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PAIN, NEED-DRIVEN BEHAVIORS IN DEMENTIA, AND NURSES' PERCEPTIONS: AN EMBEDDED MIXED METHODS STUDY

Suzanne E. Parkman
University of Texas at Tyler

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PAIN, NEED-DRIVEN BEHAVIORS IN DEMENTIA, AND NURSES' PERCEPTIONS: AN EMBEDDED MIXED METHODS STUDY

by

SUZANNE E. PARKMAN

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of the requirements for the degree of
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Beth Mastel-Smith, Ph.D., Committee Chair

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SUZANNE E. PARKMAN

has been approved for the dissertation requirement on
July 17, 2018
for the Doctor of Philosophy in Nursing degree

Approvals:

Beth M Smith

Dissertation Chair: Beth Mastel-Smith, Ph.D.

Gloria Duke

Member: Gloria Duke, Ph.D.

Sandra

Member: Sandra Peterson, Ph.D.

Member: Anthony McGuire, Ph.D.

Barbara K Haas

Barbara K. Haas, Ph.D.
Executive Director, School of Nursing

Yong Wang

Yong Tai Wang, Ph.D.
Dean, College of Nursing & Health Sciences

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Abstract

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Suzanne E. Parkman

Dissertation Chair: Beth Mastel-Smith, Ph.D.

The University of Texas at Tyler
July 2018

This dissertation is an exploration of psychosocial and behavioral concepts related to the experience of pain in persons with severe dementia and whether the use of an observational pain scale would provide better pain management and comfort for these individuals. Pain has been under-detected, under-reported, and under-treated in this population mainly because persons with dementia (PWD) are unable to self-report pain. **C**ognitive decline associated with dementia is commonly accompanied by loss of ability to communicate and neuropsychiatric behaviors known as need-driven behaviors (NDB). Nurses must correctly interpret 'pain behaviors' in order to assess and treat appropriately. The overlapping of NDBs and pain behaviors presents a methodological and clinical challenge that indicates the need for more research. The reader will notice these concepts threaded throughout the dissertation. The researcher determined a gap in current evidence related to NDBs, which may be the only expressions of pain for persons with severe dementia. The first manuscript, *Comparison of Pain Assessment Tools Used for Persons with Dementia,* written as a state-of-the-science literature review examines the most frequently used observational pain scales (OPS) in comparison to the American Geriatric Society Guideline for Persistent Pain in Older Adults and reliability and validity. *In the Eyes of the Beholder: The Historical Basis for an Integrated Model of Pain Management* is the second manuscript in this portfolio dissertation. This manuscript provides a non-traditional analysis of the concept pain by providing a historical basis for an integrated pain management model. The fourth chapter presents the primary research study. Using a local memory-care organization, an embedded mixed methods study was undertaken with a hypothetical model as the foundation to determine the utility of two OPS in clinical practice. A qualitative element was included to capture the nurses' perceptions of pain interpretation with PWD. Further analysis revealed the utility of the OPSs and the impact on NDB and pain medication administration. In completing this dissertation, the researcher was able to contribute to the extant knowledge on pain, need-driven behavior in dementia, and nurses' perceptions.

Chapter 1

Overview of the Research Study

Context for Doctoral Research Focus

Pain is common in older adults, particularly those with multiple comorbidities (Corbett et al., 2012). Pain reportedly affects 34% of older people living in the community (Corbett et al., 2012) and 80% of older adults living in nursing homes (Achterberg et al., 2013). Pain management for elders is a complex challenge. The current research reports sub-optimal management (Flo, Gulla, & Huesbo, 2014; Pieper et al., 2013), limited pain assessment (Rantala, Kankkunen, Kvist, & Hartikainen, 2012), lack of documentation, and longer waits for older adults to receive pain medication (Fry et al., 2015). Pain combined with dementia further complicates quality care and positive patient outcomes.

Worldwide, dementia affects close to 50 million people, a number which will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050 (WHO, 2015). Studies have shown up to 50% of persons with dementia (PWD) regularly suffer from some degree of pain (van Kooten et al., 2015). Because of progressive cognitive decline, lack of ability to communicate, neuro-psychiatric behaviors such as aggression and agitation, and multiple comorbidities, pain assessment and treatment presents a critical challenge for caregivers (Hadijstavropoulos et al., 2014). Behavioral signs of pain may be altered unexpectedly in PWD, and pain is also a personal and subjective experience (Lautenbacher, Niewelt, & Kunz, 2013). There is no single reliable method for understanding how PWD react to painful stimuli (Lichtner et al., 2016).

A number of observational pain assessment tools have been developed based on 'pain cues' based on expert opinion for the American Geriatric Society (2002; 2009). While there are more than 28 observational scales (OPSs) available, nurses continue to struggle with implementing these structured assessments (Lichtner et al., 2016). OPSs have been shown to improve the recognition of pain as well as rating the severity in older adults with cognitive impairment (Lukas, Barber, Johnson, & Gibson, 2013).

In response to the growing need for more reliable methods of pain assessment and management in persons with dementia, The American Society for Pain Management Nurses recommends a hierarchy of pain assessment techniques for PWD which includes incorporation of an observational tool (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). The intent of this dissertation was two-fold: 1) explore the effect of two OPSs, subsequent pain medication administration, and the impact on need-driven behaviors (NDB) for residential PWDs, and 2) explore nurses' perceptions regarding ease of and barriers to the use of each OPS. The objective of this research was to determine which of two OPS best identified pain and to help memory-care staff to use the scales and understand factors that facilitate and inhibit adequate pain management in PWD.

Introduction of Manuscripts

In the beginning phases of building this program of research, the researcher continuously discovered the importance of observational pain scales with pain assessment in PWD. However, closer scrutiny revealed that there were many pain assessment tools available and no standardized tool based on behavioral pain indicators. The first manuscript in chapter two, *Comparison of Pain Assessment Tools Used for Persons with*

Dementia, presented as a literature review, evaluated existing tools for pain assessment in PWD using the American Geriatrics Society (AGS) guideline for persistent pain. The purpose was to locate an OPS which encompassed all three of the comparison criteria and to advise nurses regarding the efficacy of the tools and provide recommendations from the American Society of Pain Management Nursing. The search results yielded 14 of the most commonly used OPSs. Comparison of the 14 tools included number of behaviors, reliability, validity, and ease of use. The second manuscript, Chapter Three, *In the Eyes of the Beholder: The Historical Basis for an Integrated Model of Pain Management,* is a non-traditional concept analysis based on a series of previous concept analyses. It was surmised that a comparison of the scholarly analyses of pain may help nursing move toward better ways to assess and treat patients as well as provided insight into creative ways of studying new pain management measures. The third manuscript, *Pain, Need-Driven Behaviors in Dementia, and Nurses' Perceptions: An Embedded Mixed Methods Study*, is a comparison of two OPSs and their correlation to NDBs and pain medication administration as well as nurses' perceptions of pain and the PWD. The study involved a cohort of in-patient PWD and a cohort of the nurses' who cared for and assessed pain. In completing this dissertation, the researcher filled a gap in professional knowledge by exploring the complexities associated with pain assessment in PWD and NDBs while relating to the issue of the subjective nurses' experience.

Chapter 2

Article 1: Comparison of Pain Assessment Tools Used for Persons with Dementia

Abstract

Advancing age has been associated with dementia and pain. Lack of pain recognition in persons with dementia (PWD) can result in behavioral disturbances, therefore an observational pain scale is necessary. The purpose of this review was to evaluate existing tools for pain assessment in PWD using the American Geriatrics Society (AGS) guidelines for persistent pain and provide guidance for nurses based on the recommendations for the American Society of Pain Management Nursing. A systematic search of CINAHL, PubMed, Cochrane, and PsycINFO was conducted using key words dementia, pain, behaviors, pain management, and assessment tools. Inclusion criteria were the tool must have behavioral indicators of pain, must be developed for non-verbal older adults, and should have one published report of psychometric evaluation. The search results yielded 14 of the most commonly used pain scales. Comparison of the 14 tools concluded only three tools incorporated all six AGS guidelines. Given the limitations in the current state-of-science, strategies should focus on accurate assessment, nurse education, and research to build on current instruments.

Comparison of Pain Assessment Tools Used for Persons with Dementia

Currently in the United States, 4.7 million people suffer from dementia-related diseases (Hebert, Weuve, Scherr, & Evans, 2013). As dementia progresses resulting in severe cognitive decline, the people affected lose the ability to communicate and carry out daily activities (Lautenbacher, Niewelt, & Kunz, 2013; Oosterman, Hendriks, Scott, Lord, White, & Sampson, 2014, May). Often times age-associated multiple comorbidities are present further increasing the burden on this population (Cipher & Clifford, 2004; Corbett et al., 2012) which frequently necessitate care and even hospitalization. Dementia is not simply a condition found in long-term care facilities; persons with dementia (PWD) often live at home with family caregivers and are frequently patients in hospitals and clinics. The need for a stable and reliable way to assess pain in PWD is a priority for both nurses and family caregivers. What happens when the patient cannot be relied upon to respond with a number between 0 and 10 or even point at a figure on a chart to symbolize pain and discomfort? The purpose of this article is to give nurses an overview of the pain assessment tools that are available and describe their suitability for use in PWD.

Background and Significance

Pain Perception and Response in People with Dementia

Pain is considered the fifth vital sign to be assessed, treated, and documented by nurses. Assessment of pain can be through self-report (preferred method) or measured physiologically or behaviorally. While it is a basic human need to be pain free, it is a subjective sensation making it difficult for the nurse to recognize, assess, and manage pain in persons with cognitive impairment (Cipher, Clifford, & Roper, 2006; Corbett et al., 2012). Older adults with dementia are less likely to receive pain medication than those who are able to communicate, even though they are just as likely to experience painful illnesses (Manfredi, Breuer, Meier, & Libow, 2003; Morrison & Siu, 2000; Sandvik et al., 2014).

Because caregivers fail to recognize pain in PWD, it often manifests in behaviors known as dementia-compromised behaviors (Ahn & Horgas, 2013; Cipher, Clifford, & Roper, 2006; Sandvik et al., 2014). The PWD is dependent on caregivers who can accurately recognize and assess pain (Pieper et al., 2013). Reduced pain recognition and reporting is most likely due to the inability of the PWD to communicate and not a decrease in painful conditions (Buffum, Sands, Miaskowski, Brod, & Washburn, 2004; Rantala, Kankkunen, Kvist, & Hartikainen, 2014).

Psychophysical studies of pain tolerance show older adults are less able to endure strong pain sensations (Gibson & Farrell, 2004; Hadjistavropoulos et al., 2014; Lautenbacher, 2012). The deterioration of endogenous pain inhibitory systems in elderly showed less than a third-strength of the induced endogenous inhibitory effects to pain sensitivity when compared to younger adults (Naugle, Cruz-Alameda, Fillingim, & Riley, 2013). In addition, dementia might exacerbate age-related impairments in pain processing associated with neurodegenerative loss in parts of the central nervous system known to process noxious information (Hadjistavropoulos et al., 2014). Some authors reported no change in pain tolerance in PWD (Jensen-Dahm et al., 2014); however, for this vulnerable group pain is frequently not recognized or reported and under-treated (Hadjistavropoulos et al., 2014).

Given all these factors, pain response can vary from individual to individual with or without cognitive impairment. The question arises “How is the PWD impacted by pain?” Scherder and Plooij (2012) suggested that the pain threshold did not diminish with dementia, particularly in those dementias with white matter lesions. White matter lesions are present in vascular, mixed, and often times Alzheimer’s type dementias (Filley, 2012). Carlino et al. (2010) further elaborated stating that PWD often behaviorally reacted to a painful stimulus. Behavioral disturbances are frequently indicators of pain in PWD resulting from an unmet need and the inability to effectively communicate (Algase et al., 1996; Cipher, Clifford, & Roper, 2006; Sandvik et al., 2014). This evidence supports the idea that persons with dementia do feel and react to pain; however, their reaction may not be the expected behavior we have come to associate with the pain response. This unanticipated pain response makes the need for instruments to measure pain in PWD a paramount issue for nurses and family caregivers.

Pain Measures for People with Dementia

While a self-report pain scale has been the standard for pain assessment, an observational pain tool is necessary for those with advanced dementia as language skill deteriorates (AGS, 2009). Non-verbal pain scales are based on observation of behaviors and functioning, involve assessment of activity, body language/facial expressions, sleep disturbances, and changes in appetite routine, and social functioning (AGS, 2009). Physiological indicators like heart rate and blood pressure may also indicate pain, but these particular phenomena are often not practical to measure or are inaccurate due to multiple comorbidities that may exist (Scherder & Plooij, 2012). The fragile nature of pain perception in PWD makes the choice of a valid and reliable tool a challenge to nurses and family caregivers.

The position statement from the American Society for Pain Management Nurses recommended a hierarchy of pain assessment techniques for PWD which includes incorporation of an observational tool (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011):

1) A self-report-self-report of pain is sometimes possible but decreases as dementia progresses.

