (1 SD), with the cohort mean US bladder volume 323ml and CT US bladder volume 313ml (Claxton & Appleyard, 2017). Self-

report by staff or participant (depending on level of cognition) of signs and symptoms of urinary discomfort were also recorded. Symptoms of urinary discomfort may include but are not limited to burning, irritation, pressure, frequency, urgency, and/or active urinary infections. Similar to simple questions of gastrointestinal discomfort, patients are commonly questioned about sources of genitourinary discomfort as routine nursing assessment (Haws, 2015).

Comorbid illness. Comorbidity is defined as the existence of two or more mental or physical diseases that do not operate independent of one another, instead simultaneously affect the overall health of a person over the life trajectory (Sartorius, 2013). Comorbid illness was measured with the Cumulative Illness Rating Scale for Geriatrics (CIRS-G) (Miller et al., 1992). The CIRS-G quantifies and tracks medical burden in geropsychiatric patients as a 14-item Likert-scale. Each item contains a rating ranging from 0 (no problem), 1 (mild problem), 2 (moderate severity requiring active therapy), 3 (severe or constant disability), and 4 (extremely severe or urgent clinical problem). Total number of organ-specific categories, total score, ratio of total score/number of organ-specific categories (yielding a severity index), and number of organ-specific categories at severity level of 3 or 4 represents scoring of CIRS-G (Miller et al., 1992). Interrater reliability was acceptable with intraclass correlations of 0.78 and 0.88 as well as significant correlations found with the Older Americans Activities of Daily Living Scale (OARS-ADL) (Miller et al., 1992). Miller et al. (1992), also report face validity of the scale which implies appropriate conceptual use of the scale to capture comorbid illness burden. Multiple comorbid illnesses may confound both the dependent and independent variables. Therefore, statistical analyses can control for levels of comorbid illness among the study population.

Level of dementia. Dementia is a symptom of neurodegenerative changes to the brain as a result of various diseases such as Alzheimer's, the most common form of dementia (S. Kim et

al., 2014; Neef & Larson, 2008). Level of dementia was measured with the Mini Mental Status Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). The MMSE is a 30-point questionnaire used to measure levels of cognitive impairment. Administration of the questionnaire takes between 5 and 10 minutes and assesses functions including orientation, recall, language, ability to follow simple commands, attention and calculation, as well as registration (Folstein, Folstein, & McHugh, 1975). A score greater than or equal to 24 points (out of 30) indicates normal cognition. Mild cognitive impairment is classified from 19-23, moderate 10-18, and severe less than or equal to 9. This tool has been used and psychometrically tested with older adults with varying levels of cognitive impairment. Moderate to high test-retest reliability with correlations of 0.38 to 0.99, internal consistency with Cronbach's alpha coefficient of 0.54-0.96, concurrent validity with other measures of cognitive impairment with correlations of 0.70-0.90, average sensitivity of 75% among dementia patients, and specificity of 62%-100% (Tombaugh & McIntyre, 1992). This tool is easy to administer, is widely used and has a substantial number of validity and reliability studies supporting its use.

Other variables. Data was collected on basic demographics such as age, gender, and education to describe the sample. Number of medications that promote and inhibit sleep were accounted for to control for this potentially confounding variable.

Research Procedures

This section describes the data collection procedures conducted in the primary study. Training of a collector in recruitment of the sample, consent processes, and data collection procedures and tools is important for consistency and clarity. Only one data collector has been utilized in the primary study which enhanced internal reliability/consistency of data collection measures.

Recruitment was completed through flyers, announcements were sent to the residents from the organizations, town hall meetings, and face to face recruitment with the social worker(s). A table was also be set up in a high traffic area for interested participants to get information, review consent procedures, have questions answered, and submit signed consent documents. A phone call was placed to residents unavailable through previously listed recruitment strategies. Screening for eligibility and consent/assent was conducted during face to face participants. Any data related to persons found ineligible to participate in the study was destroyed. For eligible participants, consent and assent procedures took place. The participants were informed of the next steps for participation in the study.

Table 3.1: Daily Procedures Following Consent and Eligibility

<u>Day of Week</u>	<u>Procedure(s)</u>
Monday	<ul style="list-style-type: none"> • Actigraph placed on non-dominant wrist before 4pm. • Sleep log distributed to participant (if cognitively intact) or staff (if cognitively impaired) to assist with documentation of sleep and wake times. • Procedures for how to use actigraph will be explained to the participant and/or staff. <ul style="list-style-type: none"> ○ The watch is waterproof, it is ok to shower or swim with watch on. ○ Keep the watch on for entire duration of study participation. ○ Press event button at time of waking for the day and time going to bed for the evening. • Contact information is made available for questions or concerns outside of normal working hours.
Tuesday or Wednesday (AM) * measures will occur on only one day during week of participation	<ul style="list-style-type: none"> • Measure musculoskeletal pain using PAINAD over 5 minutes during movement. • Measure respiratory distress using RDOS over 5 minutes and pulse oximetry over 1 minute at rest.
Tuesday or Wednesday (PM)	<ul style="list-style-type: none"> • Measure musculoskeletal pain using

<p>* measures will be repeated on same day of morning assessment</p>	<p>PAINAD over 5 minutes during movement.</p> <ul style="list-style-type: none"> • Measure respiratory distress using RDOS over 5 minutes and pulse oximetry over 1 minute at rest. Auscultate lung sounds (clear, rhales, rhonchi, wheezing, diminished) for 1 minute at rest. Number of pillows and elevation of head of bed recorded. • Measure gastrointestinal discomfort using predetermined assessment questions (constipation, diarrhea, nausea, vomiting, c/o GI discomfort, appetite, hiatal hernia). <ul style="list-style-type: none"> ○ If cognitively intact: use self-report ○ If cognitively impaired: use staff report and chart review Auscultate bowel sounds (normoactive, hypoactive, hyperactive) and palpate abdomen, observe for signs and symptoms of discomfort during assessment • Measure genitourinary discomfort using bladder scanner for urinary retention as proxy of discomfort (have participant empty bladder prior to bladder scan). Assess verbal report from participant or staff of signs and symptoms of urinary discomfort (burning, irritation, pressure, frequency, urgency, and/or active urinary infections) <ul style="list-style-type: none"> ○ If cognitively intact: use self-report ○ If cognitively impaired: use staff report and chart review
<p>Thursday</p>	<ul style="list-style-type: none"> • Actigraph removed from wrist after waking hours. • Retrieval of sleep log. • Information downloaded using Watchware program through Ambulatory monitoring for later coding and analysis. • Sleep logs and other files will be secured in a locked cabinet for later data entry into SPSS statistical software.

Table 3.2: Data Analysis Plan

Research Hypotheses	Unit of Analysis	Variable	Measurement tool	Level of Measurement	Statistical Test
Descriptive Questions					
What is the frequency of MS, respiratory, GI, and GU pain in long-term care residents with dementia?	Resident subject	<ul style="list-style-type: none"> - Musculoskeletal (MS) - Respiratory - Gastrointestinal (GI) - Genitourinary (GU) 	<p>PAINAD</p> <p>RDOS, pulse oximeter, auscultation of lung sounds</p> <p>Self-report/ staff, chart review, auscultation of bowel sounds and palpation of stomach</p> <p>Bladder scan and self-report/ staff</p>	<p>Ordinal</p> <p>Ordinal and Nominal</p> <p>Nominal</p> <p>Ordinal and Nominal</p>	Descriptive (Frequency, mean, SD, range, percentages)
What is the severity of MS, respiratory, GI, and GU pain?	Resident subject	<ul style="list-style-type: none"> - Musculoskeletal (MS) - Respiratory - Gastrointestinal (GI) 	<p>PAINAD</p> <p>RDOS, pulse oximeter, auscultation of lung sounds</p> <p>Self-report/ staff, chart review, auscultation of bowel sounds and palpation of stomach</p>	<p>Ordinal</p> <p>Ordinal and Nominal</p> <p>Nominal</p>	Descriptive (Frequency, mean, SD, range, percentages)

		- Genitourinary (GU)	Bladder scan and self-report/staff	Ordinal and Nominal	
What is the sleep quality (i.e. total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation) of PWD?	Resident subject	- Total sleep time - Sleep efficiency - Sleep latency - Wake after sleep onset - Sleep Fragmentation	Actigraph coded with sleep log	Ordinal	Descriptive (Frequency, mean, SD, range, percentages)
Hypotheses					
Controlling for level of cognitive impairment and co-morbid problems, residents with higher frequency of MS, respiratory, GI, and GU pain will have poorer sleep quality (total sleep time, sleep efficiency, sleep latency, wake after sleep onset, sleep fragmentation)	Resident subject	Covariate: - Cognitive impairment - Co-morbidity IV: - Musculoskeletal (MS) - Respiratory - Gastrointestinal (GI) - Genitourinary (GU) DV: sleep quality - total sleep time	MMSE CIRS-G PAINAD RDOS, pulse oximeter, auscultation of lung sounds Self-report/staff, chart review, auscultation of bowel sounds and palpation of stomach Bladder scan and self-report/staff Actigraph	Ordinal Ordinal Ordinal Ordinal and Nominal Nominal Ordinal and Nominal Ordinal	Binary Logistic Regression

		<ul style="list-style-type: none"> - sleep efficiency - sleep latency - wake after sleep onset - sleep fragmentation 			
There will be no differences in the severity of MS, respiratory, GI, and GU pain in residents with no and mild cognitive impairment and those with moderate to severe dementia.	Resident subject	IV: <ul style="list-style-type: none"> - Musculoskeletal (MS) - Respiratory - Gastrointestinal (GI) - Genitourinary (GU) Interaction variable: moderate to severe dementia	PAINAD RDOS, pulse oximeter, auscultation of lung sounds Self-report/staff, chart review, auscultation of bowel sounds and palpation of stomach Bladder scan and self-report/staff MMSE 0-18 = moderate to severe MMSE > 19 = mild to no impairment	Ordinal Ordinal and Nominal Nominal Ordinal and Nominal Categorical	t-test

Initially, the distributions were analyzed for skew using frequency distributions, means, standard deviations, and percentages. Normal distribution is displayed as a symmetric, unimodal, and not too peaked curve (Polit & Beck, 2012, p. 384). In a normal distribution, a fixed

percentage of cases fall within certain distances from the mean (Polit & Beck, 2012, p. 388). If severe skew was present, medians and ranges were used to describe the data rather than means and standard deviations. Transformations were used in the presence of skewed distributions. Descriptive statistics were used to describe and summarize sample characteristics. Continuous variables such as age and length of stay were described using the mean and standard deviation. Categorical variables such as gender and race were described using frequencies, frequency distributions and percentages.

It is important to analyze the descriptive statistics for normalcy of the sample, if they have a skew then other statistical tests (non-parametric) may need to be utilized for later analysis. Nonparametric tests are used when data are nominal or ordinal or when a normal distribution cannot be assumed, especially when samples are small (Polit & Beck, 2012, p. 431). Descriptive statistics give a picture of the data set and provide direction on how to proceed with appropriate analysis. Causal inferences cannot be made using correlational research (Polit & Beck, 2012, p. 228). Yet, a correlational design was appropriate for this research as it was an efficient way to collect a large amount of information about the hypothesized problem between pain and sleep.

My main research question has independent and dependent variables that are continuous, which calls for frequencies, means and standard deviations, assuming the sample was normally distributed. Comparisons were made between those with dementia and those who are cognitively intact. Since parametric assumptions were not met, the t-test was used for this analysis. Levene's test is a form of checking for homogeneity of variance among the sample. An assumption underlying the use of the t-test is the population of variances for the two groups is equal (Polit & Beck, 2012, p. 427).