2) Search for potential causes of pain; consider common pain etiologies such as musculoskeletal and neurological disorders.

3) Observe patient for six pain-related behaviors using an observational assessment tool.

4) Identify behaviors known to be baseline and what is different.

5) Attempt an analgesic trial.

Reliability and validity of instruments are usually reported in articles where they are described. In choosing a tool, it should be established that it is reliable. Reliability indicates that the assessment can be reproduced with confidence, meaning that the same results on the measurement can be repeated by different observers on different occasions. Validity means that the instrument is really measuring what it says it is measuring, in this case, pain. It is the use of several phenomena to bolster our belief that what we are seeing is really “pain” and not something else, like constipation or anxiety. The developer of the scale should have evaluated whether all relevant aspects/behaviors of pain are included in the scale. Too many scale items can reduce our confidence that the scale is reliable, but too few can give us concern as to whether it is truly measuring the phenomenon of pain. In evaluating the scales, the reliability and validity are important, but we must also take into consideration the time to complete a scale, the resources available, and the need for training and education of nursing staff or family members which may make a tool impractical for use.

Evidence suggested that the more items, the more reliable, and the fewer items used the less reliable (Churchill & Peter, 1984). However, the number of items should depend on the stimulus being evaluated. Too many items can make it harder to demonstrate statistical significance (Friedman, 1999). The wording and interpretation of the scale can introduce unintentional bias in a scale. For example, the idea that a score of 2 equates to “some of the time” as a response might mean vastly different things to different persons. The evaluation and use of pain scales involves more than just finding an instrument on an Internet search. One of the valuable services that the nurse can provide to caregivers of PWD is to help them evaluate the scales available to find one that is reliable and valid and can be incorporated successfully into daily care to help ensure comfort and freedom from pain.

Bias is always a consideration when using scales, especially those which rely on observations. Bias is a personal inclination to see what we want or expect to see. It negates the effectiveness of an objective measure of pain. The use of rating scales can be biased by the researcher either intentionally or unintentionally (Friedman, 1999). The wording and interpretation of the scale can also introduce unintentional bias in a pain scale.

The purpose of this review was to evaluate existing tools for pain assessment in PWD based on the American Geriatric Society guidelines, reliability and validity, and ease of use. Furthermore, this article will provide recommendations regarding assessment of this population and ideas for future research.

Methods

Three databases (CINAHL, PubMed, & PsycINFO) were systematically searched to identify existing tools for assessment of pain in PWD. The three individual searches were done in February 2015 and used the terms dementia, pain management, assessment tools, and behaviors with the search option of "search with AND". Limits were set on the years 2000 through 2015 to narrow the results to current best practices or usual care, and relevant articles were chosen based on those scales with psychometric properties and clinical utility. Assessment tools reviewed were compared to the American Geriatrics Society (AGS) Guidelines for persistent pain in older adults (AGS, 2009; AGS, 2002). These guidelines are based on expert opinion and not empirically validated; however, they serve as an adequate framework for comparing measures. The tool must assess behavioral indicators of pain and be developed for non-verbal older adults and dementia. The search strategy identified a possible 28 tools. However, due to lack of sufficient methodological details (Lichtner et al., 2014), only 14 observational pain assessment tools that incorporate components of the AGS guidelines were widely used in practice and included in this critique.

The AGS guidelines (2009; 2002) provided a framework to identify tools that would enable caregivers to accurately observe pain. They identified six behaviors that could be observed and recorded by nurses to diagnose pain. The behavioral pain indicators include facial expressions, verbalizations (vocalizations), body movements, changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes. Each tool is compared using the AGS framework for persistent pain in older adults (Table 1).

Several scales were used; therefore, this article reports on 14 observational pain scales which included: The Abbey Pain Scale (APS; Abbey et al., 2004), Assessment of Discomfort in Dementia (ADD; Kovach et al., 2001), Checklist of Non-Verbal Pain Behaviors (CNPI; Ersek et al., 2010; Feldt, 2000), Certified Nurse's Aide Pain Assessment Tool (CPAT; Cervo et al., 2012), Discomfort Scale for Dementia of Alzheimer's Type (DS-DAT; Pieper et al., 2013), DOLPLPUS-2 (Lefebvre-Chapiro, 2001), Geriatric Multidimensional Pain and Illness Inventory (GMPI; Clifford & Cipher, 2005), Mahoney Pain Scale (MPS; Mahoney & Peters, 2008), Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID-2; Huesbo et al., 2009), Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN; Snow et al., 2004), Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC; Cheung & Choi, 2008), Pain Assessment for Dementing Elderly (PADE; Villaneuva et al., 2003), Pain Assessment in Advanced Dementia (PAINAD; Ersek et al., 2010; Warden, Hurley, & Volicer, 2003), and Pain Assessment Instrument in Non-Communicative Elderly (PAINE; Cohen-Mansfield, 2006). These scales were assessed to determine how well each scale matches needs for pain management in this population.

Findings

The literature review yielded 14 pain assessment tools for use in PWD and a description of the scales is shown in Table 1. Each scale was compared to the American Geriatrics Society (2009; 2002) guidelines for persistent pain in older adults. Only three scales included all six guidelines: Abbey, ADD, and the PACSLAC. The CPAT, Dolophus-2, and PADE included five of the six guidelines while the GMPI and PAINE contained four of the five guidelines. The remaining scales contained only three of the six AGS criteria. All scales had at least one published report on psychometric properties; however, some were rated better than others. The APS, CNPI, DS-DAT, MOBID-2, and PAINAD seemed to have the most published data on reliability and validity (Abbey et al., 2004; Corbett et al., 2012; Ersek, Herr, Neradilek, Buck, & Black, 2010; Feldt, 2000; Huesbo, Ballard, Cohen-Mansfield, Seifert, & Aarsland, 2014; Huesbo, Strand, Moe-Nilssen, Huesbo, & Ljungren, 2009; Lichtner et al., 2014; Lints-Martindale, Hadjistavropoulos, Lix, & Thorpe, 2012). A systematic review conducted by Pieper et al. (2013) reported the DS-DAT had the best interpretation of pain and behaviors and recommended this tool for use with PWD, followed closely by the PAINAD. In a state-of-the-science review, Herr, Bjoro, and Decker (2006) found strong evidence of reliability with the DS-DAT, but due to the limitations of the state of science, they recommended a comprehensive approach to pain assessment. Another systematic review revealed moderate psychometric quality for PAINAD, PACSLAC, and DOLOPLUS-2; however, due to methodological issues the authors were hesitant to recommend any particular observational scale over another (Lichtner et al., 2014; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). It should be noted that the DOLOPLUS-2 is the second version of the tool and originally developed in French which may affect the reliability and validity of the instrument (Lefebvre-Chapiro, 2001). Despite the moderate reviews, the PAINAD is endorsed by the American Medical Directors Association (AMDA) for use in persons with severe dementia. The CPAT and GMPI evidenced reliability and validity in long-term care facilities (Cervo et al., 2012; Cipher, Clifford, & Roper, 2006). There was conflicting evidence regarding the Doloplus-2; however, it was the most extensively tested observational instrument (Clifford & Cipher, 2005; Lichtner et al., 2014). According to the developer of the MPS, there is support for validity; however, no other reports could be found in the literature search (Mahoney & Peters, 2008). The remaining scales showed good reliability and validity, but sample sizes were small or results were obtained using convenience sampling (Cheung & Choi, 2008; Cohen-Mansfield, 2006; Corbett et al., 2012; Horgas & Miller, 2008; Horgas, Nichols, Schapson, & Vietes, 2007; Lichtner et al., 2014; Villanueva, Smith, Erickson, Lee, & Singer, 2003).

The majority of the scales were intended for nurses' use; however, the CPAT, NOPPAIN, and PAINE are administered by the nurse's aide or lay caregiver. The CPAT includes reporting criteria for use by the registered nurse, the NOPPAIN lacks this criteria; furthermore, assessment is out of nurse's aides scope of practice. The NOPPAIN and PAINE are recommended for use in the community, administered by lay caregivers and have shown accuracy due to familiarization with the PWD (Horgas, Nichols, Schapson, & Vietes, 2007; Lichtner et al., 2014).

Most scales took five minutes or less to administer (Herr, Bjoro, & Decker, 2006; Lichtner et al., 2014; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). The ADD protocol and DS-DAT required more time. The PAINE tool, even though it is easy to administer, retrospectively measures occurrences of pain behaviors and requires a consistent caregiver over a two week period (Herr, Bjoro, & Decker, 2006; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). The PACSLAC is the most comprehensive of the 14 tools capable of picking up subtle pain behaviors; however, there is some discussion whether the subtle behaviors are a result of pain or some other unmet need (Corbett et al., 2012).

The ADD protocol (Kovach, Noonan, Griffie, Muchka, & Weissman, 2001) is different from the other observational pain tools because it uses a systematic approach which includes a differential assessment and treatment plan for physical pain and affective discomfort experienced by the PWD. It consists of a checklist of five categories of pain behaviors and specified subcategories of potential behaviors. It includes the following: facial expressions, mood, body language, voice, and behavior. If potential pain behaviors are observed, then the protocol consists of five steps which include: (a) assessment of physical signs and symptoms, (b) current or past history of pain, (c) assessment for increased body movements such as pacing or guarding, (d) intervene with non-pharmacological treatments, (e) if non-pharmacological is unsuccessful, medicate with a non-narcotic analgesic. If symptoms persist, the clinician is advised to consult the provider and medicate with narcotic analgesic or psychotropic medication. The instructions are clear to the clinician; however, it requires time and complex clinical decisions. There is support for the validity of the protocol, but reliability remains unclear (Corbett et al., 2012).

Finally, there is an issue of clarity of instructions regarding the tools and score interpretations. The APS and DS-DAT have the clearest instructions for clinical decision making (Herr, Bjoro, & Decker, 2006; Lichtner et al., 2014; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). The CPAT has the clearest instruction for non-professional caregivers (Cervo et al., 2012).

Discussion

The goal of pain assessment in PWD is to maintain the highest quality of life via optimal pain management. Multiple authors have discussed the lack of adequate pain control in PWD. Morrison and Siu (2000) reported that PWD received one third the amount of opioid analgesic for hip fractures compared to a control group of cognitively intact patients and cognitively intact subjects received 80% of pain medication in response to painful conditions and treatments versus 56% in patients with severe dementia for the same painful conditions (Reynolds et al., 2008). Poor pain relief was reported in PWD upon discharge from the hospital in 32% of surgical patients and 16% of medical patients (Mehta, Siegler, Henderson, & Reid, 2010). The prevalence of pain in PWD has been established; however, recognition of pain and effective use of observational pain scales remains a challenge for nurses. It appears to be a delicate balance in pain recognition, use of analgesics, and managing the harm associated with medication side effects. Pain management strategies for PWD require a multidisciplinary team approach involving pharmacological as well as behavioral approaches.

The Omnibus Reconciliation Act (OBRA) requires nursing home facilities to meet certain standards to qualify for Medicare or Medicaid reimbursement. The OBRA regulations do not directly address pain, but pain control is implied because it affects resident rights, resident assessment, resident care, and quality of life. The Centers for Medicare and Medicaid Services (CMS) requires compliance with CMS Pain F-Tag 309: Quality of Care in the recognition and management of pain (CMS Pain F-Tag 309, 2009). CMS posts a pain control report card for every facility listed on their website. Issues with pain control are public knowledge and can result in an audit by CMS which in turn has the potential to affect financial reimbursement (CMS, 2014). This national focus on the care and comfort of vulnerable persons with cognitive deficits makes the use of a valid and reliable pain assessment tool even more of a priority.

An OPS must be sensitive enough to detect subtle pain behaviors and have reliability and validity reported. However, it must also be simple for nurses to use in a timely manner. The APS, ADD, and PACSLAC included six ‘pain behaviors’ from AGS guideline. The APS also included a question about behaviors that deviated from the PWD baseline. The DS-DAT and PAINAD had the most reliability and validity reported. The ADD included a protocol which was detailed; however was time consuming. The DS-DAT did not have a scoring system, but was developed into the scale known as PAINAD which had a 0-10 pain scale similar to a numeric pain scale. Both the APS and the PAINAD had simple instructions and took less than five minutes to complete. Due to the pain behaviors represented, reliability (particularly in long-term settings), and ease of use, the APS and PAINAD were deemed the most adequate tools for use in PWD.

In the practice setting, increased nurse education in the use of effective non-verbal pain scales may help to improve pain management in PWD. In order to achieve this, professional nurses must have confidence that they have accurate and reliable methods for assessing pain and adequate education to use them. By examining and improving existing non-verbal pain scales, researchers can ensure that nurses at the bedside can engage in effective assessment and treatment of pain in PWD. It also provides nurse researchers with a strong foundation for development of better assessment tools.