Logistic regression is a method to analyze the relationship between multiple independent variables and a dependent variable and produces a predictive equation (Polit & Beck, 2012, p. 448). For this dissertation study, logistic regression was used to illustrate the relationships between the independent variables of pain and dependent variable of sleep quality while controlling for potentially confounding variables of level of dementia and comorbid illness. Since there were significant differences in sleep quality between persons with and without dementia, groups were described separately and controlled in the regression model.

Sleep quality variables, dementia, and pillow use were all recoded into dichotomous variables to indicate normal or abnormal values for logistic regression analyses. Normal values commonly used in the literature were used as guidelines to dichotomize variables into normal or abnormal values. Comorbid illness was not included in the model as it was not statistically significantly contributing to the logistic regression model.

Data Management Plan

All data was entered into a password-protected database with all patient information de-identified. Information was stored in locked file cabinets in a locked office. A codebook was created and SPSS database set up according to the codebook.

The data management plan included the following steps:

1. To ensure data accuracy, before presentation of the analysis files the Data Manager and the statistician cleaned the data using double data-entry or a two-person, crosschecking technique. As an additional safeguard, the frequency distributions of all variables were checked before proceeding with the analysis.
2. Data was checked for sufficient variability in the dependent measures.

3. When 25% of the data was collected, the Data Manager checked the resident criteria with the responding sample demographics for any problems/skew.
4. Beginning when 25% of the data was collected, data was checked to ensure that assumptions for planned statistical analyses were met.
5. To be included in the analysis, every case must have a score on both the process and outcome variables. Thus, any case with missing outcome scores or 5% or more of the process scores was planned to be excluded. Missing data was managed and no cases needed to be excluded.

If problems arose, the statistical teams at the University of Wisconsin-Milwaukee, the methodological experts (Dr. Christine Kovach, Dr. Julie Ellis, Dr. Melinda Kavanaugh) and the PI worked together to make decisions about any needed modifications. The PI kept a log by tracing the history and rationale for any needed modifications.

Strengths and Limitations

A descriptive, correlational design was a feasible and realistic way of collecting a large amount of information surrounding a hypothesized problem. Yet reporting of results was limited as no causal claims can be made. Therefore, strength of relationships and their associations were reported. In the primary study, consecutive sampling was chosen for convenience and feasibility reasons. Recruitment of all people who meet eligibility criteria in a specified population was a strength a consecutive sampling as it supports a more heterogeneous sample. Convenience sampling for this study limited generalizability and random sampling for this type of study was too costly and unrealistic. The primary study recruitment and data collection remained within one organization but utilized all three sites. The sites had differences in levels of care from independent to skilled nursing. We excluded subjects with movement disorders such as

Parkinson's or Huntington's disease. Residents with no dementia identified through medical records or the MMSE were still be used and compared to residents with dementia. This study also statistically controlled medications that promote or inhibit sleep. Measurement error can occur in any study. To minimize measurement error, data collection methods were strictly consistent and interrator reliability checks were conducted for every 10% of data collection. If interrator reliability was $< .85$ the research team planned to retrain and retest.

Repeated measures would improve accuracy of pain and sleep data. Accuracy of pain and sleep scores may not be robust due to only one day of measurement for pain (in morning and evening) and 3 days for sleep measures. This study only considered one area (pain) that could be associated with poor sleep quality. There are other factors such as environmental, psychological, biological (innate circadian rhythm), and social factors that also could contribute to the problem of sleep quality. Means of measurement is another area that may have limitations. There was difficulty obtaining accurate and reliable subjective measures from PWD, therefore the measurement needed to involve objective measures. The possibility of error in validity of tools was also a consideration. The actigraph has its limitations in that it cannot distinguish between awake and lying still or sleeping. It was possible that low levels of pain observed during data collection may be related to prior medication administration. Additionally, medications may also be administered for ongoing genitourinary or gastrointestinal discomfort that were not captured by reviewing the MAR on days of data collection.

Summary

The purpose of this descriptive correlational study was to fill the gaps that currently exist in the literature about the relationship between physiologic sources of pain and sleep quality in older adults. This chapter provided an overview of the sample, data collection procedures,

instruments, and data analysis and management plan for the proposed study. Lastly, strengths and limitations were also discussed in this chapter.

CHAPTER 4

This chapter presents findings from a descriptive study exploring physiologic sources of pain and their relationship to sleep quality. The format for chapter 4 is a manuscript prepared for submission to a peer-reviewed scientific publication. Background and significance surrounding sleep quality and pain are introduced. A description of the study design, setting, sample are presented followed by an explanation of measurement, procedures, and analyses. A description of the sample, frequency and severity of pain symptoms, and sleep quality in persons with and without dementia are presented. Factors predicting sleep quality are explicated. Results, strengths and limitations, and implications for future research are illustrated.

INTRODUCTION

Poor sleep quality is common in older adults and is particularly fragmented and impaired in people living with dementia (PWD). Many physiologic processes within the body are regulated by circadian rhythm and change as a natural process of aging. Sleep and arousal, pain perception, and cognition all have been implicated in the biologic processes of aging (Paulson, Monroe, & Mion, 2014; Roehrs & Roth, 2005). Although sleep changes are characteristic of the aging process, poor sleep quality is not considered a normal part of aging (Zdanys & Steffens, 2015). Normal aging changes include difficulty falling asleep, nighttime arousals related to physical function, and waking up earlier in the morning.

In older adults, self-reported sleep difficulties range from 50-60%, yet the literature reports a larger prevalence of poor sleep quality in PWD. Poor sleep quality affects anywhere from 25% to 80% of PWD and remains a problem even after moving to long-term care settings (Neikrug & Ancoli-Israel, 2010; Rongve et al., 2010; Roth, 2012). A cascade of negative health outcomes can occur as a result of poor sleep quality which include falls, injury, physical and emotional distress, decreased performance with activities of daily living, worsening quality of life, increased placement in long-term care settings, and mortality (Greenblum & Rowe, 2012; Martin & Ancoli-Israel, 2008; Zdanys & Steffens, 2015).

Pain is another common problem that occurs in old age (Q. Chen et al., 2011). The pathophysiology of dementia results in neurodegeneration to areas of the brain that are responsible for perception of pain and communication (Zdanys & Steffens, 2015; Zuurbier et al., 2015). Neurodegeneration of the brain further affects communication of needs such as pain, complicating the task of recognizing and reporting pain (Flo et al., 2014; Monroe et al., 2014). While limited research has been conducted on the neural networks that connect pain to sleep, it is evident that pain and sleep have some relationship that needs to be explored.

Nearly 40% of all older adults report that pain interferes with their activities of daily living (Dzierzewski et al., 2010; Monroe et al., 2014). Pain is recognized in 45-83% of long-term care residents including PWD (Dzierzewski et al., 2010; Lukas, Mayer, et al., 2013; Monroe et al., 2014). Pain is under reported, under recognized, and consequently undertreated in PWD (Flo et al., 2014; Husebo et al., 2014; Lukas, Mayer, et al., 2013; Passmore & Cunningham, 2014). Consequences of untreated pain can further lead to negative outcomes such as poor sleep quality, impaired ambulation, depression, refusal of care, worsening cognitive impairment, and agitation (Paulson et al., 2014; Roehrs & Roth, 2005).

While the concept of sleep quality remains poorly defined, empirical evidence supports that good sleep quality is associated with positive health outcomes, less daytime sleepiness, and a greater well-being and psychological functioning (Hale et al., 2013; Ohayon et al., 2017). Understanding factors related to sleep are important to management of overall quality of life in older adults and PWD. Currently, the literature supports many causes of poor sleep such as physiologic, cognitive, behavioral, environmental, and pharmacologic factors (Martin & Ancoli-Israel, 2008; Zdanys & Steffens, 2015). Pain is the physiologic factor most commonly associated with PWD experiencing poor sleep quality (Q. Chen et al., 2011; Neikrug & Ancoli-Israel, 2010; Roth, 2012). Unfortunately, specific types of physical pain that are associated with poor sleep quality in PWD have not been elucidated in the literature.

Accordingly, the purpose of this study was to determine the relationship between sources of physical pain and sleep quality in older adults and PWD. This was an exploratory study to understand if and to what degree relationships exist between sources of pain and sleep quality in older adults and PWD. The specific aims were to 1) describe the frequency and severity of musculoskeletal, respiratory, gastrointestinal and genitourinary pain and sleep quality in a sample of cognitively intact older adults and older adults with dementia, 2) evaluate the differences in severity of sources of pain between those with and without dementia, and 3) examine the association of sources of pain to sleep quality.

METHODS

Study Design, Sample, and Setting

This descriptive, observational study was conducted using convenience sampling at three Continuing Care Retirement Communities with independent apartments, assisted living, and skilled nursing care. Participants were excluded from the study if they had movement disorders

which would interfere with actigraphy, current acute illness, or were undergoing rehabilitation for a change in condition. Persons with an indwelling catheter were excluded only from bladder scanning procedures. The study was approved by an Institutional Review Board. Informed consent was obtained from participants able to make their own healthcare decisions. For persons with an activated healthcare power of attorney or guardian, informed consent procedures were completed with the appropriate person and assent was obtained by participant.

After adjusting for multiple relationships, sample size was calculated based on an effect size of 0.2 (small-medium), power level of 0.8, and probability (alpha) level of 0.05. The minimum sample size to be adequately powered was 83 participants. A total of 244 residents were solicited and 103 residents were consented. Per eligibility criteria, four residents were not eligible related to movement disorder. Two residents were resistant to keeping the watch on and seven withdrew due to scheduling conflicts. In addition, one resident was dropped due to comorbid illness interfering with actigraphy measurement. A total of 89 participants were included for data analysis.

Measurement

Dependent Variable: *Nighttime Sleep Quality.*

Measurement of sleep quality was performed using the Micro Mini-Motionlogger® actigraph by Ambulatory Monitoring Inc. (Ardsley, New York). This device is particularly feasible for use in older adults with dementia residing in long-term care settings due to its ease of use and low invasiveness (Shambroom et al., 2012). The actigraph is a biophysical tool typically worn on the non-dominant wrist for a minimum of 72 hours. Self-reported sleep logs were utilized as an adjunct to actigraphy for an accurate mark of the nighttime sleep period. Sleep logs have been used in research to code actigraphy data and generally have good agreement in

capturing changes in sleep patterns (Johansson et al., 2014). Agreements between actigraphy and polysomnography for sleep and wake were 86.3% and 85.7% in healthy community dwelling adults, respectively (Shambroom, Fabregas, & Johnstone, 2012).

Sleep quality was characterized objectively by total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation captured through actigraphy. Total sleep time is the length in minutes of nighttime sleep (Moore et al., 2015). The percentage of time spent asleep is characterized as sleep efficiency (Enderlin et al., 2011). Sleep latency is defined as the duration in minutes to fall asleep or the first period of persistent inactivity (Moore et al., 2015). Wake after sleep onset (WASO) is the percent of minutes awake during nighttime from sleep onset to final awakening (Ancoli-Israel et al., 2003). Sleep fragmentation refers to the brief arousals that occur during a period of sleep. The fragmentation index is demonstrated by the variability of body movements from hour to hour during sleep hours (Ancoli-Israel et al., 2003).

Predictor Variables and Procedures

Observational measures, clinical assessment data, and bio-physiological measures were used in data collection. Pain has been described as an unpleasant sensory or emotional occurrence associated with actual or potential tissue damage (Ferrell & Coyle, 2010). Pain is a highly subjective experience. This study identified pain or discomfort in the musculoskeletal, respiratory, gastrointestinal, and genitourinary systems. Acute and chronic pain were not differentiated.

In PWD, pain can theoretically be difficult to measure due to the questionable accuracy of self-report. Because people with cognitive impairment cannot always accurately self-report symptoms, observational scales that measure pain and respiratory distress were used. In addition,

self-report by the participant or staff report in cases of impaired verbal self-report were used to capture symptoms of gastrointestinal and genitourinary discomfort. Assessments of discomfort in the morning and prior to nighttime sleep are reasonable to evaluate the associations of pain as close to nighttime sleep as possible. One trained research nurse conducted all observations based on the guidelines of each tool or routine clinical nursing assessment.

Data collection for this study occurred over nine months. Up to six new participants started the study on a Monday and completed participation on a Thursday of each week that did not include religious work-restricted holidays. Based on resident availability and unit convenience, approximately half of the residents were scheduled for pain assessments on a Tuesday and half received their pain assessments on a Wednesday. To avoid missing data, assessments were scheduled around resident or staff schedules for the four days of data collection. If conflicts to the schedule occurred, the data collector either returned at a different time or rescheduled assessment for a different week.

Following consent, the MMSE was administered and the medical record was reviewed for exclusion criteria, demographics, and medications that may promote or inhibit sleep. On Monday morning, the actigraph was placed on the non-dominant wrist and a sleep log was distributed to the participant or staff depending on level of cognition. Procedures for how to use the actigraph were explained to the participant and/or staff. On the pain assessment day (Tuesday or Wednesday), measurement of musculoskeletal pain and respiratory distress were completed in the morning and evening and gastrointestinal (GI) and genitourinary (GU) discomfort were assessed in the evening. On Thursday, the actigraph was removed and sleep log was retrieved.

Measurement of musculoskeletal pain using the PAINAD occurred over 5 minutes during movement. Measures of respiratory distress using the RDOS occurred over 5 minutes and pulse oximetry over 1 minute at rest. GI discomfort was evaluated using self-report and/or staff report with chart review of constipation, diarrhea, nausea, vomiting, complaining of GI discomfort, loss of appetite, and current or history of hiatal hernia. Bowel sounds were auscultated, and the abdomen was palpated with observation for signs and symptoms of discomfort. Evaluation with the bladder scanner for urinary retention was completed with participant lying flat after emptying bladder. Assessment of signs and symptoms of discomfort such as frequency, urgency, burning, irritation, pressure, and/or active urinary infections was conducted through self-report and/or staff report with chart review.

Musculoskeletal pain. Musculoskeletal pain assessment was measured using the PAINAD (Warden, Hurley, & Volicer, 2003). This five-item Likert-scale requires 5-minutes of observations. Total scores range from 0 to 10 and higher scores indicate more severe pain. The PAINAD primarily targets assessment of musculoskeletal pain during activities. Assessments of pain in the morning after sleep and at nighttime prior to sleep were the most logical times to assess pain surrounding sleep quality assessment. According to Warden, Hurley, and Volicer (2003), internal consistency using Cronbach alpha was 0.70. Construct validity and reliability has been shown with the PAINAD tool among other similar observational pain assessment tools (Warden et al., 2003). In this study, the PAINAD was reliable with a Cronbach alpha of 0.782.

Respiratory discomfort. Respiratory discomfort was captured using the Respiratory Distress Observation Scale (RDOS) (Campbell, 2008; Campbell, Templin, & Walch, 2010). The RDOS is an 8-item Likert-scale with scores ranging from 0 to 16, with a higher score indicating more severe respiratory distress. The RDOS is simple to use and scoring takes less than 5 minutes

(Campbell et al., 2010). Internal consistency and convergent validity with dyspnea self-report and discriminant validity with pain and no dyspnea has been shown and includes a Cronbach alpha of 0.64 (Campbell et al., 2010). Perfect interrater reliability across data collectors was reported (Campbell et al., 2010). In this study, the Cronbach alpha for RDOS was 0.735 (8 items). Oxygen saturation was also measured using a pulse oximeter at rest during morning and evening times. Number of pillows and elevation of head of bed were also assessed.

Gastrointestinal discomfort. Gastrointestinal (GI) discomfort was captured through identification of same day symptoms of diarrhea, constipation, nausea, vomiting, GI discomfort, decreased appetite, or hiatal hernia. Because there is no known tool that specifically targets gastrointestinal pain, chart review and staff report were used to collect symptom information. If participants were cognitively intact based on Mini-Mental Status Examination (MMSE), self-report was utilized. A scale was used to measure GI discomfort based on one point for each symptom that day: diarrhea, constipation, nausea, vomiting, c/o GI distress, decreased appetite ($\leq 50\%$ of diet eaten compared to the previous day or past 1 or 3 days $\leq 50\%$ of past 1 to 3 days), and current or history of hiatal hernia. While no reliability or validity information was found for simple questions of gastrointestinal discomfort, patients are commonly questioned about these sources of discomfort as a part of routine physical assessments (Haws, 2015). Standard clinical questions evaluating gastrointestinal discomfort in this study was found to have poor reliability (Cronbach alpha = 0.352).

Genitourinary discomfort. Genitourinary (GU) discomfort included assessment of urinary retention using a bladder scanner (Cubescan™ BioCon-700) at bedtime with a proxy value of 100ml or more as an indication discomfort (AUA, 2016). The bladder scanner is a clinical device that uses ultrasound waves to determine the volume of urine inside the bladder. This

brand of bladder scanner was equivalent to computed tomography (CT) scan volumes of bladder volume (Claxton & Appleyard, 2017). Self-report by staff or participant (depending on level of cognition) of signs and symptoms of urinary discomfort was also recorded. Symptoms of urinary discomfort included burning, irritation, pressure, frequency, urgency, and/or active urinary infections.

Level of dementia. Dementia is a symptom of neurodegenerative changes to the brain as a result of various diseases such as Alzheimer's, the most common form of dementia (S. Kim et al., 2014; Neef & Larson, 2008). Level of dementia was measured with the Mini Mental Status Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). The MMSE is a 30-point questionnaire (Folstein et al., 1975). A score greater than or equal to 24 points (out of 30) indicates normal cognition, mild cognitive impairment is classified from 19-23, moderate 10-18, and severe less than or equal to 9. Moderate to high test-retest reliability has been found with correlations of 0.38 to 0.99, internal consistency with Cronbach's alpha coefficient of 0.54-0.96, concurrent validity with other measures of cognitive impairment with correlations of 0.70-0.90, average sensitivity of 75% among dementia patients, and specificity of 62%-100% (Tombaugh & McIntyre, 1992).

Comorbid illness. Comorbidity is defined as the existence of two or more mental or physical diseases that do not operate independent of one another, but instead simultaneously affect the overall health of a person over the life trajectory (Sartorius, 2013). Comorbid illness was measured with the Cumulative Illness Rating Scale for Geriatrics (CIRS-G) (Miller et al., 1992). The CIRS-G quantifies and tracks medical burden in geropsychiatric patients as a 14-item Likert-scale. Each item contains a rating ranging from 0 (no problem), 1 (mild problem), 2 (moderate severity requiring active therapy), 3 (severe or constant disability), and 4 (extremely

severe or urgent clinical problem) (Miller et al., 1992). Interrater reliability was acceptable with intraclass correlations of 0.78 and 0.88 as well as significant correlations found with the Older Americans Activities of Daily Living Scale (OARS-ADL) (Miller et al., 1992). Miller et al. (1992), also report face validity of the scale which implies appropriate conceptual use of the scale to capture comorbid illness burden. Multiple comorbid illnesses may confound both the sleep and pain variables. Therefore, statistical analyses will be used to control for levels of comorbid illness among the study population. The Cronbach alpha for the CIRS-G tool was 0.67 in this study.

Analyses

To ensure data accuracy, the data was cleaned and examined for errors and missing data using a two-person crosschecking technique. The frequency of distributions of all variables were checked for skew before proceeding with analyses. No data or cases needed to be excluded for analyses. Bladder volume was the only variable with missing data related to exclusion criteria of catheter use. Initially, the distributions of each process and outcome variable was analyzed using frequency distributions, means, and standard deviations. Data with skew was managed by reporting medians, ranges, and percentages. Continuous variables such as age and length of stay were described using the mean and standard deviation. Categorical variables such as gender and race were described using frequencies and percentages.

Chi-square analyses and independent sample t-tests were used to examine associations of sleep quality with independent variables of pain, dementia, comorbid illness, medications that promote and inhibit sleep, and demographic data. The variables of dementia, comorbid illness, medications that promote and inhibit sleep were tested for inclusion as possible covariates. Dementia was the only variable included as covariate in regression because it was the only one

with significance. All other variables were not included as covariates because they were not significantly related to sleep quality. Since there are significant differences in sleep quality (sleep efficiency and sleep fragmentation) between persons with and without dementia, these groups will be described in separately and controlled in the regression model.

Sleep quality variables, dementia, and pillow use were all recoded into dichotomous variables to indicate normal or abnormal values for logistic regression analyses. Normal values commonly used in the literature were used as guidelines to dichotomize variables into normal or abnormal values. A total sleep time of equal to or greater than 420 minutes, sleep efficiency greater than or equal to 80%, sleep latency values less than or equal to 20 minutes, WASO values of less than or equal to 10% of total sleep minutes, and sleep fragmentation values of less than or equal to 20 indicated normal coding in SPSS (Ancoli-Israel et al., 2003). Binary logistic regression analysis was performed to identify significant predictors of sleep quality. Statistical assumptions of multiple regression analysis were examined, and multicollinearity of the independent variables were checked. SPSS (IBM© SPSS© Statistics Version 24) was used for all analyses. For all analyses, the alpha coefficient was set at 0.05.

RESULTS OR FINDINGS

Description of Sample

As seen in Table 1, the sample of 89 was primarily female (n = 66, 74%), white (n = 88, 99%), and had an average age of 87.5 (SD = 9.6, range 51-100). The sample was highly educated with 17 (19%) having completed high school, 44 (49.5%) attending college and 25 (28%) with graduate level degrees. The median length of stay was 30 months (SD = 36.09, range 1-152).

Forty-five persons (50.6%) had no dementia or cognitive impairment while 49.4% (n = 44) had some level of cognitive impairment. The average severity of medical burden using the

Cumulative Illness Rating Scale - Geriatrics (GIRS-G) was 2.56 (SD = 0.37, range 1.8-3.67), with scores 1-2 indicating mild to moderate burden and scores of 3-4 demonstrating severe medical burden (Miller et al., 1992). The sample had on average 9.5 (SD = 2.06) categories endorsed out of 14 possible categories. Only 37 people (41.6%) were taking medications that promoted sleep versus 87.6% (n = 78) participants were prescribed sleep inhibiting medications. Medications that promote and inhibit sleep were evaluated for possible inclusion as a covariate.

Description of Frequency and Severity of Pain Symptoms

As seen in Table 2, the median musculoskeletal pain score was 3.0 (range 0-9), indicating the sample had mild musculoskeletal pain prior to nighttime sleep. The median respiratory discomfort score was 3.00 (range 0-12), suggesting the sample had mild respiratory discomfort prior to nighttime sleep. A large portion of the sample elicited residual bladder volume (73.8%) while 37.1% had urinary retention greater than 100ml. The average residual bladder volume was 99.07 (SD = 123.358, range 0-724). Twenty-seven participants (30.3%) had some report of genitourinary discomfort. Forty-eight participants (53.9%) had reports of gastrointestinal (GI) discomfort the day prior to nighttime sleep. Symptoms of decreased appetite were reported in 27%, complaints of GI discomfort were 20%, and 22.5% had symptoms of constipation, nausea, vomiting, and/or diarrhea day of testing.