Current Gaps in Existing Pain Assessment Tools

One of the challenges for researchers in developing a standardized assessment tool is the individuality of PWD and their unique expressions of pain. Because of the unique nature of the varying instances of dementia, it appears that pain assessment tools with a broader scope have greater clinical utility. However, these broad tools tend to pick up behaviors that are not exclusive to pain (Huesbo, Ballard, & Aarsland, 2011). Many tools have shown promising validity detecting the presence of pain, but measuring the intensity has been hard to validate (Lichtner et al., 2014; Manfredi, Breuer, Meier, & Libow, 2003). Furthermore, comparison of the pain tools is difficult due to the varying designs, methods, research populations, and rater’s concept of pain (Pieper et al., 2013). Even though the current scales are based on the AGS framework, there is some subjectivity involved. Most of the tools critiqued have limited psychometric evaluation, and nurses are not clear on how to appropriately use them at the bedside (Huesbo, Ballard, Cohen-Mansfield, Siefert, & Aarsland, 2014; Lichtner et al., 2014).

There appears to be a complex relationship between pain and behaviors in PWD. The majority of the research has only been tested once and may be difficult to replicate. Large scale studies are needed which delve into the complex relationship to give more insight into which interventions and outcomes are the most effective (Pieper et al., 2013). Currently, the quality of life for dementia patients lies in the assessment and management skill of caregivers. No evidence was located which examined the effects of pain management treatments and the different types of dementia. In particular, inflammatory types of dementia may respond differently to analgesics (Corbett et al., 2012) which further complicate the assessment of pain and pain relief. No research was found addressing the effect of cultural background on pain and this population.

Conclusions and Recommendations

The 14 tools included in this review were evaluated for comprehensiveness using the AGS (2002, 2009) guidelines. A desirable but unrealistic goal would be to point a large sign at one instrument that says “This Is It!” Unfortunately, there is no way to identify the perfect scale for every situation. The goal of this article was to provide an objective way to compare the instruments which are available to give nurses better information upon which to base decisions. In summary, all pain tools in this article included the core of non-verbal indicators for pain, and some incorporated more subtle indicators of pain. Only three tools incorporated all six guidelines (Abbey, ADD, & PACSLAC). Given the limitations, comprehensiveness of non-verbal pain indicators, subjectivity of user, and content validity of AGS guidelines, it is clear that more research must be conducted to develop a more comprehensive pain scale. In addition, nurses must be educated regarding pain recognition, available methods and resources. Nursing leaders must conduct and encourage further research to determine solid reliability and validity of instruments and build on the current instruments.

The literature provides no clear-cut guidelines for pain assessment in PWD, particularly regarding the reliability and validity of instruments used in this population. Lichtner et al. (2014) conclude that no recommendation for an observational pain scale can be made due to the limited evidence of reliability, validity, and clinical utility. Many studies recommend the combination of the ADD protocol in conjunction with an observational scale (Corbett et al., 2012; Herr, Bjoro, & Decker, 2006; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). The position statement from the American Society for Pain Management Nurses recommends a hierarchy of pain assessment techniques for PWD which includes incorporation of an observational tool (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011).

Registered nurse clinicians find themselves pulled in many directions in today's health care environment. It is essential that nurses assess the practicality, utility, and reliability of available OPS, engage with and apply current evidence-based practice. Input from nurses engaged in care of PWD is the only way to develop, perfect, and evaluate the validity of pain assessment instruments and will promote translation to family caregivers. Providers at all levels must collaborate and create a comprehensive approach to pain assessment and management in PWD. Managing the PWD's pain has the potential to improve quality of life, prevent need-driven behaviors and encourage maintenance in the community rather than institutionalization.

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Table 1

Pain Assessment Tools for Use in PWD

PAIN SCALES	DESCRIPTION	RELIABILITY AND VALIDITY	INCLUDE AGS GUIDE-LINES	EASE OF USE	PROS AND CONS
The Abbey Pain Scale (Abbey PS)	4-point scale for intensity of behavior with total score ranging from 0-18. The total score is then interpreted as intensity of pain. The rater is then asked to indicate the type of pain the PWD has such as acute, chronic, or acute on chronic.[19]	Internal consistency reliability within acceptable level.	Includes all 6 of the AGS guidelines	Takes < 5 minutes to administer; Some instructions provided on the tool schema; unclear what behavior triggers pain assessment	
Assessment of Discomfort in Dementia (ADD)	Check list of 5categories of pain behaviors and specified subcategories of potential behaviors.[33]	Validity established, however, reliability remains unclear.	Includes all 6 AGS guidelines	Instructions are clear; however, requires time and complex clinical decisions	Only pain scale with a protocol
Checklist of Non-verbal Pain Behaviors (CNPI)	List of six cluster behaviors; Each behavior scored on a dichotomous scale of 1=present or 0=absent, measured both at rest and on movement. Possible total scores ranging from 0-12.[21]	Adequate reliability and validity.	Addresses 3 of 6 AGS guidelines	Takes < 5 minutes to administer Interpretation of score is not provided	
Certified Nurse's Aide Pain Assessment Tool (CPAT)	Designed to be used by nurse's aides after one minute of observation; 41 items in five major categories; PWD observed for behaviors from each of the 5 categories. An "X" is placed in the appropriate box that shows the presence or absence of pain. Behaviors consistent with the presence of pain receive a score of 1 and those behaviors supporting an absence of pain receive a score of 0. [24]	Adequate levels of reliability and validity when used with PWD in nursing homes.	Addresses 5 of the 6 AGS guidelines	Takes < 5 minutes to administer. The scoring scale ranged from 0-5 and a score of 1 or greater requires the aide to report to the nurse for further assessment.	
Discomfort Scale for Dementia of Alzheimer's Type (DS-DAT)	Consists of nine items; Each item is measured for presence or absence of discomfort; if present, scored for intensity, frequency, and duration of pain.[20]	Reliable and valid.	Addresses 3 of the 6 AGS guidelines	Requires extra time and training of the pain raters	Doesn't account for pain with non-movement
Doloplus-2	Consists of three subscales with a total of 10 items. Subscales include somatic, psychomotor, and psychosocial reactions. Scores range from 0-30, with the pain threshold being identified at five points.[26]	Conflicting evidence on the reliability and validity of the instrument.	Addresses 5 of the 6 AGS guidelines	Takes < 5 minutes to administer	

Table 1 Pain Assessment Tools for Use in PWD (Continued)

PAIN SCALES	DESCRIPTION	RELIABILITY AND VALIDITY	INCLUDE AGS GUIDELINES	EASE OF USE	PROS AND CONS
Geriatric Multi-dimensional Pain and Illness Inventory (GMPI)	12-item instrument designed to rate pain and its social, functional, and emotional consequences. All items are rated on a 10 point scale, with each point associated with specific behavioral criteria. The GMPI consists of 3 subscales dealing with pain severity, functional limitations , and emotional distress associated with pain.[3,4]	Evidenced to be a reliable and valid assessment tool for assessing pain of residents in long term care facilities.	Addresses 4 of the 6 AGS guidelines	Takes < 5 minutes to administer. Its brevity and clearly defined assessment criteria are make it easy to administer	The GMPI includes severity of pain, functional limitations, and distress associated with pain
Mahoney Pain Scale (MPS)	Eight behavioral items are rated on a scale from 0 to 3, with higher ratings indicating higher pain intensity; associates unique facial descriptions with different levels of pain. For example, a score of zero is given if a blank expression is identified, whereas, a score of one corresponds to a sad expression.[27]	The scale developers indicate there is support for its construct and concurrent validity.	Addresses 3 of the 6 AGS guidelines	Takes < 5 minutes to administer	
Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID-2)	Nurse administered instrument comprised of two parts. Part one is the assessment of inferred pain intensity based on the PWD behavior in connection with standardized movements of different body parts. Part two includes the observation of pain behaviors related to internal organs, head, and skin registered on pain drawings and monitored over time.[37]	Moderate to very good inter-rater reliability and a test-retest reliability of pain behavior indicators.	Addresses 3 of the 6 AGS guidelines	Takes < 5 minutes to administer	
Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)	Administered by a nurse's aide. Pain is observed at rest and at movement based on care conditions such as bathing, dressing, and transfers. Intensity is rated using a 6-point Likert scale. No criteria is established for reporting observations to the nurse and assessment is beyond the scope of a nursing assistant.[31]	Support for instrument reliability and validity, but no clinical testing has been done.	Contains 3 of the 6 AGS guidelines	Takes < 5 minutes to administer	

Table 1 Pain Assessment Tools for Use in PWD (Continued)

PAIN SCALES	DESCRIPTION	RELIABILITY AND VALIDITY	INCLUDE AGS GUIDELINES	EASE OF USE	PROS AND CONS
Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)	Four subscales and a total of 60 items including facial expression, activity/body movements, personality/mood, and physiological indicators such as eating and sleeping. Each item is scored as either present or absent and scores range from 0 to 60.[28]	Reliability and validity limited due to small sample sizes.	Contains all 6 categories of the AGS guidelines	Takes < 5 minutes to administer Further evaluation is required to discriminate between pain behavior and behavior related to another unmet need	
Pain Assessment for Dementing Elderly (PADE)	Three parts with a total of 24 items. Part 1 is physical and includes facial expression, posture, and breathing patterns. Part 2 involves pain intensity assessment by proxy, and Part 3 encompasses functional activities of daily living such as dressing, bathing, and transfers.[32]	Sample sizes to test reliability and validity were small and there are issues regarding clarity in scoring and interpretation of instrument.	Contains 5 of the 6 AGS guidelines	Takes < 5 minutes to administer.	Assumption that caregivers can accurately assess pain is not substantiated
Pain Assessment in Advanced Dementia (PAIN-AD)	Includes five items: breathing, negative vocalization, facial expression, body language, and consolability. Each item is graded on a 3-point scale from 0-2 for intensity.[30]	Reliability and validity limited due to small sample sizes.	Contains 3 of the 6 AGS guidelines	Takes < 5 minutes to administer Easy to use with limited training; scoring procedures clearly described	Short, easy to use, similar to numerical scale, dose not detect subtle pain indicators
Pain Assessment Instrument in Non-communicative Elderly (PAINE)	Tool consists of 22 items used to measure the occurrence of pain behaviors ranging from 1 (never) to 7 (several times an hour). It includes such items as repetitive behaviors, repetitive vocalizations, and a change from normal habits.[29]	The validation of the tool is limited based on convenience sampling.	Addresses 4 of the 6 AGS guidelines		It is designed to measure pain over the last two weeks.

Chapter 3

Article 2: In the Eyes of the Beholder: The Historical Basis for an Integrated Model of Pain Management

Abstract

To develop effective pain management, the phenomena of pain was explored comparing five concept analyses which have appeared in the nursing literature. Pain has been the subject of much attention for years. Nurses should strive to help patients reach a goal that is personally meaningful. Identification and management of pain depends on the patient's subjective statements and in combination with the nurse's observation of non-verbal behaviors. Using a comparative concept analysis design CINAHL, MEDLINE, and PubMed were searched and relevant articles retrieved. An in depth review and comparison on pain management, pain and suffering, and conditions related to pain was completed. Defining attributes, antecedents, and consequences were compared side by side to determine common themes and outliers. Comparison of the defining attributes in the five studies reveal four common themes which are *individualization*, *multidimensional*, *meaning given to pain,* and *subjective.* A comparison of the scholarly analyses of pain-related concepts helps nurses assess and treat patients as well as provides insight into creative ways of studying pain management measures.

In the Eyes of the Beholder: The Historical Basis for an Integrated Model of Pain Management

Pain is a subjective experience. The measurement of pain intensity, or even proof of its presence, has depended on the individual's self-report. Since nurses retain primary responsibility for diagnosing and treating pain, it is essential that factors related to pain and pain management be well understood by these primary caregivers. To this end, pain-related concepts have been studied and articles published for years. Multidisciplinary professional journals devoted entirely to the identification, treatment, and alleviation of pain are available. Several nurse researchers provided in-depth analyses of pain-related concepts in many populations. However, the identification and management of pain still depends on subjective statements by the patient and observation of non-verbal behaviors as the basis for nursing actions. A comparison of the scholarly analyses of pain-related concepts may help nurses assess and treat patients as well as provide insight into creative ways of studying pain management measures.

To develop effective pain management, the phenomena of pain was explored comparing different concept analyses. In order to clarify and conceptualize pain, the following questions were addressed:

1) What analyses have been done on pain-related concepts?
2) What are the commonalities among the defining attributes and what are the outliers reported in previous pain-related concept analyses?
3) What are the consistent antecedents and consequences of pain-related concepts, and how have they evolved over the years?
4) What is the relevance for nursing practice today and research in the future?

Historical Overview

Pain Theories

One of the original theories of pain was developed in the 17th century by Descartes. He was one of the first philosophers to be influenced by the scientific method and proposed that even though humans have a mind and soul, basically the body runs like a machine. His theory states pain is produced by a direct transmission system from injured tissues to the pain center in the brain ("Pain Theory", 2015, para. 1).