Description of Sleep Quality Variables

As seen in Table 3, 59 (66.3%) participants slept less than 7 hours at night. The average total sleep time was normal, 476.5 min (SD = 144, range 1-825). Thirty participants (33.7%) had poor sleep efficiency. The median sleep efficiency was 87 (range 35.7-99.3). Only 14.6% of the sample (n=13) had poor sleep latency. The median time for this sample to fall asleep was 8.0 min (range 0-212). Fifty-six participants (62.9%) had high values for wake after sleep onset (WASO)

with a median of 74 min (range 0-679). Sleep fragmentation was observed in 51.7% (n=46) of the sample with a median value of 4.1 (range 0.59-100).

There were no statistically significant differences between persons with and without dementia in their total sleep time, sleep latency, and wake after sleep onset. There were significant differences found between groups in sleep efficiency ($t = 5.374$, $p = 0.020$) and sleep fragmentation ($t = 8.181$, $p = 0.004$).

In persons with normal cognition, the median sleep efficiency was 90.36 (range 55.01-97.95). The average sleep fragmentation was 3.22 (range 0.92 – 12.85). This group elicits normal sleep efficiency and sleep fragmentation values. In persons with cognitive impairment, the median sleep efficiency was 81.52 (range 35.70 – 99.27). The median sleep fragmentation was 5.04 (range = 0.59 – 100). Values for sleep efficiency in persons with cognitive impairment was abnormal and median values for sleep fragmentation were normal.

Factors Predicting Sleep Quality

As seen in Table 4, dementia, gender, urinary retention, pillow use, and respiratory distress were statistically significant predictors of sleep quality. Those without dementia are 7.52 times more likely to have normal sleep efficiency than those with dementia. Those using 2 or more pillows are 7.49 times more likely to have normal sleep efficiency than those using zero to 1 pillow. Females are 8.67 times more likely to have normal sleep efficiency than males. The model was classified correctly 78.6% of the time.

Those without dementia are 6.03 times more likely to have normal WASO than those with dementia. Females are 5.02 times more likely to have normal WASO than males. Those without urinary retention are 6.05 times more likely to have normal WASO than those with urinary retention. Cases were classified correctly 70.2% of the time.

Those without dementia are 8.84 times more likely to have normal sleep fragmentation than those with dementia. Those using 2 or more pillows are 6.61 times more likely to have normal sleep fragmentation than those using zero to 1 pillow. Females are 6.18 times more likely to have normal sleep fragmentation than males. For a unit change in respiratory distress, the odds of sleep fragmentation increase by 1.23 times. Cases were classified correctly 79.8% of the time.

Discussion

We examined the association of dementia, comorbidity, and physiologic sources of pain with sleep quality in older adults and people with dementia. We found dementia, gender, pillow use, urinary retention, and respiratory distress were factors significantly predicting level of sleep quality. This study has added to the body of literature supporting poor sleep quality in people with dementia (J. C. Chen et al., 2016; Fung et al., 2012; S. Kim et al., 2014). In particular, the percent of time actually spent asleep and arousals during the nighttime were two characteristics of sleep quality that were below normal for this group.

Females in this sample were more likely to have better sleep quality than males. Burgard and Ailshire (2013) illustrate females sleep more than males in a sample of same working age adults with similar day to day responsibilities. Contrarily, research by Cheng et al. (2017) suggest females with diabetes, depression, and anxiety were more likely to have poor sleep quality than males. Specifically, 54.2% of females reported sleep disturbance compared to males at 38.1% (Cheng et al., 2017). The role of gender in the literature is not conclusive, suggesting further research is needed through replication or larger powered studies to continue to build on current evidence.

The sample elicited a small to moderate prevalence in musculoskeletal, respiratory, and gastrointestinal discomfort. Almost 74% of participants had some residual bladder volume while 37% of the sample had retained volume over 100ml, indicative of urinary retention. The relationship of pain to sleep quality has not been thoroughly investigated, but pain prevalence in the older adult population is known (Flo et al., 2014; Lukas, Barber, et al., 2013; Monroe et al., 2014). This is first study to report a high incidence of urinary retention at bedtime while Bliwise et al. (2015) and Borrie et al. (2001) reported urinary retention prevalence in approximately 33% of older adults or men aged 80 years or older. Urinary retention has been associated with comorbid health conditions, increase in age, anticholinergic medication use, diabetes, and constipation (Borrie et al., 2001; Chew et al., 2008; Griebing, 2013).

Gordon, Grimmer-Somers, and Trott (2009) found the type of pillow used, rather than number of pillows was related to sleep quality and cervical pain outcomes. Their research suggests that the use of a rubber pillow instead of standard or feather pillows promotes sleep quality by preventing cervical pain. Other literature promotes good sleep hygiene and physical comfort that involves the use of a few pillows or placing essential oils on the pillow prior to nighttime sleep (Bephage, 2005; P. H. Chen, Kuo, & Chueh, 2010). Respiratory distress may be related to pillow use, but this study does not examine this association. Chronic health conditions involving the lungs or heart are associated with difficulty breathing and pillow use. Prevalence of severe heart conditions was 24.7% and lung conditions was 32.6% in this study. Congestive obstructive pulmonary disease and heart failure are just two conditions that are prevalent in older adults that require management through physical comfort measures like positioning the head of bed, increased pillow use, and medication management (Ali Zohal, Yazdi, & Kazemifar, 2013; Lainscak & Anker, 2015; Neikrug et al., 2014).

Our findings suggest there is a need to further investigate the effects of gender, dementia, and physiologic sources of pain in older adults on sleep quality. Varying levels of discomfort were identified in this study with 77.5% of the sample with musculoskeletal pain, 85.2% with respiratory distress, 37.1% with urinary retention and 53.9% with signs and symptoms of gastrointestinal discomfort. Therefore, assessment of pain and sleep should be included as vital signs (Chasens, Yang, Baniak, Choi, & Imes, 2017; Purser, Warfield, & Richardson, 2014). Additionally, future research should examine the relationship of timing of pain medication administration and timing pain assessments prior to nighttime sleep.

Replication and interventional studies with a larger sample sizes are needed to build upon current evidence supporting poor sleep quality. Future data collection may include more nights of testing and more time points of measurement during day and evening hours. Future research could include nighttime observation of sleep quality and behaviors in addition to actigraphy to add to the strength of evidence.

Strengths and Limitations

Causal claims cannot be inferred through this exploratory study. Although the study was adequately powered, replication studies with larger sample size or studies testing the interventions of managing comfort surrounding sleep hygiene are needed. This study occurred within one long-term care organization known for high quality care and adequate staffing. Use of a convenience sample threatens generalizability of findings but was chosen for convenience and feasibility reasons.

Since measurement error can occur in any study, the research team was consistent in all data collection methods and interrater reliability checks were performed periodically through data collection between two nurse researchers to reduce Type I error. One nurse researcher

conducted testing of all participants. Validity of assessment strategies surrounding gastrointestinal discomfort need to be explored since current assessment strategies are lacking. There is difficulty obtaining accurate and reliable subjective measures from persons with dementia, therefore the measurement needs to involve objective measures. The actigraph has its limitations in that it cannot distinguish between awake and lying still or sleeping. Yet the actigraph remains the best way to objectively measure sleep outcomes due to feasibility, ease of use, low participant burden, and cost effectiveness. In addition to the actigraph, future research may include subjective tools for sleep assessment reported by staff or caregivers of PWD.

Repeated measures would improve accuracy of pain and sleep data. Accuracy of pain and sleep scores may not be robust due to only one day of measurement for pain and three days of sleep measures. Future studies should be conducted at multiple sites comparing health outcomes among older adults with and without dementia stratified by payer source Medicare, Medicaid, and Private Pay. This study only considered sources of physical pain that can be associated with sleep quality. Future research may investigate concurrent associations not limited to physiologic pain, psychologic distress, social, environmental, and biological factors. It is not feasible to wake people up in the middle of the night for assessments. Instead, measurement of pain can occur prior to nighttime sleep to prevent poor sleep quality. Lastly, it is possible that low levels of pain observed during data collection may be related to prior medication administration. Medications administered for on-going genitourinary and gastrointestinal discomfort were not captured in this study.

Conclusion

Sleep problems, pain, dementia, and co-morbid health conditions in long-term care settings are prevalent and require further investigation in order to optimize quality of life,

comfort outcomes, and management of associated healthcare costs. Sleep patterns and quality of life may be improved through understanding factors associated with poor sleep and developing and testing interventions that address contributing factors. Comprehensive assessment strategies need to be targeted and implemented to evaluate effectiveness of identifying antecedents of poor sleep quality. Methods for understanding and measuring sleep quality in PWD are inadequate, which limits the ability to identify and effectively manage poor sleep and the associated negative outcomes (Gitlin, Hodgson, Piersol, Hess, & Hauck, 2014; Simpson & Carter, 2013). The study aimed to comprehensively assess specific physiologic sources of pain and nighttime sleep quality in older adults and PWD. Dementia, gender, pillow use, respiratory distress, and genitourinary discomfort were found to significantly contribute to nighttime sleep quality in this population. Knowledge gained from this research should stress the importance of further developing and conducting a more comprehensive pain assessment for older adults and PWD. Promoting routine sleep assessments of PWD and evaluating the long-term effects of poor sleep quality may be vital to achieving positive health outcomes for the patient within health care settings.

Summary

This chapter presented findings from a descriptive study exploring physiologic sources of pain and their relationship to sleep quality. A description of sample characteristics, frequency and severity of sources of pain, and sleep quality in older adults and PWD were presented. Factors predicting sleep quality were also illustrated with discussion of results, strengths and limitations, and implications for future research.

CHAPTER 5

Chapter Introduction

This chapter is focused on reviewing the findings of the study. A discussion of how the specific findings are consistent with the proposed illustration of pain and sleep quality in persons with dementia will be presented. Limitations of the study and implications for nursing education, clinical practice, and health policy are also discussed. Recommendations for future research and a concluding statement are presented.

Synthesis of Findings

Sleep quality remains abstract and difficult to define, especially in persons unable to reliably or accurately self-report. For the purposes of this study, sleep quality was defined by objective measurements of total sleep time, sleep efficiency, sleep latency, wake after sleep onset, and sleep fragmentation using actigraphy. Poor sleep quality has been associated with a multitude of negative health consequences. Understanding etiology and risk factors surrounding sleep quality is an essential step towards the development of new methods of assessment, management of risk factors, and development of effective strategies to improve sleep hygiene in older adults and people with dementia.

This study examined the relationship between sources of physical pain and sleep quality in older adults and people with dementia (PWD). Dementia, gender, pillow use, urinary retention, and respiratory distress were found to be factors that significantly predicted level of sleep quality. This indicates that PWD at may be at greater risk for negative health

consequences associated with poor sleep than persons able to communicate their needs. These findings suggest conditions involving the respiratory and genitourinary systems need more comprehensive assessment included in routine care.

Consistent with other literature, findings from this study continue to support poor sleep quality in PWD (J. C. Chen et al., 2016; Fung et al., 2012; S. Kim et al., 2014). Meanwhile, research on the role of gender and sleep disturbance remains inconclusive. Females in this sample were more likely to have better sleep quality than males. This finding is supported by literature comparing pairs of same age working adults and older adults with similar day to day responsibilities (Burgard & Ailshire, 2013). However, research by Cheng et al. (2017) report females with diabetes, depression, and anxiety were more likely to have poor sleep quality than males. Specifically, 54.2% of females reported sleep disturbance compared to males at 38.1% (Cheng et al., 2017). Future research is needed to build on current evidence through replication and larger powered studies.