Through the centuries, scientists have slowly built on Descartes' legacy creating a pattern of scientific progress. Kuhn (1970) described this process of normal science to a science revolution as a paradigm shift. Within this new paradigm, normal science produces new data that proceeds until anomaly arises again. The Specificity Theory by von Frey Bishop, a variation of the Descartes model, was the accepted normal science of pain in the 1950s. This theory proposed that the experience of pain was equated with peripheral injury (Melzack & Wall, 1965). According to Melzack (1996), the emergence of trigger pain, referred pain, placebo effect, and memory of pain was introduced in the late 1950s creating a science revolution and a paradigm shift and led to the birth of the *Gate Control Theory of Pain* in 1965 (Melzack & Wall, 1965). Early pain models concentrated on specific pathways of pain, while the Gate Control Theory included the connection between pain and emotion, taking into account a person's past experiences and emotions as an influence on pain impulses (Melzack & Wall, 1965). In 1997, Lenz, Pugh, Milligan, Gift, and Suppe added to this model stating that patients can have varying levels of response to the same painful stimulus suggesting there are more dimensions to pain which require more accurate assessments. Current concepts of pain assessment include the patient's and caregiver's perceptions of pain suggesting individual pain management for those with less inherent coping abilities (Schiavenato & Craig, 2010). While the Gate Control Theory still holds, it fails to explain phantom pain in paraplegics first recognized in the 1970s (Melzack & Loeser, 1978).

While the Gate Control Theory continues to have a strong foothold today, there are more contemporary pain theories. Loeser and Melzack (1999) suggest that pain can be broken down into four broad categories which are *nociception, perception of pain, suffering*, and *pain behaviors*. Each of these categories has an anatomical, physiological, and psychological underlying component (Loeser & Melzack, 1999). The first category, *nociception*, is the detection of tissue damage by neural receptors creating an inflammatory response. Nociceptors are receptors that are specifically designed to detect stimuli that may cause harm to the body, which may be mechanical, chemical or thermal in nature. These receptors sense when there is physical damage to the skin, muscles, bones or connective tissue in the body, or when they are exposed to toxic chemicals or extreme temperatures (Loeser & Melzack, 1999). Chronic pain is usually caused by nociceptor or neuropathic pain (Blumstein & Barkley, 2015). Neuropathic pain occurs when there is actual nerve damage. Nerves connect the spinal cord to the rest of the body and allow the brain to communicate with the skin, muscles, and internal organs, and when this is interrupted the patient often complains of burning, heavy sensation, or numbness along the nerve pathway (Blumstein & Barkley, 2015). *Perception of pain* is triggered by disease or injury and associated with autonomic and somatic impulses. *Suffering* occurs when an individual's physical and / or psychological wellbeing is threatened causing anxiety, fear, and stress. *Pain behaviors* manifest in response to pain and are observable and measurable, such as limping or grimacing (Loeser & Melzack, 1999).

The psychophysiological theory of pain further elaborated that the sensation of pain is very complex and affects several levels of awareness (Waddell, 2004). According to Waddell (2004), the three aspects of experienced pain are biological, psychological, and social. The biological basis of the pain experience is a function of the nervous system. As nerve pathways are stimulated, they release chemicals to modulate the pain experience. The psychological aspect reveals the complexity of the pain experience. Pain can be influenced by life experiences, anxiety level, and genetics. The social aspect of pain reflects a person's memory of pain and how that memory can influence the pain experience, such as how a person has coped in the past (Waddell, 2004). Interference with any of these aspects of pain sensation, such as occurs in dementia or mental illness, can distort the perception of pain and further complicate the management of the pain experience.

Defining Pain

Pain originates from the old French word *peine*, the Latin word *poena,* and the Greek word *poine* meaning 'punishment or penalty' ("Pain Etymology", 2015, para. 1). According to the Merriam-Webster dictionary, *pain* can be defined as 'the physical feeling caused by disease, injury, or something that hurts the body, mental or emotional suffering, sadness caused by some emotional or mental problem, someone or something that causes trouble or makes you feel annoyed or angry' ("Pain", 2015, para. 1). The most cited definition in the health science literature was developed by the International

Association for the Study of Pain (IASP, 1994) which states “pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in term of such damage” (para. 4) and go on to state that pain is subjective; if an emotional experience is reported as pain, it should be accepted as pain. The Institute of Medicine (IOM; 2011) supports this definition further describing pain as a “complex and evolving interplay of biological, behavioral, societal, and environmental factors” (p. xi).

According to Walker and Avant (2005), the purpose of a concept analysis is to examine the structure and function of a concept with the goal of clarifying the concept. The traditional Walker and Avant (2005) method is a formal eight-step process thought to be rigorous and precise which creates expanded knowledge of a concept. In comparing different pain-related concept analyses in nursing literature, a clearer, more integrated model of pain may emerge enhancing its utility in healthcare settings as well as the community.

Nursing Analyses of Pain-Related Concepts

Methods

Based on the psycho-socio-cultural complexities of pain, the search included pain-related concepts such as suffering, discomfort, perception or expression of pain, and other unpleasant sensations directly linked to the intensity of pain. Nursing databases were systematically searched in March 2015 using the key words pain, pain-related concepts, and concept analysis. Limits were set on English; the search literature (CINAHL, MEDLINE, and PubMed) revealed five analyses on pain-related concepts

(Davis, 1992; Rodgers & Cowles, 1997; Larner, 2014; Quallich & Arskinian-Engoran, 2014; Stewart et al, 2014).

Defining Attributes

Walker and Avant (2005) explain that the purpose of a systematic analysis of a concept is to identify the defining attributes of that phenomenon so that it can be consistently identified by other persons and differentiated from other concepts. These attributes are a cluster of traits that are most commonly associated with the term so it is more clearly understood. Defining attributes described in each of the concept analyses are shown in Table 2.

Table 2

Comparison of Defining Attributes from Five Concept Analyses

Articles in Chronological Order	**Davis**	**Rodgers & Cowles**	**Larner**	**Quallich & Arslanian-Engoren**	**Stewart, et al**
Defining Attributes: Theme #1 Individualization	Pain relief	Individualization	Individual pain variability	Individual (Present in males <18 years old)	
Theme #2 Multi-dimensional	Pain modulation	Complex	Multifactorial appraisal		Multidimensional process involving active individuals
Theme #3 Meaning	Self-efficacy	Meaning assigned (negative)	Self-efficacy	Subjective negative experience	Personal Development
Theme #4 Subjective		Subjective-Difficulty to assess		Subjective negative experience	
Other			Symptom onset Symptom intensity Symptom duration	Present for 3 months Intermittent or continuous Physical findings absent No organic cause	System response System control

While Walker and Avant (2005) acknowledged that the defining attributes are not finite and may change over situations and time, it seems reasonable that they should be fairly consistent in different analyses if the concept is well understood, as pain is thought to be. However, a comparison of the five pain-related concept analyses available over the past two decades showed inconsistencies or outliers which are the basis for discussion.

Davis (1992) studied the general term, pain management, and identified three defining attributes as pain relief, pain modulation, and self-efficacy. Her article was based on the Gate Control Theory and intended to contribute to instrument development of the Pain Management Inventory (PMI) and the Vanderbilt Pain Management Inventory (VPMI). Rodgers and Cowles (1997) laid the conceptual foundation for recognition and understanding of the human phenomena of suffering often hidden in the pain experience. Their defining attributes included: individualization, subjective, complex, and meaning assigned (mainly negative connotations). Larner (2014) identified six attributes in his study of chronic pain transition as: individual pain variability, multifactorial appraisal, symptom onset, symptom intensity, symptom duration, and self-efficacy. Quallich and Arslanian-Engoren (2014) identified six defining attributes in chronic orchialgia, or long-term pain in the testes, as being present in males 18 years and older. These attributes are subjective negative experience, individual experience, present for three months or more, intermittent or continuous, physical findings absent, and no organic cause or pathology. A concept analysis on persistent pain self-management identified “a multidimensional process involving active individuals, personal development, system response, and symptom control" as attributes (Stewart, Schofield, Elliot, Torrance, & Leveille, 2014, p. 219).

Comparison of the Attributes

Comparison of the defining attributes in the five studies reveal common themes. The first is *individualization* seen in the literature as individual pain variability (Larner, 2014), individual experience (Quallich & Arslanian-Engoren, 2014), and unique to each individual (Rodgers & Cowles, 1997). These attributes speak to the individual nature of pain and gives credibility to the common belief that "pain is whatever the patient says it is." Acknowledging the individual nature of pain also takes into consideration the cultural aspects of pain where showing that one is in pain may be seen as a sign of weakness. Trying to fulfill one's cultural obligation may be one reason that different persons react so differently to the same type of pain (Chen, Tang, & Chen, 2011).

The second theme is *multidimensional* as evidenced by multifactorial appraisal (Larner, 2014), multidimensional process (Stewart, et al, 2014), and complex (Rodgers & Cowles, 1997). The complex nature of pain is what makes it so challenging to nurses who are trying to manage the symptoms and help facilitate relief and comfort. This complexity has also been a challenge in deciding what kinds and strengths of medications are optimal for pain management. Many of the complementary pain relief methods are based on the complex nature and multiple origins of pain in the human body. Although conventional allopathic medicine often treats pain with anti- inflammatory or opioid medications, the use of complementary medicine to treat pain may help to identify and address the many inter-related factors associated with a patient's pain (Schulenburg, 2015).

The third theme is *meaning given to pain* as seen in attributes of negative experience (Quallich & Arslanian-Engoren, 2014), personal development (Larner, 2014), and meaning being mainly negative connotation (Rodgers & Cowles, 1997). Pain is a negative sensation causing most people to take immediate, and often dire, actions to relieve it. The reason that most nurses encounter pain in patients is because the person is in need of relief. Failure to relieve pain is often seen by both the patient and the nurse as a shortcoming on the part of the healthcare system, and in particular the nurse who is charged with pain management. The negative side of pain transcends the nurse-patient interaction to include the possibility of self-doubt on the part of the patient and decreased self-confidence on the part of the nurse. Evidence suggested that patients' ongoing pain has a negative impact on nurses such as exhaustion, distress, and fatigue (Blomberg, Hylander, & Tornkvist, 2008). This can lead to loss of empathy, compassion fatigue and disengagement from patient's pain (Slatyer, Williams, & Michael, 2015).

The forth theme is *subjective* as identified in literature as subjective negative experience (Quallich & Arslanian-Engoren, 2014) and difficult to assess/measure (Rodgers & Cowles, 1997). The subjective experience has always been the cornerstone in pain perception. However, nurses often have judgments regarding patient's pain. In order to acknowledge the subjectivity of the pain experience, the assessment of individual pain treatment thresholds should have a personalized approach. One way to do this is to provide a marker of the clinical significance of pain intensity for a specific patient at the time of assessment (Birnie, McGrath, & Chambers, 2012). As advocates for patient comfort, nurses should strive to reach a goal that is personally meaningful to the patient and not what is simply satisfactory for the average patient.

Outliers

According to Walker and Avant (2005), an outlier is an observation that lies an abnormal distance from other values. The four themes (individualization, multidimensional, meaning given to pain, & subjective) seem to reflect Loeser and Melzack's (1999) pain theory which includes four broad pain categories (nociception, perception of pain, suffering, and pain behaviors) each with a physiological, anatomical, and psychological underlying component. However, the *meaning given to pain* might be influenced by perception (Rodgers & Cowles, 1997). Does changing the meaning eliminate suffering from pain? According to Bates, Burns, and Moorey (1989), the meaning of pain can be changed if one changes the perception. This is part of the theory behind placebo effect.

The relationship between pain and personality (Larner, 2014) is not addressed in psychological components of pain theory nor did it appear in previous concept analyses. Individuals who have a "pain personality" tend to have a neurotic/negative affect (Arntz, Dreessen, & de Jong, 1994; Vassend, Roylamb, & Nielsen, 2013). Pain personality can be described as patients who repeatedly or chronically suffer from one or more painful disabilities, with or without any recognizable peripheral change. The pain is considered an adjustment, a way of adaptation usually acquired through psychic experience (Raphael, Wisdom, & Lange, 2001). Although pain personality constructs have been shown to link to various pain-related emotions, beliefs, and coping mechanisms, they seem to be unrelated to immediate sensory pain responses (Asghari & Nicholas, 2006). According to Vassend, et al. (2013), the profile of the "pain personality" depicts less empathy, lower optimism, and higher neuroticism.

Phantom pain and *referred pain* are two experiences not included in pain-related concept analyses reviewed. *Phantom pain* has gained more understanding and acceptance in recent years with traumatic amputations of military personnel, might be considered an outlier when considering pain. The idea of phantom pain sensations are described as perceptions that a person experiences relating to a limb or an organ that is not physically part of the body. Phantom pain differs from *referred pain*, which is pain perceived at a location other than the site of the painful stimulus ("Referred Pain", 2015, para. 1). The mechanisms behind the cause of phantom pain are not well known or defined; however, there are many overlapping theories and observations in the literature (Giummarra, Gibson, Georgiou-Karistianis, & Bradshaw, 2007).