Varying levels of discomfort were identified in this study with mild levels of discomfort observed in musculoskeletal, respiratory, and gastrointestinal systems. Interestingly, almost 74% of the participants had some residual bladder volume while 37% of the sample had retained volume over 100ml, indicative of urinary retention. Logistic regression analysis found that only respiratory distress and urinary retention were factors that significantly contributed to sleep quality. Pillow use was another variable with a statistical significant relationship with sleep quality. Respiratory distress may be related to pillow use, but this study did not examine that association. Severe prevalence of heart conditions (24.7%) and lung conditions (32.6%) were found in this study. It is possible these factors further illustrate the need for management of chronic health conditions such as congestive heart failure or pulmonary disease. Conditions

involving the heart and lungs such as congestive obstructive pulmonary disease and heart failure are prevalent in older adults (Pirmohamed, Kitzman, & Maurer, 2016; Zhong et al., 2007).

These conditions require management through physical comfort measures like positioning the head of bed, increased pillow use, and medication management (Ali Zohal et al., 2013; Lainscak & Anker, 2015; Neikrug et al., 2014). Research has tested the effects different pillow use and cervical pain on sleep outcomes (Gordon et al., 2009). Other literature promotes good sleep hygiene and physical comfort involving the use of more than one pillow or applying essential oils on the pillow prior to nighttime sleep (Bephage, 2005; P. H. Chen et al., 2010).

This study adds to existing literature on incidence of urinary retention at bedtime as urinary retention was seen in 37% of the sample. Bliwise et al. (2015) and Borrie et al. (2001) reported urinary retention prevalence in approximately 33% of older adults of men aged 80 years or older. Prevalence of pain in older adults is known but the specific relationship to sleep quality has not been thoroughly investigated (Flo et al., 2014; Lukas, Barber, et al., 2013; Monroe et al., 2014). Although pain prevalence among the different physiologic systems may have not been high in this sample, this does not negate the importance of managing pain even if it is a small subsample. Instead this suggests the need to continue to advocate for comprehensive assessment strategies to target sources of discomfort that can affect sleep quality.

Implications for Nursing Theory

Findings from the study suggest persons without dementia or sources of pain are more likely to have better sleep quality. These findings are consistent with the illustration proposed for this study. The premise of this research suggests there are antecedents of pain that affect sleep quality, resulting in changes to health outcomes, quality of life, and nursing home

placement. Addressing antecedents that affect sleep quality may improve comfort and quality of life outcomes among older adults and people living with dementia in long-term care settings.

Continued development of nursing theory examining the relationship between pain and sleep quality in PWD can lay the foundation to design multicomponent nursing intervention to improve sleep quality and quality of life in PWD. Additional replication studies and interventional research is needed to better understand the antecedents to sleep quality to build on current evidence.

Further development and testing of nursing theory is imperative to driving nursing science forward. Incorporating other contextual factors known to affect sleep quality such as physiologic including pain, psychiatric, cognitive, behavioral, environmental, and pharmacologic factors will produce a more robust nursing theory. Nursing research grounded in well-established nursing theory is imperative to making strong implications and suggestions for changes in clinical practice. Interventions driven by nursing theory can be tested and tailored to address sleep quality concerns in conjunction with informing nursing practice.

Implications for Education, Clinical Practice, and Policy

Implications for Nursing Education

Geriatric nursing education needs to be a fundamental piece of nursing curriculum and practice. Comprehensive geriatric education is essential to preventing adverse health outcomes and providing clinically competent nursing care (Scherer, Bruce, Montgomery, & Ball, 2008). Research evaluating clinical competence of geriatric nursing care proposes the need for advancement in education of comorbidities, medication management, cognitive impairment, nursing measures and documentation (Bing-Jonsson, Hofoss, Kirkevold, Bjork, & Foss, 2016). Cho et al. (2015) present evidence of nurse staffing, nurse work environments, and level of

education are associated with patient mortality. Therefore, incorporating geriatric training and content in undergraduate nursing curriculum could be one helpful strategy to increase knowledge with care of the older adult and improve the quality of care, quality of life, and decrease mortality. Continuing education courses offered to practicing nurses has the potential to directly improve health outcomes and quality of care, especially in long-term care settings where many older adults receive care (Ramaswamy et al., 2015).

This dissertation has implications for nursing education focusing on the assessment of pain and sleep in older adults. Literature evaluating barriers and facilitators of nursing assessment and management of pain in older adults illustrated adequate education facilitated better pain management (Fitzgerald, Halksworth-Smith, & Tripp, 2017). This dissertation aimed to comprehensively assess different sources of pain from musculoskeletal, respiratory, gastrointestinal, and genitourinary systems. Although this study was a descriptive, observational design, results suggest the need for a more comprehensive assessment of pain incorporated into nursing documentation requirements. Additionally, the findings illustrated the lack of assessment of sleep in nursing practice. Research has exemplified nurses have limited knowledge of sleep and current sleep assessment tools are inaccurate (Brown, Wielandt, Wilson, Jones, & Crick, 2014). Interestingly, one study illustrated nurses understated the incidence of sleep concerns in PWD and awareness of the relationship between sleep disordered breathing and dementia was lacking (Brown et al., 2014). Promotion of education concerning sleep hygiene, assessment strategies, and nursing interventions to manage poor sleep is another method to address sleep quality concerns and should be a national nursing initiative.

Implications for Clinical Practice

Documentation modalities used in clinical practice need to be inclusive of comprehensive pain assessment tools and routine assessments of sleep. Evaluation of the effectiveness and usefulness of current assessment policies can be a useful initial step in addressing inaccurate assessment strategies (Kelley, Brandon, & Docherty, 2011; Moody, Slocumb, Berg, & Jackson, 2004). Quality improvement projects evaluating the functional utility and accuracy of assessments among nursing staff can be an effective way to evaluate appropriateness of tools and staff opinions. Research has already suggested pain to be incorporated as the fifth vital sign, but the routine assessment of sleep can also be established as the sixth vital sign (Molony, Kobayashi, Holleran, & Mezey, 2005; Purser et al., 2014). Advocacy from nurses for uniform, valid assessments of older adults may be another important step to creating higher continuity of care across all settings. Although the electronic medical record is important to clinical practice, there remains a large variety of systems for healthcare organizations to choose from leading to varying charting practices (Kelley et al., 2011). Consistency in nursing charting requirements across healthcare systems may be another method employed to create better continuity of care and health outcomes.

The actigraph is a novel, cost-effective, and non-invasive method available to assess sleep in older adults and PWD in long-term care settings. The actigraph is comparable to polysomnography as the gold standard of sleep assessment (Martin & Hakim, 2011). Using an objective measurement tool such as the actigraph produces a higher accuracy of sleep assessment data in long-term care settings than current caregiver reports, self-report, and subjective tools (Martin & Ancoli-Israel, 2008; Martin & Hakim, 2011; Zinkhan et al., 2014). Current nursing practice does not require comprehensive sleep assessments nor promotes use of tools such as the actigraph. Nurse practitioners are highly utilized in long-term care settings and may be the most

suitable discipline to learn how to use and interpret the actigraph. Nurse practitioners have the skill set to understand implications for poor sleep quality, prescribe and oversee interventions that address sleep quality concerns while allowing residents to remain in their current environments. Training of nurses on use and interpretation of actigraph results may be a useful step in accurate assessment of sleep quality. Evaluation of sleep using the actigraph can be incorporated into routine nursing assessment upon moving into long-term care setting, quarterly, and individually as care needs change from person to person.

Implications for Health Policy

Prevention and management of sleep quality concerns in older adults and PWD requires policy solutions and a wide range of interrelated programs and actions from both the public and private sectors. Using results from this study and other research on sleep quality to raise awareness about the short-term and long-term implications of poor sleep quality in PWD is a crucial step to improvement of health outcomes for all older adults (Neikrug & Ancoli-Israel, 2010). The most effective approach to preventing sleep quality concerns is proper assessment and management of factors contributing to sleep quality like undertreated pain. Policy makers should be concerned about the implications for health care spending surrounding the increasing population of older adults with and without dementia. Proper assessments can be an effective way to improve health outcomes, maintain quality of life, and prevent costly hospitalizations (Bepthage, 2005; Kelley et al., 2011). Public policy should focus on increasing accessibility of assessment tools for all electronic charting systems. Additionally, a larger portion of funding for health care should be targeted at persons living in the community and long-term care settings instead of tertiary care. Funding care be targeted at management of facilities, proper pay for staff, and geriatric education of healthcare professionals.

Stakeholders from healthcare organizations, academia, centers for nursing research, health care consumers, and institutes on aging across the country should begin a national dialogue to discuss the importance of adequate sleep quality assessment strategies and prevention of adverse costly health outcomes to the patient, family, and healthcare system. Stakeholders should make an effort to secure funding and resources for future research with focus on assessment and interventions targeting sleep quality in long-term care settings. Supporting research in this area is crucial to better understanding the etiology of sleep quality, proper assessment and documentation strategies, and development of new interventions to address areas of concern.

Limitations

Causality cannot be inferred, given the cross-sectional design. Although the study was adequately powered, replication studies with larger sample size or studies testing the interventions of managing comfort surrounding sleep hygiene are necessary. This study occurred within one long-term care organization known for high quality care and adequate staffing. It is possible the prevalence of pain may be different in organizations that have limited funding and staffing issues. Future studies should be conducted at multiple sites comparing health outcomes among older adults with and without dementia stratified by payer source Medicare, Medicaid, and Private Pay. This study only considered sources of physical pain that can be associated with sleep quality. Future research may investigate concurrent associations not limited to physiologic pain, psychologic distress, social, environmental, and biological factors. Validity of assessment strategies surrounding gastrointestinal discomfort need to be explored since current assessment strategies are lacking. Type I error was reduced with consistency of all data collection methods and interrater reliability checks performed periodically between two

nurse researchers. Lastly, it is possible that low levels of pain observed during data collection may be related to prior medication administration. Medications administered for on-going genitourinary and gastrointestinal discomfort were not captured in this study.

Recommendation for Research

Our findings suggest there is a need to further investigate the effects of gender, dementia, and physiologic sources of pain on sleep quality in older adults. A review of the literature by (Corbett et al., 2014) support the need to continue to develop more accurate assessment and solidify alternative treatment options rather than only medication management. While this research supports literature surrounding sleep quality and dementia, respiratory and genitourinary discomfort, replication and interventional studies with a larger sample are needed. Future research could include nighttime observation of sleep quality and behaviors in addition to actigraphy to add to the strength of evidence. Future research should include nighttime observation of sleep quality and behaviors in addition to actigraphy.

Conclusion

Sleep problems, pain, dementia, and co-morbid health conditions in long-term care settings are prevalent and require further investigation in order to optimize quality of life, comfort outcomes, and management of associated healthcare costs. Sleep patterns and quality of life may be improved through understanding factors associated with poor sleep and developing and testing interventions that address contributing factors. Comprehensive assessment strategies need to be targeted and implemented to evaluate effectiveness of identifying antecedents of poor sleep quality. Methods for understanding and measuring sleep quality in PWD are inadequate, which limits the ability to identify and effectively manage poor sleep and the associated negative outcomes (Gitlin, Hodgson, Piersol, Hess, & Hauck, 2014; Simpson & Carter, 2013). The study

aimed to comprehensively assess specific physiologic sources of pain and nighttime sleep quality in older adults and PWD. Dementia, gender, pillow use, respiratory distress, and genitourinary discomfort were found to significantly contribute to nighttime sleep quality in this population. Results from this study suggest that further developing and conducting a more comprehensive pain assessment for older adults and PWD may be needed. Promoting routine sleep assessments of PWD and evaluating the long-term effects of poor sleep quality may be vital to achieving positive health outcomes for the patient within health care settings.