Antecedents to and Consequences of Pain

Antecedents are those events or incidences that must be present before the occurrence of the concept (Walker & Avant, 2005). Consequences are those events or incidences that happen as a result of the occurrence of the concept (Walker & Avant, 2005). The antecedents and consequences derived from the five analyses were compared to understand the evolution of pain-related concepts and identify common themes (Table 3).

Previous pain-related concept analyses in nursing literature were based on the Gate Control Theory (Melzack, 1965). The antecedents identified by Davis (1992) were pain recognition, ability to express pain, and an individual's involvement in pain management. Rodgers and Cowles (1997), whose focus was more on the suffering aspect of pain, identified antecedents as a physical illness, sense of loss, consciousness, and humanness. In later analyses, antecedents elaborated on more psychological factors, psychosocial support, as well as, genetic and behavioral factors (Larner, 2014; Quallich & Arslanian-Engoren, 2014; Stewart et al, 2014). The most common antecedents were physical, psychological, pain identification, and a willingness to participate in a pain solution. In comparing the antecedents side by side, the concept analyses of pain have evolved to include more psycho-social issues and the inclusion of genomics.

Table 3

Comparison of Antecedents and Consequences from Five Concept Analyses

Articles in Chronological Order	Davis	Rodgers & Cowles	Larner	Quallich & Arslanian-Engoren	Stewart, et al.
Antecedents	Pain identification	Physical illness Sense of loss	Physical Genetic	Recognition of sensatio of pain	Self-awareness of perceived need to manage pain
	Ability of patient to express pain	Humanness	Behavioral		Support from Others
	Willing to participate	Consciousness	Psychological Psychosocial	Choosing to seek evaluation	Willingness and ability to participate in pain management
Consequences	Enhanced pain management		Living with pain	Decline in overall function	
	Patient empowerment	Feelings of helplessness	Decreased quality of life Coping with pain	Lower quality of life	Improvements in Physical, Psychological, and social health & function Increased quality of life
	Individual's involvement in pain management	Withdrawal Change in value	Impaired memory Insomnia Diminished health	Demonstrate avoidance behaviors Excessive medication use Loss of productivity Alteration in roles	Engagement with pain techniques

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& Arslanian-Engoren, 2014; Stewart et al, 2014). The most common antecedents were physical, psychological, pain identification, and a willingness to participate in a pain solution. In comparing the antecedents side by side, the concept analyses of pain have evolved to include more psycho-social issues and the inclusion of genomics.

In comparing pain consequences (Table 3), both negative (Larner, 2014; Quallich & Arlanian-Engoren, 2014; Rodgers & Cowles, 1997) and positive consequences of taking control of one's pain were identified (Davis, 1992). All of the consequences seem inversely proportionate; i.e. when the patient took control of the pain, it led to improved quality of life and when the patient lived with pain, it decreased the quality of life. While all pain-related concept analyses had a common thread of pain, the different authors focused on different types of pain, and some looked at pain management and self-efficacy. The common themes of attributes, antecedents, and consequences from all five articles were collapsed into a table to create an integrated analysis of the concept based on the previously-published findings (Table 4).

Relevance to Current Nursing Practice and Education

An integral part of the nurse's mission is to provide comfort and relief from pain. While the pain self-report has been the standard criterion for pain assessment, patient pain is often undertreated (Pieper, et al, 2013). Because of the subjective and multifaceted nature of pain, accurate assessment is often a challenge (Alspach, 2010).

Table 3

Integrated Analysis of Pain-related Concepts

Model	Attributes	Antecedents	Consequences
Integrated Concept Analysis	Individualization Multidimensional Meaning given to pain Subjective	Recognition or expression of pain Physical aspect Psychological aspect Psychosocial aspect Genetic Behavioral aspects	Patient comfort vs. discomfort Enhanced vs. lowered quality of life Enhanced vs. diminished health Patient empowerment vs. feelings of hopelessness Effective coping skills vs. ineffective coping skills Appropriate vs. inappropriate behaviors

Exploring the differences and commonalities among pain concepts can help nurses establish effective tools. Enhanced outcomes can be achieved by synthesizing and actualizing pain concepts into nursing practice. Nurse advocacy regarding pain management has been lacking; and in order to bridge this gap, nursing faculty must use their influence on students to address pain management during educational preparation and in research during advanced education programs (Duke, Haas, Yarbrough, & Northam, 2013). Nurses in practice must understand the basic attributes of pain as management protocols are developed, utilized, and evaluated. Efforts to move the nursing dynamic away from the pain itself toward a focus and goal of patient comfort meet the priorities indicated by the integrated picture of pain as individualized, multidimensional, meaningful to the patient, and subjective. Currently, the trend is not so much on the patient's pain, but the patient's comfort. Nursing is not only focusing on pain assessment and treatment, but on developing strategies of enhanced communication, education, and non-pharmacological measures to promote comfort (Slatyer, Williams, & Michael, 2015).

Comparison of pain-related concept analyses aids in theory development. Theory development requires examination of phenomena components and relationships providing a clear basis for future research and practice (Walker & Avant, 2005). Overlap between concepts examined in this analysis emerged and suggests the need for further theory development. As new ideas are generated, they can be added to develop a multidimensional, integrated view of pain. This integrated pain model broadens the scope and deepens the understanding of pain assessments. Patient comfort can then be conceptualized as the goal, i.e. a dynamic state, ever evolving, and strengthening nurses' resolve to fulfill the mission to alleviate pain and promote comfort.

Conclusions

Results of this analysis provide an integrated presentation of the current evidence regarding pain-related concepts. This is a starting point for further development and use of this concept. However, despite a comprehensive literature search strategy, only a small number of publications were found. The various concept analyses investigated focused on different aspects of the pain experience making comparisons difficult.

While a multidimensional approach was identified as effective, the question arises, "how can this knowledge be transferred to a one-dimensional assessment tool?" To clarify theories and measures of pain, one should explore the perspectives and experiences of patients and healthcare providers (Schiavenato & Craig, 2010). This mosaic will give researchers deeper insight and refine existing attributes, thus providing a clearer understanding of the concept of pain.

A final question relates to applicability of this information. Can the integrated pain-related concept analysis be applied to all age levels? The answer to this question was unclear in the literature. Further research needs to be conducted on elderly persons with more complex health issues, particularly elderly with dementia where language, communication, and memory are lacking. Since dementia clients are unable to collaborate and participate in their pain management, it makes understanding the utility of this concept more urgent. Pain in infants has received additional attention in recent years and brings a different dynamic to the pain discussion where “meaning given to pain” cannot be understood directly and reliably from the patient.

All of these challenges support the ultimate goal of the nurse as care provider and pain manager. This article adds a historical perspective and comprehensive review of pain-related concept analyses. It shows common themes throughout the decades and some of the outliers. While trends are moving toward patient comfort and nurse empowerment in pain management, more theory development and theory testing are still needed in this area, as well as examining the patient-nurse relationship. Pain management is a complex issue with many physical, social, and psychological components for the nurse to consider. Knowing more about the complex nature of pain increases the chances for the nurse to make a meaningful difference in the health of persons who are seeking relief from pain.

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Chapter 4

Pain, Need-Driven Behaviors in Dementia, and Nurses' Perceptions: An Embedded Mixed Methods Study

Abstract

Problem: Identification of pain is challenging in persons with dementia (PWD) resulting in inadequate management. An observational pain scale (OPS) is often used to assess pain in PWD. Pain is associated with need-driven behaviors in PWD.

Purpose: The purpose of this study was to explore the relationship between two OPSs and need-driven behaviors (NDB) and the relationship between two OPSs and medication administration for residential PWD. Nurses' perceptions regarding ease of and barriers to the use of each OPS was explored.

Theory: Algase's Need Driven Behavior Model (NDBM) guided the study. NDBM posits that NDBs arise from the pursuit of a goal or expression of a need caused by proximal and background factors. The qualitative strand examined nurses' perceptions and was supported by the philosophical underpinnings of phenomenology.

Research Questions:

1. What is the relationship between NDBs and pain as measured by the APS?
2. What is the relationship between NDBs and pain as measured by the PAINAD?
3. Is there an increase in pain medication administration when nurses use the APS to assess and treat pain compared to the PAINAD?
4. What are nurses' experiences with using the APS or PAINAD assessment tool in PWD?

Design/Methods: This study used an embedded mixed methods design involving a quasi-experimental quantitative strand in which residential PWD served as their own controls and nurse caregivers participated in a descriptive qualitative strand. The setting was an in-patient memory care unit. A counter-balanced protocol was applied in which scales, APS and PAINAD or the PAINAD and the APS, were used to assess pain in two groups of residents for four weeks and then switched. NDBs and medication quantification (MQS III) were measured during the eight week period. During one-to-one interviews, nurses' perceptions regarding barriers and practicality of the two OPSs were explored.

Analysis: Quantitative data analysis was conducted using Pearson's *r* bivariate test of correlation. APS was significantly correlated with NDBs and approached significance with the mean MQS III scores. PAINAD was not significant for both NDBs and MQS III. Qualitative data was coded and thematic analysis done. Three core themes and two sub-themes emerged from the data: (a) assessing PWD for pain (sub-themes: assessing for pain versus another need, measurement scales for PWD including APS and PAINAD scale), (b) facilitators and barriers to pain management, and (c) caring for PWD.

Pain, Need-Driven Behaviors in Dementia, and Nurses' Perceptions:
An Embedded Mixed Methods Study

In the United States, approximately 5.4 million people suffer from dementia related diseases, and this number is expected to triple by the year 2050 (CDC, 2016). Dementia, which encompasses Alzheimer's disease as well as other types of cognitive deficits, is a progressive disease characterized by severe cognitive decline, loss of ability to carry out daily activities, and loss of language and the ability to communicate (Hadijstavropoulos et al., 2014; Lautenbacher, Niewelt, & Kunz, 2013; Oosterman, Hendriks, Scott, Lord, White, & Sampson, 2014, May).

The burden of dementia in the geriatric population is compounded by the presence of other painful conditions and comorbidities associated with aging which frequently necessitate care (Brecher & West, 2016). Untreated pain can lead to need-driven behaviors (NDBs) and thus affects quality of life for PWD and are a potential source of stress for caregivers (Ahn & Horgas, 2013; Herr, 2010).

Several barriers to treating pain in PWD were identified. The lack of standardized assessment tools is a significant barrier to successful pain management (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Coker, et al., 2010; Corbett, et al., 2012; McAuliffe, Nay, O'Donnell, & Fetherstonhaugh, 2008). Much effort has been made over the last decade to improve pain management for PWD and these efforts have resulted in the development of more than 28 observational pain scales (OPSs) (Flo, Gulla, & Huesbo, 2014; Lichtner, et al., 2014; Tsai, Jeong, & Hunter, 2018). Many of these OPSs were psychometrically valid; however, scale application and score interpretation in daily clinical practice remains a challenge (Huesbo, Achterberg, & Flo, 2016; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006).

The incidence and prevalence of poor pain management in PWD is well documented. However, many studies were conducted using secondary data or were retrospective in nature. A few international studies examined the effects of various OPSs and pain behaviors in cluster randomized controlled trials (Ahn & Horgas, 2013; Huesbo, Ballard, Fritze, Sandvik, & Aarsland, 2014; Sandvik et al., 2014). Many pain protocols exist; however, the recommendations are based on expert opinion rather than empirical evaluation (AGS, 2002; 2009) which raises questions regarding content validity and suggests the need for evidence to support pain assessment protocols for PWD.

Review of Literature

Four databases (CINAHL Plus, PsycINFO, MEDLINE, & Cochrane) were systematically searched using the key terms dementia, pain, and behaviors with the search option of "search with AND". Limits were set on the years 2012 through 2018 to narrow the results to current best practices or usual care. CINAHL Plus yielded approximately ninety articles, PsycINFO yielded a total of one-hundred and twenty-four articles, MEDLINE revealed forty-two articles, and Cochrane yielded two. An additional 51 articles cited in reference lists were also retrieved. The term "nurses perceptions" was then added to narrow the search and limits were broadened to include 2010-2018 due to lack of current qualitative research, which yielded a total of seven additional articles.

Pain. Pain is defined as "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Bogduk, 1994, p. 214). The sensation of pain is complex and affects several levels of awareness. Four broad categories of pain are nociception, perception of pain, suffering, and pain behaviors (Loeser & Melzack, 1999). The first category, nociception, is the detection of tissue damage by neural receptors creating an inflammatory response.

Perception of pain is triggered by disease or injury and associated with autonomic and somatic impulses (Loeser & Melzack, 1999). The suffering category is created in an individual when physical and psychological wellbeing is threatened causing stress. Pain behaviors are a result of the person's reaction to pain and are observable and measurable, such as limping or grimacing when a painful event occurs (Loeser & Melzack, 1999).

Pain is both a physiological and psychological experience and can be influenced by life experiences, anxiety, and genetics (Waddell, 2004). Waddell (2004) recognized that pain also exists within a social plane influenced by memory and how the person has previously coped with the sensation. Interference with any of these aspects of pain sensation, such as occurs in dementia, can distort the perception and further complicate pain management.

Pain Perception in PWD

Cognition and pain. The pain response can vary from individual to individual with or without cognitive impairment and is considered the fifth vital sign treated and documented by nurses. It is estimated that 80% of PWD living in nursing homes experience pain (Achterberg, et al., 2013). Pain is a subjective sensation making it difficult for the nurse to recognize, assess, and manage in persons with cognitive impairment (Kolanowski et al., 2015; Pieper et al., 2013; Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008). Because pain goes unrecognized and under-treated in PWD, it often results in behavioral disturbances (Ahn & Horgas, 2013; Burfield, Wan, Sole, & Cooper, 2012; Huesbo, Ballard, Cohen-Mansfield, Seifert, & Aarsland, 2014). Persons with dementia are grossly under medicated for the same painful conditions as cognitively intact patients (Fry, Arendts, Chenoweth, & MacGregor, 2015; Jensen-Dahm, Palm, Gasse, Dahl, & Waldemar, 2016; Manfredi, Breuer, Meier, & Libow, 2003; McDermott, Nichols, & Lowell, 2014; Moschinski, et al., 2017; Morrison & Sui, 2000; Rantala, Kankkunen, Kvist, & Hartikainen, 2014), cannot verbalize pain and are in crucial need of observers able to recognize and assess pain (Lautenbacher, Niewelt, & Kunz, 2013; Pieper et al., 2013)

Conflicting evidence regarding pathophysiology of pain in PWD was located. According to Cole et al. (2011), there is limited evidence that the pathology associated with dementia includes degeneration of pain centers in the brain. An increase in inter-regional functional connectivity among regions of the pre-defined pain network in PWD (Cole et al., 2011; Fletcher et al., 2015) suggests that pain might actually be greater for this population (Carlino et al., 2010; Scherder et al., 2015; Scherder & Plooij, 2012). On the other hand, no increase in pain pathways as measured through electroencephalogram (EEG), magnetic resonance imaging (MRI), and other psychosocial measures were documented (Corbett et al., 2012; Scherder et al., 2009). There is limited evidence to support significant differences between pain and dementia subtypes (van Kooten et al., 2016); however, underlying brain mechanisms of pain hamper communication of distress and ability of PWD to self-report (Fletcher et al., 2015; Hadijstavropoulos et al., 2014; Oosterman et al., 2014, May). The combination of increased pain and decreased cognition puts the PWD at risk for suboptimal pain management (Hadjistavropoulos, et al., 2014, December). Conflicting evidence contributes to lack of basic standards of pain detection in this population (Corbett, et al., 2012; Kolanowski, et al., 2015). For this reason, it is thought that pain is grossly under-reported due to the PWD's difficulty expressing pain and the inability of caregivers to recognize pain behaviors (Moschinski, et al., 2017; Pieper, et al., 2013).

Pain and need-driven behaviors (NDBs)

Cognitive decline associated with dementia is commonly accompanied by neuropsychiatric behaviors known as need-driven behaviors (Algase et al, 1996; Corbett et al., 2014; Huesbo, Ballard, & Aarsland, 2011; Norton, Allen, Snow, Hardin, & Burgio, 2010). Many times PWD are inappropriately treated for behaviors by the use of physical or chemical restraints such as antipsychotic medications (Pratt, Roughead, Salter, & Ryan, 2012). A possible reason for inappropriate treatment is that the etiology of these behaviors is poorly understood (Flo, Gulla, & Huesbo, 2014). The cause may be multifactorial, based on anatomical, neurotransmitter, and chemical changes in the brain (Norton et al., 2010). Due to physical changes in the brain and inability to communicate or express oneself, pain might trigger need-driven dementia behaviors such as aggression, agitation, and problematic vocalizations (Hodgson, Gitlin, Winter, & Hauck, 2014;

Huesbo, Ballard, Sandvik, Nilsen, & Aarsland, 2011; Lukas, Barber, Johnson, & Gibson, 2013; Malara et al., 2016; Tosato et al., 2012).

Observational Pain Scales

Of the 28 OPS, most were modeled after the American Geriatric Society (AGS) Guideline for Persistent Pain in Older adults (2002; 2009). Six observable behaviors were identified to diagnose pain: facial expressions, verbalizations (vocalizations), body movements, changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes. While the majority of OPSs included three or more of AGS behavioral pain indicators (facial expression, body language, and vocalizations), more comprehensive instruments were more likely to identify pain behaviors (Corbett et al., 2014; Huesbo & Corbett, 2014; Jordan, Hughes, Pakresi, Hepburn, & O'Brien, 2011; Stolee, Hillier, Esbaugh, Bol, McKellar, & Gauthier, 2005; Van der Steen et al., 2015). However, longer instruments required more time and effort to complete potentially preventing their use (Huesbo, Achterberg, & Flo, 2016; Rantala, Kankkunen, Kvist, & Hartikainen, 2014) and suggested a delicate balance between accuracy and ease of administration. One study casted doubt on the utility of an OPS, reporting that nurses preferred to redirect rather than use analgesic medication (Cohen-Mansfield, 2014). However, if comfort and prevention of NDBs are the goals for PWD, a comprehensive OPS may be indicated.

Two commonly used OPS are The Abbey Pain Scale (APS) and the PAINAD (PAINAD). The APS includes six pain behavior indicators: facial expressions, verbalizations (vocalizations), body movements, changes in behavior, physiological changes, and physical changes (Abbey et al., 2004) and is endorsed by the Australian Pain Society. The PAINAD reports cues from three of the six categories: facial expressions, verbalizations (vocalizations), and body movements (Herr, Bjoro, & Decker, 2006; Herr, Zwakhalen, & Swafford, 2017; Zwakhalen et al., 2006), is recommended by the American Medical Directors and has greater reliability and validity than the APS (Ellis-Smith et al., 2016; Herr, Bjoro, & Decker, 2006; Herr, Zwakhalen, & Swafford, 2017; Leong, Chong, & Gibson, 2006; Pieper et al., 2013; Warden, Hurley, & Volicer, 2003). The PAINAD and APS tools are quantified numerically and scored as absent, mild, moderate, and severe. Both tools require five minutes or less to complete and were deemed relevant by current state of the science (Corbett et al., 2012; Ellis-Smith, et al., 2016; Herr, Bjoro, & Decker, 2006; Lichtner et al., 2014; Park, Castellanos-Brown, Belcher, 2010; Zwakhalen, Hamers, Abu-Saad, & Berger, 2006). However, since the APS includes all six pain behaviors, it is more inclusive of pain indicators and therefore might be considered a more comprehensive assessment tool. Statistical comparison between the Pain Assessment in Advanced Dementia scale (PAINAD) and Cohen-Mansfield Agitation Inventory (CMAI) instruments revealed an extensive item overlap (Kutschar, Bauer, Gnass, and Osterbrink, 2017). The authors posit that item overlap may lead to biased conclusions and assumptions in research as well as to inadequate care measures in nursing practice.

Current Evidence

Systematic Reviews

NDBs are positively correlated with pain in PWD (Chandler, Zwakhalen, Docking, Bruneau, & Schofield, 2016; Flo, Gulla, & Huesbo, 2014). Recognition of NDBs as an indication of pain followed by appropriate treatment were effective in reducing both pain and NDBs (Flo, Gulla, & Huesbo, 2014; Pieper et al., 2013). However, the overlap between need-driven behaviors and pain behaviors can cause nurses to misinterpret the cause of behaviors as symptoms of dementia or another unmet need (Chandler, Zwakhalen, Docking, Bruneau, & Schofield, 2016; Flo, Gulla, & Huesbo, 2014). Among nurses, frustration from NDBs and lack of knowledge about dementia and pain medications created additional barriers to accurate pain assessment (Chandler et al., 2016; Rantala, Hartikainen, Kvist, & Kankkunen, 2015).

The subjectivity of OPSs present a clinical challenge for nurses resulting in unsatisfactory pain management for PWD (Chandler et al., 2016; Huesbo, Achterberg, & Flo, 2016; Moschinski et al., 2017; Pieper et al., 2013; Rantala et al., 2015; Zwakhalen et al., 2006). Thus, there is the need for more high level studies with adequate statistical power (Herr, Zwakhalen, & Swafford, 2017).

Although the American Society for Pain Management Nurses recommends a hierarchy of pain assessment techniques for PWD which includes incorporation of an observational tool (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011), the literature provides no clear-cut guidelines for pain assessment in PWD, particularly, regarding the reliability and validity of instruments and clinical utility. A systematic review of systematic reviews (Lichtner et al., 2014) concluded that no recommendation for a specific OPS can be made, reporting that the process of interpretation is only as good as the person using it. Synthesis of current research supported the conclusion that overall pain management for this population was inadequate (Tsai, Jeong, & Hunter, 2018).

Randomized Control Trials (RCTs)

Pain protocols improved need-driven behaviors such as verbal agitation, aggression, and night time behaviors (Huesbo, Ballard, Cohen-Mansfield, Seifert, & Aarsland, 2014; Huesbo, Ballard, Fritze, Sandvik, & Aarsland, 2014, July; Huesbo, Ballard, Sandvik, Nilsen, & Aarsland, 2011). Significant relationships were found between pain and specific types of verbal agitation such as complaining, negativism, and repetitious speech (Cohen-Mansfield et al., 2015; Huesbo, Ballard, Cohen-Mansfield, Seifert, & Aarsland, 2014). Scheduled pain medication, particularly acetaminophen, significantly improved pain and participation in activities of daily living for PWD compared to “as needed” doses (Huesbo, Ballard, Cohen-Mansfield, Seifert, & Aarsland, 2014; Huesbo, Ballard, Fritze, Sandvik, & Aarsland, 2014, July; Huesbo, Ballard, Sandvik, Nilsen, & Aarsland, 2011; Sandvik et al., 2014). The median time to analgesia for cognitively intact group was 72 minutes compared to 149 minutes for cognitively impaired group ($p \leq .001$) (Fry et al., 2015). The use of APS and PAINAD improved the recognition of pain presence/absence as well as severity in PWD compared to a self-report pain scale (Lukas, Barber, Johnson, & Gibson, 2013). In addition, significant findings were reported in the use of non-pharmacological approaches to pain relief (Liu & Lai, 2017).

Cross Sectional Studies

Pain was significantly related to behavioral and psychiatric symptoms (Ahn, Garvan, & Lyon, 2015; Tosato et al., 2012; van Kooten et al., 2017), socially inappropriate behavior, aggression, and resistance to care (Ahn, Garvan, & Lyon, 2015; Tosato et al., 2012). Professional healthcare observers did not show superior competence over lay observers in assessing pain in PWD (Lautenbacher, Niewelt, & Kunz, 2013). Less than one-third of nurses reported using an OPS when caring for a PWD post-operatively (Rantala, Kankkunen, Kvist, & Hartikainen, 2012). Caregivers' attitudes were also barriers to post- operative pain in PWD due to lack of empathy, trivializing the pain experience, not knowing the baseline pain threshold (Rantala, Kankkunen, Kvist, & Hartikainen, 2014) and a lack of knowledge regarding adverse side effects of pain medications such as NSAIDS and opioid analgesics (Rantala, Hartikainen, Kvist, and Kankkunen, 2015).

Mixed Methods and Qualitative Studies

Barriers to adequate pain management were identified. Seventy-six percent of nurses indicated that PWD should be assessed for pain every four hours; however, only 28% indicated that they actually did so and 66 percent reported difficulty assessing pain in this population, the biggest barrier to pain management (Coker et al., 2010). Nurses tended not to use pain assessment tools and relied on "common sense" and experience to assess pain in PWD (Dowding et al., 2015). Poor communication with PWD and other nurses/healthcare providers, lack of pain recognition (Gilmore-Bykovskyi & Bowers, 2013; Monroe, Parish, & Mion, 2015), unfamiliarity with patients, workload pressures, poor staffing (Burns & McIlfatrick, 2015; Corbett et al., 2014), inadequacies or inconsistent use of the pain assessment tools (Burns & McIlfatrick, 2015; Gilmore-Bykovskyi, & Bowers, 2013; Lichtner, Dowding, & Closs, 2015), challenges administering analgesics (Brorson, Plymoth, Orman, & Balmsjo, 2014; de Witt Jansen et al., 2016), workload pressures, and inadequate training and education (Brorson et al., 2014; Burns & McIlfatrick, 2015; Corbett, et al. 2014; Lichtner et al., 2016; Rantala et al., 2015, August) were other barriers identified. Nurses' reported a sense of powerlessness, being challenged ethically, unable to connect with the patient, fear of not meeting patient needs, and lack of satisfaction (not relieving suffering) regarding pain management for PWD (Brorson et al., 2014).