Chapter Summary

The current study revealed that older adults with respiratory and genitourinary pain and dementia are more likely to have poor sleep quality. Nurses are key stake holders with the opportunity to make instrumental changes to nursing education, clinical practice, and health policy. Further education and implementation of care surrounding the older adult and sleep quality has the potential to improve quality of life, comfort, and health outcomes. Advocacy at the state and national level for funding to support research further developing nursing theory, interventions, and evaluating health outcomes is needed. In summary, the results of this study require a broader examination of antecedents of sleep quality, exploring potential intervention modalities, and employing novel objective methods of assessment to this area of research.

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APPENDICES

Appendix A: Studies of Factors Associated with Sleep in PWD

Author Year Location	Purpose	Type of study Population Sample size	Measures	Results	Strengths/Limitations
Bhalsing, Suresh, Muthane, & Pal, 2013 India	To determine the prevalence of RLS in PD, PSP, MSA, and DLB compared to controls	Descriptive, correlational; Parkinsonian disorders pt n=187 (PD - 134, PSP - 27, MSA - 21, DLB - 5) and controls n=172	Sleep: PSQI, ESS, PDSS	Prevalence of RLS higher for pt compared to controls (9.6% and 2.9%; p=0.0009), highest in PD (11.9%); no RLS present in DLB; PSQI and ESS higher in pt compared to controls (p<0.001); PD with RLS had lower PDSS score compared to pt without RLS (p=0.023).	Cofoundings symptoms of RLS with sensorimotor manifestations of PD could not be ruled out Questionnaire based study - reliability and validity of self-report (recall bias). Need more validation studies
Bliwise et al., 2009 USA	To examine the prevalence of nocturia and its role in self-reported insomnia and poor sleep quality.	Descriptive, correlational n=424 community-dwelling elderly aged 55-84	Questionnaire: Insomnia (yes/no) Sleep quality (Poor/Fair/Good/ Very Good/Excellent)	53% of sample reported nocturia (4x more frequent than pain (12%) associated causes of nighttime arousals.	Survey – subject to reporting bias Unknown cognitive status – no level assessed, results need to be reported and

			Nocturia (every night/almost every night, few nights/wk, few nights/month, rarely, never)	In multivariate logistic models, nocturia was an independent predictor both of self-reported insomnia (75% increased risk) and reduced sleep quality (71% increased risk), along with female gender and other medical and psychiatric conditions.	interpreted with caution Large sample size Nocturia – the questionnaire did not specify if there was difficulty returning to sleep or not.
			Other causes of disturbed sleep: Medical conditions, NT heartburn, headache, physical pain, cough, health concerns, money problems, family problems, caregiver, uncomfortable bed		
Cooke et al., 2009 USA	What are the effects on sleep, mood, and cognition in PWD living with OSA using CPAP.	Exploratory study, PWD (n=10) *apnea CPAP+ (n=5) CPAP- (n=5)	Apnea: AHI Sleep: Daytime somnolence (ESS) and Sleep quality (PSQI) Mood: Depression (CSD) and Psychopathology (NPI) Cognition: MMSE	CPAP+ showed less cognitive decline, stabilization of depressive symptoms (CSD) and daytime somnolence (ESS), improvement of psychopathological behavior, and significant improvement in subjective sleep quality (PSQI)	Generalizability – only includes mild to moderate AD No causal inferences can be made – small sample size and lack of randomization Selection bias – participants' choice to continue or discontinue CPAP

				compared to the CPAP- group.	
Cuellar, Strumpf, & Ratcliffe, 2007 USA	What is the effect of RLS symptom severity on sleep quality, sleepiness, fatigue, depression, and quality of life in older adults with RLS?	Descriptive, comparative study; cross-sectional design Older adults (n=39) with RLS symptoms at least 3 nights per week.	RLSSS PSQI (sleep quality) ESS (sleepiness, fatigue, depression, and QOL) FSS CES-D RLS-QLI	Significant differences were found in SQ (p=0.007), sleep duration (p=0.04), and PSQI global score (p=0.007). RLS-QLI (p<0.001) and sleepiness (p=0.01) were significantly related to PSQI global score. Subjects with severe symptoms were 5 times as likely to use medication to treat RLS.	Small sample size small, mostly Caucasian females Limited generalizability and causal inferences cannot be made. Unknown cognitive status
Esbensen, 2016 USA	What is the relationship between sleep problems in adults with DS and other factors of physical and mental health, functional abilities and behavior problems?	Secondary analysis, n=75 families (aged 37-65 years)	Sleep (sleep apnea and behavioral sleep disturbances) – self-report from caregivers Physical health conditions – chart review	Sleep apnea was associated with more common other respiratory concerns, and more frequent visits to physicians, but not with some expected medical comorbidities (cardiac). Behavioral sleep	Sample is not older adults and small size, but adults that have cognitive impairments. Caregivers reported on sleep problems, subjective reporting bias. Study comprehensively

			<p>Mental health – chart review (dementia included)</p> <p>Daily living – functional status measured by W-ADL and behavior by SIB-R</p>	<p>disturbances (delayed sleep onset, night-time awakenings, morning awakenings) were associated with poorer health, more frequent overnight hospital and emergency department visits, more common cardiac conditions, less common thyroid condition, more common mental health conditions (anxiety, depression, dementia), and a higher rate of daytime behavior problems.</p>	<p>assessed status of individual.</p>
<p>Fernandez-Arcos, Iranzo, Serradell, Gaig, & Santamaria, 2016 Spain</p>	<p>Describe the clinical phenotype of idiopathic rapid eye movement sleep behavior disorder.</p>	<p>Descriptive, cross-sectional and longitudinal design n=203 referred from tertiary sleep center</p>	<p>Demographic characteristics, description of motor behaviors, depression</p>	<p>Sample was mostly males aged >65 years. 34% pt had neurodegenerative syndrome after follow-up of 5 years – DLB, PD, MSA, and MCI. 24% of sample eventually</p>	<p>Study occurred in a sleep center. Sample typically do not have cognitive or motor complaints. Large sample size but generalizability is limited due to biased nature of referrals –</p>

				developed DLB. Sleep disorder results in increased motor behaviors and persons do experience cognitive decline over the years, may contribute to behaviors seen in LTC settings.	cannot be generalized to all persons living in the community. Retrospective data collection, semi-structured interview (not systematic analysis).
Gitlin, Hodgson, Verrier Piersol, Hess, & Hauck, 2014 USA	To examine prevalence of modifiable risk factors and their contribution to patient QOL as rated by dementia patients and caregivers.	Exploratory, descriptive, correlational, cross-sectional design (n=88 pt and caregivers)	Characteristics of home environments, patients, caregivers through observations and interviews of pt and caregiver QoL – Quality of life in Alzheimer Disease Scale Home environment – observe home hazards, adaptations, and unmet assistive device/home navigation needs using Home Environmental Assessment Protocol and	Pt had mild to moderate cognitive impairment, 52% female, Caucasian (76%), average age 82 years. Environment – 8-27 safety concerns. Pt related risk factors – average of 6 (range 0-15) health conditions, average of 7.7 neuropsychiatric behaviors, and moderate functional challenges, 70.7% had fall risk, 60.5% had sleep problems at least once	Excluded severe dementia, bed-bound, and unresponsive pt. Recruitment practices increases generalizability but have potential for do-gooders to participate and may not capture all dyads in the community. Most dyads reported little to no financial difficulty. Assessments completed in the home setting.

			<p>questions to caregivers.</p> <p>Patient related factors – health conditions (list of common conditions), behavioral frequency (NPI), fall risk (TUG), pain (VAS with Faces Pain Scale), and sleep quality (PSQI).</p> <p>Caregiver based factors – mood, positive caregiving, and communication.</p>	weekly, 42.5% had pain.	
Hibi, et al., 2012 Japan	What is the association between DLB and PLM?	DLB (n=9) AD (n=12) No dementia (n=10)	PSG (Sleep quality, oxygen-desaturation index, and PLM)	The number of PLM during sleep per hour of total sleep time (PLMS index) was significantly higher in the DLB patients than the AD patients or the non-demented patients. No significant differences were found between the AD patients and the non-demented	Small sample size and bias of results based on size – need larger studies with variety Study did not include objective or subjective measures of daytime sleepiness or day-night schedule. Hospital setting, not community or LTC

				patients. To differentiate DLB from AD, a PLMS index of more than 15.0 had a sensitivity of 88.9% and a specificity of 83.3%.	
Hodgson, Gitlin, & Huang, 2014	To evaluate the influence of sleep quality and pain perceptions on different dimensions of quality of life in community-dwelling PWD.	Cross-sectional design, n=88 PWD and their caregivers	Pain – VAS with the Faces Pain Scale Sleep – PSQI QOL – DemQOL-Proxy	Lower QOL was associated with the presence of pain and symptoms of sleep disruption when controlling for mental status, age, and number of health conditions. Most patients (55%) reported pain ranging from some to extreme pain, and 49% had ≥ 1 sleep problems which occurred \geq once a week.	Sleep evaluation was based on subjective caregiver support – reliability has to be questioned. Subjective pain report – duration of pain nor intensity was captured. No causal claims can be made. Limited generalizability
Kim, Lee, Lee, Jhoo, & Woo, 2010 Korea	To illustrate the sleep characteristics related to the specific neurocognitive decline in the	Cross-sectional (semi-structured interview) MCI (n=30) and normal CI (n=30)	Sleep – PSG Neurocognitive testing – VF, BNT, Word List Memory, CP, Word List Recall, Word List	NSD in sleep parameters between MCI and normal comparison groups. Sleep efficiency was positively	Sample size was small for comparison between groups – type I error. Tests were limited, interpret results with

community-dwelling elderly including pt with MCI.

Recognition, and CR
Depression – GDS
Sleep – ESS
SAS – Sleep Apnea subscale of the Sleep Disorders Questionnaire

correlated with Constructional Recall scores in both groups. SWS was positively correlated with Boston Naming test scores in both groups. SWS and apnea index were significantly associated with BNT score in the MCI group, amount of REM sleep was significantly associated with CR score in NC group.