The purpose of this study was to examine whether nurses' use of the Abbey Pain Scale (APS) to assess pain in PWD correlated to NDBs compared to when nurses' used the Pain Assessment in Advanced Dementia (PAINAD). It was hypothesized that the APS was more correlated to NDBs than the PAINAD and nurses administered more pain medication while using the APS compared to PAINAD scale. A second aim explored nurses' experience, the perceived barriers, and facilitators of pain management using different OPSs.

Theoretical Framework

The framework most commonly used in current literature was the 'Need-Driven Behavior' model (NDBM) (Algase et al., 1996; Figure 1) and implemented in this study. The NDBM proposes that need-driven behaviors (NDBs) arise from the pursuit of a goal or expression of a need and are caused by proximal and background factors (Algase et al., 1996). Relatively stable individual characteristics (background factors) interact with current situational variables (proximal factors) to produce dementia-related behaviors. These behaviors are seen as the most integrated and meaningful response a person with dementia can make at that time (Algase et al., 1996).

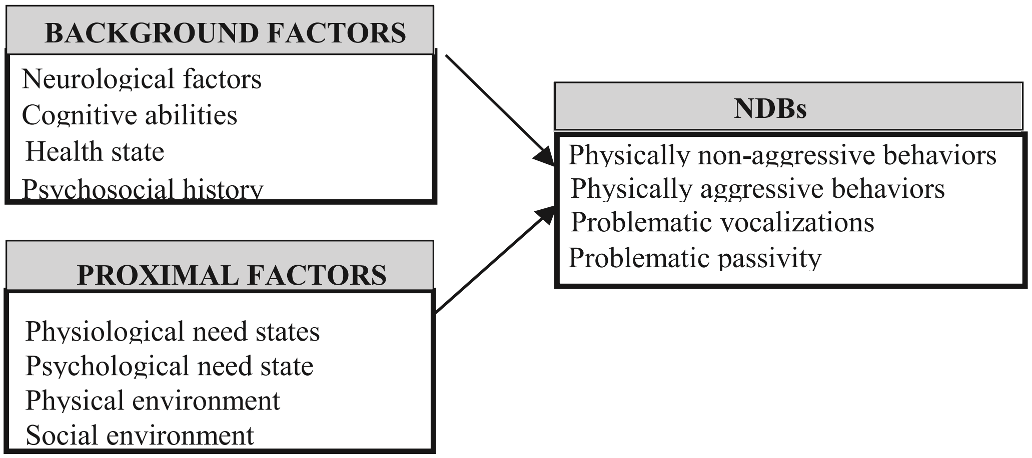

Figure 1. Need-Driven Behavior Model, used with permission

Background factors represent those characteristics that place a PWD at risk for disruptive behaviors and are the more enduring characteristics that shape behavior patterns overall. These factors include demographic characteristics, neurological factors, cognitive ability, functional impairment, and psychosocial aspects (Algase et al., 1996). Background factors have established relationships with pain and problematic behaviors and may influence the relationship between pain and behaviors (Reynolds, Hanson, DeVellis, Henderson & Steinhauser, 2008).

Proximal factors represent the conditions in which these disruptive behaviors occur and include psychological and physiological need states and the physical and social environment (Algase et al., 1996). Pain is a psychological and physiological need state (proximal factor) and therefore has a direct relationship with disruptive behaviors. Table 5 presents theoretical constructs along with study variables and lists conceptual and operational definitions. For the purpose of this study, medication administration will be implemented in response to NDBs and the effect assessed.

Algase et al. (1996) developed the Need-driven Behavior model which posits that NDBs arise from the pursuit of a goal or expression of a need and are caused by general Background Factors (i.e. cognitive impairment) and immediate Proximal Factors (i.e. pain sensation). Because PWD are unable to self-report pain; nurses must correctly interpret ‘pain behaviors’ in order to assess and treat appropriately (Lautenbacher, Niewelt, & Kunz, 2013). Correctly interpreting pain behaviors which might be the only expressions of pain for persons with severe dementia (Flo, Gulla, & Huesbo, 2014; Tsai, Jeong, & Hunter, 2018) has been challenging for nurses (Brorson, Plymoth, Orman, & Balmsjo, 2014; de Witt Jansen et al., 2016). The overlapping of NDBs and pain behaviors presents a methodological and clinical challenge indicating the need for more research (Flo, Gulla, & Huesbo, 2014; Tsai, Jeong, & Hunter, 2018).

The qualitative strand was based on the philosophical underpinnings of descriptive phenomenological philosophy (Giorgi, 2009). Giorgi’s (2009) method is founded on Husserl’s epistemology for human science research. This approach provided insight into nurses’ experience via in-depth interviews and direct observation. The goal was to achieve understanding of the nurses’ experience using the OPSs from the perspective of the nurses.

Conceptual and Operational Definitions

The following table (Table 5) presents the major concepts and definitions of the NDB model and operational definitions.

Research Question and Hypothesis

The research questions were:

1. What is the relationship between NDBs and pain as measured by the APS?
2. What is the relationship between NDBs and pain as measured by the PAINAD?
3. Is there an increase in pain medication administration when nurses use the APS to assess and treat pain compared to the PAINAD?
4. What are nurses' experiences with using the APS or PAINAD assessment tool in PWD?

Because the APS encompasses all six pain behaviors identified by the AGS (2002; 2009) compared with the PAINAD which includes three of the six pain behaviors, it was hypothesized that the APS would be more correlated to NDBs than the PAINAD and nurses would administer more pain medication while using the APS compared to PAINAD scale. The independent variables were APS and PAINAD and the dependent variables were the amount of pain medication administered and NDBs.

Table 4

Conceptual and Operational Definitions

Variable	Conceptual definition	Operational definition
Background Factors		

Cognitive Impairment	Decline in orientation, recall, working memory, language, and visual construction (Folstein, Folstein, & McHugh, 1975).	Modified Mini-mental State Examination (3MS).
Proximal Factors		
Pain	"Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in term of such damage" (IASP, 1994, para. 4).	Abbey Pain Scale (APS). Pain Assessment in Advanced Dementia (PAINAD).
Behavior		
Need-driven Behaviors	Defined as a variety of behavioral symptoms that accompany dementia. The individual who wanders, screams, or strikes out is pursuing a goal or trying to express a need. These behaviors include vocalizations, wandering, and agitation (Algase, et al, 1996).	Cohen Mansfield Agitation Inventory (CMAI).
Medication Administration		
Medication Quantification	"To numerically represent the negative "detriment" each medication has in treating patients' pain" (Gallizzi, et al. 2008, p. 1). Quantifies according to daily dose, pharmacological class, and detriment weight	Medication Quantification Scale Version III (MQS III)

Research Design

This study used an embedded mixed methods design to examine the efficacy of the APS to measure and treat pain compared to PAINAD and the relationship with NDBs and medication administration. Qualitative data was embedded within a major quantitative design. The initial quantitative phase was a quasi-experimental design in which the protocols were counter-balanced to minimize the effect of outside factors on study outcomes (Portney & Watkins, 2009). The quantitative data was used to test the modified NDB-theory that predicts assessment of pain in PWD will be correlated to NDBs and increased medication administration. The participants were in-patient PWD with severe cognitive impairment who served as their own control at a 50-bed memory care unit in New England. The qualitative data elicited an understanding of nurses' perceptions of using both OPS. Because much of pain assessment in non-communicative PWD is based on the nurse's subjective assessment, the qualitative data explored nurses' experiences, practicality, facilitators and barriers associated with the APS and PAINAD.

Methods

Sample. One group of in-patient PWD population was recruited and served as its own control. Pain intensity can differ according to the type and variations of resident's pain which suggests that the in-patient group was heterogeneous. To avoid a type II error, a power analysis using G*Power was utilized to determine sample size (Faul, Erdfelder, Lang & Buchner, 2007). With a power of .80, alpha of .05, and an effect size of 0.5, calculated for difference between two dependent means, a total sample size of 27 residents was required. Fifty-seven letters and consents were mailed to proxies of residents who met the criteria; 35 were returned. Of the 35 returned consents, two residents were hospitalized, one passed away, and one was transferred to another facility leaving the sample at 31 subjects who met the criteria. All 31 participants were included, however, during the data collection period, three subjects passed away leaving the total sample size at 28 participants (*N* = 28).

Eligibility criteria included: (a) $\geq$65 years old, of either gender; (b) diagnosis of some type of dementia according to DSM IV; (c) scoring <48 on the Modified Mini-Mental State Exam (3MS) indicating severe cognitive impairment (Teng & Chiu, 1987); (d) have a least one pain related diagnosis; (e) must not have current medical condition for which they are frequently admitted ($\geq$2 times per month) to the hospital such as heart failure, pulmonary disease, or exacerbation of a chronic condition; (f) must not have co-morbid psychiatric disorders such as schizophrenia or bi-polar disorder; (g) must not have recent distressing social circumstances such as death of a spouse; (h) and not receiving palliative care. Please see Appendix A for the eligibility check list. Data for participants who left the study was not included in analyses.

A purposive, convenience sample of nurses was recruited by the principle investigator (PI) for the qualitative strand. The inclusion criteria included: a) must be a licensed nurse; b) must have specifically cared for PWD using APS and PAINAD during the 8 week phase. Exclusion criteria: a) nurse from float pool or registry. The sample size consisted of six nurses which provided for data saturation.

Setting. The protocol took place at a 50-bed memory care unit in northern New England. The memory care unit is part of a public 218-bed long-term care campus owned by a municipality. The 50-bed memory care unit was designed for persons with severe dementia and their safety needs. The memory care unit consisted of five neighborhoods with 10 beds in each neighborhood. Residents were allowed into any neighborhood to sleep, eat, socialize, or attend activities. Workshops and nurse interviews took place in classrooms/offices at the facility but in a separate area from residents.

Protection of Human Subjects. Prior to initiation of research activities, approval was obtained from the University of Texas at Tyler Institutional Review Board (IRB) and Saint Joseph's College of Maine (Appendix B). The memory care facility provided written permission to conduct the study (Appendix B). The director of nursing services and designees identified potential PWD subjects. A hard-copy letter signed by the Director of Nursing and PI (Appendix C), consent form (Appendix D) and HIPPA authorization (Appendix E) was mailed with a self-addressed stamped envelope to residents' proxies informing them of the study and requesting their written permission. Only subjects for whom proxies provided signed consent were included in the study. The proxy letter and consent explained: (a) the purpose of the study, (b) data collection procedures, (c) expectations, (d) potential risks and benefits, (e) protection of participant's medical information as indicated by HIPPA guidelines, (f) right to withdraw from the study at any time without prejudice and, (g) the researcher's contact information. Please see Appendix F for Application for Protected Health Information use.

Data was de-identified and unique codes assigned so that information could be matched for analysis. Data was stored in a password-protected database located in the researchers locked office after it was collected. Potential benefits included regular pain assessment and treatment for residents and pain assessment education for nurses. The potential risk was loss of confidentiality.

Nurses were recruited by the researcher. Written consent was obtained prior to the interview (Appendix G) and names were de-identified using pseudonyms.

Instruments. Demographic information (Appendix H) of age, race, gender, and comorbidities was assessed at baseline by chart review and after receipt of the proxy consent. Current cognition was assessed to determine eligibility via Modified Mini-Mental State Examination (3MS) administered by principle investigator (see Appendix I). The 3MS is a widely used, 15-item global assessment of cognitive function (Teng & Chiu, 1987). The measure required approximately 10 to 15 minutes to complete and one point was given for each correct answer with a score range from 0 to 100. The cognitive domains assessed were temporal and spatial orientation, registration, immediate and delayed recall, language, construction, verbal fluency, abstract thinking, executive function, animal fluency, and abstract reasoning. Scores less than 79 suggest cognitive impairment and scores less than 48 suggest severe cognitive impairment (Teng & Chiu, 1987). In a sample of older adults with no cognitive impairments, reliability analysis yielded an α of .82 and .88 for individuals diagnosed with Alzheimer's disease (Tombaugh, McDowell, Kristjansson, & Hubley, 1996). Inter-rater reliability was $r = .98$ (Teng & Chiu, 1987), internal consistency was $\alpha = .87$ (McDowell, Kristjansson, Hill, & Hebert, 1997, April). Scale reliability for this study was $\alpha = 0.91$. Permission to use the instrument appears in Appendix J.