Poor sleep quality and greater severity of SAS were associated with impaired language function reflecting frontal-subcortical pathology in pt with MCI. Suggests that vulnerability to a specific brain damage associated with SAS could

caution due to inferences from tests (not gold standard), neurocognitive eval was limited to one timeframe, first-night effect PSG (only used one night data)

				increase the risk for dementia.	
Mazzotti et al., 2012 Brazil United Kingdom Mexico	To estimate the prevalence and prevalence ratios of the correlates of sleep complaints in a large population of older adults from low and middle income countries (LAMICs).	Cross-sectional survey (n=16,680)	Socio-demographic factors, lifestyle, health, sleep complaints	The standardized prevalence of sleep complaints varied from 9.1% (China) to 37.7% (India). The meta-analysis showed that female gender, urban residence, low educational level, low physical activity status, high pain scores, poor health, higher memory impairment score, presence of major depression, mild cognitive impairment, and high number of co-morbidities were associated with sleep complaints.	Large sample size Sample is from many different countries – developed and non-developed Heterogeneity of sample, interpret with caution Sleep was characterized broadly with a question, not measured objectively.
Onen et al., 2010	To assess whether continuous positive airway pressure (CPAP) treatment in elderly patients with OSA would	Randomized, double-blind crossover study N=11 OSA pt aged 70+	Sleep – overnight ambulatory in-hospital sleep recording, VAS (subjective), ESS	Both low- and high CPAP treatment significantly improved respiratory parameters.	Pain threshold was captured using device (objective) versus self-report Sleep characterized by ambulatory was

	result in improved pain tolerance.	community dwelling	Pain – Pain Matcher (PM)	However, compared with baseline, the electrical pain tolerance score was significantly enhanced (analgesic effect) only under high CPAP treatment (21.2 +/- 10.9 versus 28.4 +/- 16.0; P = .03).	not PSG or actigraphy, sleep medicine physician interpreted results but not a commonly reported test. Sample size was small, but targeted since inclusion and exclusion criteria were so detailed. Sample selection was very skewed related to strict criteria to participate. Treatment was short-term, long-term effects cannot be understood.
Pao, et al., 2013 USA	To characterize PSG findings in DLB pt with sleep-related complaints.	Retrospective, descriptive study (n=78: 71M, 7F)	RSWA Respiratory disturbance index (RDI) in disordered breathing events/hour PLM arousal index AFNAR Total arousal index Presence of REM sleep without atonia % SE	96% pts had histories of recurrent dream enactment during sleep with 83% showing confirmation of REM sleep without atonia ± dream enactment during PSG. Mean RDI = 11.9 ± 5.8, PLM arousal index = 5.9±8.5, AFNAR	Sample is biased towards sleep disturbances and disorders versus healthy sleepers. Results from PSGs in DLB need to be interpreted with caution due to performing and scoring is challenging due to refusals or behavioral disturbances.

index=10.7±12.0, and total arousal index = 26.6 ± 17.4. SE was <80% in 72% of the sample, <70% in 49%, and <60% in 24%. In patients who did not show evidence of significant disordered breathing (23 with RDI < 5), 62% of arousals were AFNARs. In those patients who had significant disordered breathing (55 with RDI ≥ 5), 36% of arousals were AFNARs. 6 pts underwent evaluations with PSG plus MSLT. 2 pts had mean initial SL of <5 minutes, and both had RDI < 5. No pt had any sleep onset REM periods. 19 pt have undergone neuropathologic

examination, and 18 have had limbic-predominant or neocortical-predominant Lewy body pathology. One had progressive supranuclear palsy, but no REM sleep was recorded in prior PSG. In pts with DLB and sleep-related complaints, several sleep disturbances in addition to RBD are frequently present. In this sample, about 3/4 had a significant number of arousals not accounted for by a movement or breathing disturbance, and the primary sleep disorders do not seem to entirely account for the poor SE in DLB, especially in those without a

				significant breathing disorder.	
Piano, 2015 Italy	To evaluate the sleep pattern and the motor activity during sleep in a cohort of pts affected by HD	Cross-sectional, cohort study in sleep lab. (n=30 HD and n=30 healthy controls)	ESS Berlin's Questionnaire Interview for RLS Questionnaire for RBD Clinical eval – disease duration, clinical severity, genetic tests, PSG	The duration of the disease was 9.4 ± 4.4 y, UHMDRS score was 55.5 ± 23.4 , CAG repeats were 44.3 ± 4.1 . BMI was 21.9 ± 4.0 kg/m ² . No pts or caregivers reported poor SQ. 2 pts reported symptoms of RLS. 8 pts had an ESS score ≥ 9 . 8 pts had high risk of OSA. At the RBD questionnaire, 2 pts had a pathological score. HD pts showed shorter sleep, reduced SE index, and increased arousals and awakenings. 4 pts presented with SDB. PLMs during wake and sleep were observed in all patients. No episode of RBD was observed in the video PSG	Sample was only targeted at HD pt. PSG evaluations – no other variables assessed. Small sample size, results only generalizable to HD population.

				recordings, and no pts showed REM sleep without atonia. The disease duration correlated with ESS score ($P < 0.02$). UHMDRS correlated positively with the ESS score ($P < 0.005$), and negatively with the % REM sleep.	
Terpening, et al., 2015	to determine whether changes in sleep-disordered breathing and sleep fragmentation during nocturnal sleep were related to neuropsychological dysfunction in patients with mild cognitive impairment.	Descriptive, cross-sectional design MCI (n=46), healthy controls (n=40)	Medical burden – CIRSG Depression – Hamilton depression rating scale Medication use – antidepressants, SSRI, serotonin-norepinephrine reuptake inhibitors, noradrenergic and serotonergic antidepressants Neuropsychological assessment – processing speed, verbal memory,	Pts with MCI did not differ from healthy aging on any measure of SDB or sleep fragmentation. In MCI, processing speed was negatively correlated with greater sleep time spent below 90% oxygen saturation and a higher AHI. In contrast, in the healthy aging, processing speed was negatively correlated with an	Participants sought to be a part of the study – biased sampling, but had age-matched comparison group. Neuropsychological assessments were comprehensive No causal claims can be made regarding SDB and neuropsychological impairments Use of anti-depressants (sleep inhibiting drug)

			language, and executive functioning	increased oxygen desaturation index and the arousal index. SDB is evident in both healthy aging and MCI with associated decrements in processing speed.	
			Sleep – PSG (SDB and PLM), Self-report PSQI, and ESS		
Vitiello et al., 2014	What is the relationship between short-term improvement in sleep and long-term sleep, pain, and fatigue outcomes?	Secondary analysis, descriptive, correlational N=367 older adults (aged 60+)	Pain – pain severity, arthritis symptoms, catastrophizing, fear avoidance Sleep and fatigue – insomnia severity, sleep efficiency, sleep quality, sleep beliefs and attitudes, fatigue, daytime sleepiness, daytime function Other – depression Covariates – pt characteristics, mental status, antidepressant, analgesic, and/or sedating medication	After controlling for treatment arm and potential confounders, improvers showed significant, sustained improvements across 18 months compared with non-improvers in pain severity (P < 0.001, adjusted mean difference = 0.51 [95% CI: 0.80, 0.21]), arthritis symptoms (P < 0.001, 0.63 [0.26, 1.00]), and fear avoidance (P = 0.009, 2.27 [3.95, 0.58]) but not	Exclusion criteria – dementia Large sample size and regression analysis Secondary analysis, descriptive – no causal claims can be made High retention rates

				<p>in catastrophizing or depression. Improvers also showed significant, sustained improvements in ISI ($P < 0.001$, 3.03 [3.74, 2.32]), PSQI Total ($P < 0.001$, 1.45 [1.97, 0.93]) and general SQ ($P < 0.001$, 0.28 [0.39, 0.16]) scores, FFS ($P < 0.001$, 1.99 [3.01, 0.98]), and DBASS ($P = 0.037$, 2.44 [4.74, 0.15]), but no improvements on the FOSQ or the ESS.</p>	
Zuurbier, et al., 2015 Netherlands	Is cerebral small vessel disease associated with sleep disturbances and 24-h activity rhythms	Descriptive, cross-sectional Part of larger cohort – n=970 of community-dwelling, stroke-free population	MRI – small vessel disease Actigraphy – TST and WASO PSQI – sleep quality and sleep apnea (loud snoring)	The mean age of the total population of 970 persons was 59.2 yrs (7.5 SD) and 52%F The 24-h activity rhythm parameters inter- daily instability and	Large sample size Multiple objective indicators of cerebral small vessel disease used Limited information on the pt clinical sleep disorders

Covariates – age, sex, BMI, depression, ADL, possible sleep apnea, fasting blood glucose, cholesterol, SBP, use of anti-hypertensives, lipid lowering and sleep medication	fragmentation were moderately correlated ($r = 0.53$, $P < 0.001$). These activity rhythm parameters were also moderately correlated with total sleep time ($r = 0.34$, $P < 0.001$; $r = 0.31$, $P < 0.001$, respectively). WMLs, CMBs and lacunar infarcts were not related to TST, WASO and SQ.	including sleep apnea. Actigraphy is indirect measure of circadian rhythm. Causal claims cannot be made. Sample has middle to older adults, community-dwelling
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Appendix B: PAINAD

<i>Pain Assessment in Advanced Dementia (PAINAD)</i>				
	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
			TOTAL	

Breathing

1. *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. *Occasional labored breathing* is characterized by episodic bursts of harsh, difficult or wearing respirations
3. *Short period of hyperventilation* is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. *Noisy labored breathing* is characterized by negative sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.

5. *Long period of hyperventilation* is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. *Cheyne-Stokes respirations* are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization

1. *None* is characterized by speech or vocalization that has a neutral or pleasant quality.
2. *Occasional moan or groan* is characterized by mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. *Low level speech with a negative or disapproving quality* is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic or caustic tone.
4. *Repeated troubled calling out* is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. *Loud moaning or groaning* is characterized by mournful or murmuring sounds, wails or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. *Crying* is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial expression

1. *Smiling or inexpressive*. Smiling is characterized by upturned corners of mouth, brightening of the eyes and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. *Sad* is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. *Frightened* is characterized by a look of fear, alarm or heightened anxiety. Eyes appear wide open.
4. *Frown* is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. *Facial grimacing* is characterized by a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

Body Language

1. *Relaxed* is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. *Tense* is characterized by a strained, apprehensive or worried appearance. The jaw may be clenched. (exclude any contractures)
3. *Distressed pacing* is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. *Fidgeting* is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging or rubbing body parts can also be observed.

5. *Rigid* is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight or unyielding. (exclude any contractures)
6. *Fists clenched* is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. *Knees pulled up* is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (exclude any contractures)
8. *Pulling or pushing away* is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him or herself free or shoving you away.
9. *Striking out* is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability

1. *No need to console* is characterized by a sense of wellbeing. The person appears content.
2. *Distracted or reassured by voice or touch* is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction with no indication that the person is at all distressed.
3. *Unable to console, distract or reassure* is characterized by the inability to sooth the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.

Appendix C: RDOS

APPENDIX A. Respiratory Distress Observation Scale[®]

<i>Variable</i>	<i>0 points</i>	<i>1 point</i>	<i>2 points</i>	<i>Total</i>
Heart rate per minute	<90 beats	90–109 beats	≥110 beats	
Respiratory rate per minute	≤18 breaths	19–30 breaths	>30 breaths	
Restlessness: nonpurposeful movements	None	Occasional, slight movements	Frequent movements	
Paradoxical breathing pattern: abdomen moves in on inspiration	None		Present	
Accessory muscle use: rise in clavicle during inspiration	None	Slight rise	Pronounced rise	
Grunting at end-expiration: guttural sound	None		Present	
Nasal flaring: involuntary movement of nares	None		Present	
Look of fear	None		Eyes wide open, facial muscles tense, brow furrowed, mouth open, teeth together	
Total				

Instruction for use:

1. RDOS is not a substitute for patient self-report if able.
2. RDOS is an adult assessment tool.
3. RDOS cannot be used when the patient is paralyzed with a neuromuscular blocking agent.
4. Count respiratory and heart rates for one-minute; auscultate if necessary.
5. Grunting may be audible with intubated patients on auscultation.
6. Fearful facial expressions:



Margaret L. Campbell, PhD, RN 2/19/09.

Appendix D: Pulse Oximetry Procedure

1. Wash your hands and gather equipment and supplies.
2. Identify the patient and guide him or her to the treatment area.
3. Explain the procedure to the patient.
4. Select the appropriate size sensor (pediatric, small, or large).
5. Instruct the patient to breathe normally.
6. Prepare the selected site (earlobe or finger).
7. Remove nail polish or earrings if necessary.
8. Wipe the selected site with alcohol and allow to air dry.
9. Attach the sensor to the site and connect to the pulse oximeter. Turn on the pulse oximeter and listen to the tone.
10. Read the saturation level and document in the patient's chart. Report to the physician readings that are less than 95%.

Theory and rationale

Pulse oximetry is a noninvasive method to measure the oxygen saturation of hemoglobin in arterial blood. The pulse oximeter is a handheld device used by many medical facilities to assess a patient's oxygenation status with such respiratory disorders as pneumonia, bronchitis, emphysema, and asthma. The pulse oximeter sensor can be placed on a patient's finger, earlobe, toe, or bridge of the nose. An appropriate site can be selected by assessing capillary refill in the patient's toe or finger. If the patient has poor circulation in his fingers or toes, then use the bridge of the nose or an earlobe. Nail polish can alter results and must be removed. The pulse oximeter uses a beam of infrared light to pass through the tissue, and the device measures the pulse and the amount of light absorbed by the hemoglobin, which is displayed as a percentage on the screen. Instruct the patient to breathe normally during the procedure. A normal pulse oximeter reading is greater than or equal to 95%. Any reading less than 95% could indicate hypoxemia and may require some type of intervention or treatment such as oxygen or bronchodilator therapies.

Appendix E: Bladder Scanning Procedure

1. Wash hands and put on gloves.
2. Have patient urinate prior to test and explain procedure.
3. Have patient lay in supine position.
4. Select proper exam mode on machine.
5. Position patient clothing.
6. Find placement of bladder over pubic bone with hand.
7. Place gel on ultrasound.
8. Aim ultrasound downward towards pubic bone.
9. Press scan button and use machine screen to locate the bladder.
10. Record volume reported.
11. Repeat steps 1-10 two times or until consistent results.

1. Put on clean (nonsterile) gloves.
2. Clean off scanner head before and after each patient use according to manufacturer instructions using hospital-approved disinfectant.
3. Check that battery is in place and probe is plugged in.
4. Scan may be done with patient in sitting or supine position, preferred supine.
5. Remove or adjust patient's clothing to expose abdominal area.
6. Turn bladder scanner on. Self-testing will display on panel as well as identifying buttons.
7. Press scan and then note gender. (NOTE: If the patient is female and has had a hysterectomy, use the male key for gender. If the patient is very thin or obese, use more ultrasound gel. For patients with large amounts of lower abdominal hair, apply the gel directly to the skin. Advise the patient the gel will be cool.
8. Apply gel to the scanner head, being careful to remove air bubbles.
9. Place scanner head about 1 inch above symphysis pubis, pointing slightly down toward the expected bladder location. Make sure the head of icon on the scan head is pointed towards the patient's head.
10. Press the "scan" button making sure to hold scanner steady until you hear a beep. The bladder scanner will display the volume measured and an aiming display with crosshairs. If the crosshairs are not centered on the bladder, adjust the probe and rescan until they are properly centered.
11. When you are satisfied the results are accurate, press the : "done" button. The bladder scan will display the largest volume measures for the longitudinal and horizontal areas.
12. Record the volume.

Appendix F. Mini-Mental State Examination

Mini-Mental State Examination (MMSE)

Patient's Name:

Date:

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)
30		TOTAL

Interpretation of the MMSE:

Method	Score	Interpretation
Single Cutoff	<24	Abnormal
Range	<21 >25	Increased odds of dementia Decreased odds of dementia
Education	21 <23 >24	Abnormal for 8 th grade education Abnormal for high school education Abnormal for college education

Severity	24-30 18-23 0-17	No cognitive impairment Mild cognitive impairment Severe cognitive impairment
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Interpretation of MMSE Scores:

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
25-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.
20-25	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-20	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24-hour supervision.
0-10	Severe	Patient not likely to be testable.	Marked impairment. Likely to require 24-hour supervision and assistance with ADL.

Source:

Folstein MF, Folstein SE, McHugh PR: "Mini-mental state: A practical method for grading the cognitive state of patients for the clinician." *J Psychiatr Res* 1975;12:189-198.

Appendix G. Cumulative Illness Rating Scale for Geriatrics

Scoring Sheet

CUMULATIVE ILLNESS RATING SCALE FOR GERIATRICS (CIRS-G)

Miller, Paradis, and Reynolds 1991

PATIENT _____ AGE _____

RATER _____ DATE _____

Instructions: Please refer to the CIRS-G Manual. Write brief descriptions of the medical problem(s) that justified the endorsed score on the line following each item. (Use the reverse side for more writing space).

RATING STRATEGY

- 0 - No Problem
- 1 - Current mild problem or past significant problem
- 2 - Moderate disability or morbidity/requires "first line" therapy
- 3 - Severe/constant significant disability/"uncontrollable" chronic problems
- 4 - Extremely Severe/immediate treatment required/end organ failure/severe impairment in function

SCORE

HEART..... _____

VASCULAR..... _____

HEMATOPOIETIC..... _____

RESPIRATORY..... _____

EYES, EARS, NOSE AND THROAT AND LARYNX..... _____

UPPER GI..... _____

LOWER GI..... _____

LIVER..... _____

RENAL..... _____

GENITOURINARY..... _____

MUSCULOSKELETAL/INTEGUMENT..... _____

NEUROLOGICAL..... _____

ENDOCRINE/METABOLIC AND BREAST..... _____

PSYCHIATRIC ILLNESS..... _____

TOTAL NUMBER CATEGORIES ENDORSED..... _____

TOTAL SCORE..... _____

Severity Index: (total score/total number of categories endorsed)..... _____

Number of categories at level 3 severity..... _____

Number of categories at level 4 severity..... _____

Table 1
Demographic and Clinical Characteristics of Participants (n=89)

Characteristic	M	SD	Range
Age (years)	87.5	9.6	51-100
Length of stay (months)	30	36.09	1-153
Characteristic	n		%
Gender (female)	66		74
Race (Caucasian)	88		99
Dementia			
<i>No dementia</i>	45		50.6
<i>Dementia</i>	44		49.4
Education			
<i>High School</i>	17		19
<i>Attended College</i>	44		49.5
<i>Graduate Degree</i>	25		28
Medications			
<i>Sleep Promoting</i>	37		41.6
<i>Sleep Inhibiting</i>	78		87.6
Comorbid Illness (severe)			
<i>Musculoskeletal</i>	78		87.6
<i>Psychiatric Illness</i>	62		69.7
<i>Genitourinary</i>	57		64
<i>Neurological</i>	48		53.9
<i>Endocrine</i>	34		38.2
<i>Vascular</i>	34		38.2
<i>EENT</i>	29		32.6
<i>Respiratory</i>	29		32.6
<i>Heart</i>	22		24.7
<i>Lower GI</i>	10		11.2
<i>Hematopoietic</i>	7		7.9
<i>Upper GI</i>	5		5.6
<i>Renal</i>	5		5.6
<i>Liver</i>	0		0

Table 2
Descriptive Characteristics of Pain (n=89)

	Pain						Normal Values
	Mean	SD	Range	Median	n	%	
Musculoskeletal	3.33	2.73	0-9	3.0	69	77.5	0-10
Respiratory	3.61	3.21	0-12	3.0	75	85.2	0-16
Genitourinary							
Retained volume	99.07	123.36	0-724	60.5	62	73.8	<100
Urinary retention	0.39	0.49	0-1	0.0	33	37.1	>100
Reported discomfort	0.30	0.46	0-1	0.0	27	30.3	0-1
Gastrointestinal							
Total score	0.84	1.0	0-4	1.0	48	53.9	0-7
Decreased appetite	0.27	0.45	0-1	0.0	24	27.0	0-1
Symptoms discomfort	0.25	0.48	0-2	0.0	27	22.5	0-4
Reported discomfort	0.20	0.40	0-1	0.0	18	20.0	0-1

Table 3
Descriptive Characteristics of Sleep Quality (n=89)

	Sleep Quality						
	Mean	SD	Range	Median	n	%	Normal Values
Total Sleep Time (min)	476.5	144	1-825	495.0	59	66.3	420-540
Sleep Efficiency (%)	82.5	14.7	35.7-99.3	87.0	30	33.7	80-85
Sleep Latency (min)	15.4	27.2	0-212	8.0	13	14.6	<20
Wake After Sleep Onset (min)	106.3	107	0-679	74.0	56	62.9	10% TST
Sleep Fragmentation	6	10.8	0.59-100	4.1	46	51.7	<20

Table 4
 Summary of Logistic Regression Analysis Predicting Sleep Quality in Older Adults and People with Dementia

Sleep Efficiency						
Variable	B	SE	OR	95% CI	Wald Statistic	<i>p</i>
Dementia	1.56	0.57	4.78	[1.56, 14.62]	7.52	.006
Pillow use	1.93	0.70	6.86	[1.73, 27.23]	7.49	.006
Gender	2.03	0.69	7.61	[1.97, 29.36]	8.67	.003
Wake After Sleep Onset						
Variable	B	SE	OR	95% CI	Wald Statistic	<i>p</i>
Dementia	1.32	0.54	3.75	[1.31, 10.74]	6.03	.014
Gender	1.60	0.71	4.93	[1.22, 19.89]	5.02	.025
Urinary Retention	-1.348	0.55	0.26	[0.09, 0.76]	6.05	.014
Sleep Fragmentation						
Variable	B	SE	OR	95% CI	Wald Statistic	<i>p</i>
Dementia	-1.57	0.53	0.21	[0.07, 0.59]	8.84	.003
Pillow use	-1.52	0.59	0.22	[0.07, 0.70]	6.61	.010
Gender	-1.72	0.69	0.18	[0.05, 0.70]	6.18	.013
Respiratory Distress	0.20	0.09	1.23	[1.04, 1.45]	5.72	.017

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2012-2013 Froedtert Lutheran Memorial Hospital - Milwaukee, WI - Registered Nurse in Medical Intensive Care Unit
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PUBLICATIONS

- Kovach, C. R., Ellis, J., & **Evans, C. R.** (2017). Patterns of New Physical Problems Emerging in Long-Term Care Residents With Dementia. *Journal of gerontological nursing*, 1-7. doi:10.3928/00989134-20170310-01.
- Leske, J. S., McAndrew, N. S., **Evans, C. D.**, Garcia, A. E., Brasel, K., J. (2012). Challenges in Conducting Research After Family Presence During Resuscitation. *Journal of Trauma Nursing*, 19(3):190-4. doi: 10.1097/JTN.0b013e318261d041.
- Kovach, C. R., **Evans, C.**, Sattell, L., & Gopalakrishnan, S. (In Press). Feasibility and Pilot Testing of a Mindfulness Intervention for Frail Older Adults and People with Dementia. *Research in Gerontological Nursing*
- Kovach, C. R., & **Evans, C. D.** (In Press). Assessing pain and unmet need in patients with Advanced Dementia: The role of the Serial Trial Intervention (STI). In R. J. Moore (Ed.), *Handbook of pain and palliative care*. New York: Springer.

AWARDS/HONORS/SERVICE

- 2017-18 University of Wisconsin-Milwaukee Chancellor's award (\$9,000)
- 2016-17 University of Wisconsin-Milwaukee Chancellor's award (\$8,000)
- 2015-16 University of Wisconsin-Milwaukee Chancellor's award (\$8,000)
- 2015-current Academic Honors Graduate School 3.984
- 2011 Undergraduate Research Symposium: Speaker/Presenter
- 2010 National Conference for Undergraduate Research: Speaker/Presenter
- 2009 Undergraduate Research Symposium: Speaker/Presenter
- 2007-11 Dorothy Coogan Scholarship (\$14,000)

ACTIVE PROFESSIONAL MEMBERSHIPS

- Doctoral Nursing Student Organization
 Midwest Nursing Research Society
 Sigma Theta Tau Nursing Honors Society - Eta Nu Chapter

PROFESSIONAL/PERSONAL REFERENCES

Available upon request