The APS tool (Appendix K) served as the experimental condition and measures discomfort in PWD who have lost cognitive capacity, verbal communication abilities, and are dependent on caregivers. Severity of six pain behaviors is rated on 0-3 scale; the total ranges from 0-18. Severity of pain is interpreted as follows: 0–2 = absent; 3–7 = mild; 8–13 = moderate; and 14+ = severe. The rater indicates type of pain: chronic, acute, or acute on chronic. The APS detected change in pain level before and after pain-relieving interventions and had a moderate level of correlation with nurses' proxy-pain scores (Abbey, et al., 2004). According to Liu, Briggs, and Closs (2010), the APS has limited available psychometric findings, although it is recommended by the Australian Pain Society and the British Geriatrics Society. For this study, scale reliability was $\alpha = 0.84$. The APS is in the public domain and may be used with appropriate reference to the authors (Abbey, et al., 2004).

The Pain Assessment in Advanced Dementia (PAINAD; Appendix L) was the current standard for this geographical region of the US and considered the control condition. The tool included five items: breathing, negative vocalization, facial expression, body language, and consolability. Each item is graded on a 3-point scale from 0-2 for intensity and summed for a total score of 0-10 (Warden, Hurley, & Volicer, 2003). Scoring for pain severity is as follows: 0 = absent, 1-3 = mild, 4-6 = moderate, and 7-10 = severe. Three of the AGS (2002; 2009) guidelines are addressed in this instrument. It is easy to administer; however, the items are not comprehensive enough to detect subtle pain (Horgas & Miller, 2008; Leong, Chong, & Gibson, 2006). This scale demonstrated strong scale reliability ($\alpha = 0.83$). The PAINAD is in the public domain and available for use with appropriate reference to the authors (Warden, Hurley, & Volicer, 2003).

The Cohen-Mansfield Agitation Inventory (CMAI) was used to measure NDBs (Appendix M). Factor analyses demonstated that agitation is a construct consisting of behaviors that tend to occur within individuals and suggest four factor groups in which behavioral disturbances are present (Cohen-Mansfield, Marx, & Rosenthal, 1989). The CMAI is a caregiver rating questionnaire addressing frequency of 29 agitated behaviors (Cohen-Mansfield, 1997). For the purpose of this study, response options for the frequency of behaviors were modified with permission (Appendix N). In the standardized version of the questionnaire, behaviors are reported for the previous week. Because this research is specifically interested in the relationship between behaviors, pain and medication administration, responses were modified to include responses for the previous shift. Inter-rater agreement was calculated for each behavior on the CMAI (using 0- or 1-point discrepancy as agreement) for 3 sets of raters (in 3 units of a nursing home). These averaged 0.92 ($n = 16$), 0.92 ($n = 23$), and 0.88 ($n = 31$) (Cohen-Mansfield, Marx, & Rosenthal, 1989). Scale reliability for this study was $\alpha = 0.87$.

The Medication Quantification Scale: Version III (MQS III) was used to quantify pain medications administered. The MQS III quantifies pain medications according to dosage, pharmacological class, and detriment weight of a medication (Gallizzi, Gagnon, Harden, Stanos, & Khan, 2008). The concurrent validity of the MQS I was established reporting a correlation coefficient between MQS I scores and the mean clinical judgement of pain study professionals ($r = .76$, $P < .01$; 2-tailed) (Harden, et al., 2005).

The MQS was updated in 2003 to account for additional medication classes. The MQS III has been validated and applied to various pain studies (Gallizzi, et al., 2008). Scale reliability for this study was $\alpha = 0.92$. Permission to use MQS III formula was obtained and may be used with appropriate reference (Appendix O).

Procedures/Data Collection. The quantitative phase of study commenced upon receipt of proxy and HIPPA consents. Resident demographic information and a baseline medication quantification was collected via chart review and the 3MS was administered to determine eligibility. Pain diagnosis, co-morbid diagnoses, and other eligibility criteria were extracted from the resident's chart.

Once the subjects were enrolled and before pain and NDB data were collected, the researcher facilitated two 1-hour workshops. The objective of the first workshop was for nurses and nurses' aides caring for the PWD subjects to understand and apply propositions of the NDB model to dementia care, specifically, behaviors associated with pain and appropriate responses. A total of nine nurses and 11 nurses' aides attended the first workshop. The second 1-hour workshop instructed nurses in appropriate use of the PAINAD, APS, and CMAI tools, behaviors assessed, and scoring practices using clinical video vignettes of PWD in pain. A total of nine nurses attended one of five workshops offered to accommodate all shifts. The researcher did a short didactic presentation about the PAINAD. Nurses were shown a video of a PWD in pain. Nurses first completed the scales individually. They were then were asked to complete the PAINAD in pairs and discuss the appropriate score. Afterwards, the group discussed correct responses. Another video was shown and the same process used with the APS. Nurses were given the video title or description and videos were in random order. For a detailed description of workshop see Appendix P.

Over the following four weeks, nurses assessed half of the participants' (Group 1) pain using the APS and the PAINAD in the remainder of the participants (Group 2). Assessment tools were switched after four weeks: pain was assessed for Group 1 using the PAINAD and the APS for Group 2. This counterbalanced design reduced the chances that the order of treatment adversely influenced the results. Nurses documented NDBs using the CMAI and medications administered on the resident's Medication Administration Record (MAR). This data as well as the MQS III was retrieved by the PI twice a week and entered into an excel spreadsheet only identifying residents by unique codes. Upon completion of the first two week data collection period, additional follow up with nurses was conducted to review the OPS, behaviors assessed, and scoring practices to ensure treatment fidelity.

Nurses documented pain assessments every eight hours and upon recognition of pain symptoms which complies with Center for Medicare and Medicaid Services pain management guidelines for nursing homes under F309 (CMS Manual System, 2009; CMS Pain F-Tag, 2009). NDBs were documented using the CMAI at the end of the shift. The appropriate pain scale (either PAINAD or APS) and the CMAI were attached to the MAR to allow nurses to document assessments/reassessments in one location. PWD were treated with prescribed pain medications. Reassessment was completed 30 minutes after medication administration and results documented in MAR. All assessments and medication administration times were recorded on MAR and collected by researcher.

Once assessed, if a need other than pain was identified, staff ensured that the PWD's basic needs were met per usual residence procedures. An additional checklist was included with MAR for the nurse to indicate the perceived need (i.e. thirst; Appendix Q), and how the need was met. Over the eight week period, nurses reported that constipation contributed to 23% of behaviors not considered pain. Physically non-aggressive behaviors (18%) were the most common category of behaviors considered not pain related.

If evidence showed that behaviors were likely to be caused by pain, nurses used an OPS and treated for pain. If the PWD had no doctor's order for analgesics, nurses discussed a treatment plan with healthcare providers.

After quantitative data collection, qualitative data was collected. Nurses completed a demographic form (Appendix R). A semi-structured interview guide was followed (Appendix S). The guide was developed from the review of the literature and refined to suit the focus of the research questions. The audio-recorded interviews lasted 30-45 minutes allowing sufficient time for participants to share essential information. The PI kept field notes during or immediately after the interview to record thoughts, ideas, and reflections on the interview itself.

Quantitative Data Analysis. IBM SPSS Statistics 25 was used and PAINAD, APS, MSQ III and CMAI group data were pooled for statistical analysis. The data analysis plan was conducted in two phases. First, all study variables were presented using descriptive statistics including means, standard deviation, and minimum/maximum values for continuous variables (Interval/Ratio level) and frequencies and percentages for categorical variables (Nominal/Ratio level). Next, to address research questions one and two, inferential analysis was conducted using Pearson's *r* bivariate test of correlation to determine if scores reflecting NDB were correlated with APS Sum Total and PAINAD scores at a statistically significant level. To answer research question three, Pearson's *r* bivariate test of correlation was used to determine if scores reflecting MQS III correlated with APS Sum Total and PAINAD scores at a statistically significant level.

Within the inferential analysis presented, the parametric test assumptions of normality, linearity, and no undue influence of outlier scores were examined. While the assumption of linearity was met, the distribution of some of the continuous scores was somewhat non-normal. Skewness and kurtosis are more than 3 times the standard error for certain variables. These non-normal distributions were found to be related to several outlier scores within the distribution of scores for the NDB Weeks 1-4 (3 outlier scores), NDB Weeks 5-8 (5 outlier scores), and PAINAD (1 outlier score) scores.

Therefore, the outlier scores were removed, which produced an approximately normal distribution for each variable. The inferential analysis was repeated without the outlier scores and revealed the same relationships evidenced with the inclusion of the outliers scores. Subsequently, this indicated that the tests were robust against the non-normal distribution and that the outlier scores did not evidence an undue effect on study findings. Thereby, the final analysis includes all study participants with all parametric test assumptions being met. The APS Sum Total Weeks, MQS III Weeks 1-4, and MQS III Weeks 5-8 scores did not have any outlier scores and evidenced a normal distribution in the original form of the variables.

In terms of statistical power for the correlation analysis, the G*power software indicated that a medium/large size effect size (*r* = .30) with power set at .80 and alpha set at .05, would require a sample size of 27 study participants. Thus, the current sample of 28 study participants would provide approximately sufficient statistical power to detect a medium/large effect in the correlation analysis.

Qualitative Data Analysis. Qualitative data was reduced, managed, and analyzed using NVivo software. Giorgi's (2009) five step process was used: (1) assume the phenomenological attitude, (2) read entire written account for a sense of the whole, (3) delineate meaning units, (4) transform the meaning units into sensitive statements of their lived-meanings, and (5) synthesize a general psychological structure of the experience based on the constituents of the experience.

Following several re-readings of each transcript, passages were assigned descriptive codes reflecting the concepts expressed by those data. To demonstrate validity, reliability, and rigor all transcripts were transcribed verbatim and checked for accuracy using original recordings (Patton, 2015). The process of data analysis and identification of core themes was discussed with committee chair. An audit trail of analysis was kept, detailing steps in the development of the coding frame for each level of analysis. Finally, the core themes or concepts were shared with participants to ensure it reflects what they expected or felt.

Findings

Descriptive Analysis. Table 6 presents a descriptive analysis of categorical study participant characteristics. Table 7 presents a descriptive analysis of the continuous study variables, including study participant age, 3MS scores, pain comorbidities, total comorbidities, MQS III scores, NDBs, as well as, sum total of APS and PAINAD.

Table 6

Descriptive Analysis of Categorical Demographic Characteristics

	Variable	N	%
Gender	Male	9	32.1
	Female	19	67.9
Race/Ethnicity	White	28	100.0
Marital Status	Married	12	42.9
	Divorced	3	10.7
	Widowed	12	42.9
	Other	1	3.6
Religion	Catholic	12	42.9
	Protestant	7	25.0
	Born-again Christian	4	14.3
	No religious affiliation	5	17.9
Education Level	Less than High School	3	10.7
	High School Diploma	14	50.0
	Some College	3	10.7
	College Graduate	8	28.6
Occupation	Blue Collar	16	57.1
	White Collar	12	42.9
Type of Dementia	Alzheimer's	5	17.9
	Vascular	12	42.9
	ETOH	1	3.6
	Unspecified	10	35.7

(N=28)

Table 7

Descriptive Analysis of Continuous Study Variable Scores

Variable	**M (SD)**	**Minimum/ Maximum**	**Skew (SE)/Kurtosis (SE)**
Age	81.89 (6.38)	67.00-91.00	-.52 (.44)/-.30 (.86)
3MS Score	16.8 (15.6)	0.00-46.00	.48 (.44)/-.01 (.43)
Pain Comorbidities	2.14 (1.11)	1.00-5.00	.74 (.44)/-.01 (.86)

Number of Comorbidities	13.36 (2.53)	6.00-18.00	-.72 (.44)/1.63 (.86)
MQS Weeks 1-4	107.47 (44.07)	14.10-200.70	.10 (.44)/-.29 (.86)
MQS Weeks 5-8	105.13 (42.25)	11.90-197.00	.00 (.44)/-.17 (.86)
NDB Weeks 1-4	1384.00 (2123.32)	13.00-10409.00	3.24 (.44)/12.22 (.86)
APS Sum Total	2.57 (3.33)	0.00-11.00	1.37 (.44)/1.16 (.86)
NDB Weeks 5-8	1596.00 (2208.24)	0.00-8245.00	1.95 (.44)/2.96 (.86)
PAINAD Sum total	3.86 (5.07)	0.00-21.00	1.96 (.44)/4.10 (.86)

(*n* = 28)

Inferential Analysis. Table 8 presents a Pearson's r correlation examining the relationship between NDB APS sum total scores. The 2-tailed correlation indicated that NDB and APS sum total scores were positively correlated at a statistically significant level with a medium/large effect size, *r*(26)=.41, *p*<.05.

Table 8

Correlation between NDB and APS Sum Total Weeks

Variable Weeks 1-4	**NDB Weeks 1-4**	**APS Sum Total**
NDB	--	.41*
APS Sum Total		--

**p*<.05 (2-tailed); (*n*=28)

Table 9 presents a Pearson's r correlation examining the relationship between NDB and PAINAD sum total scores. The 2-tailed correlation indicated that NDB and

PAINAD sum total scores were not correlated at a statistically significant level, *r*(26)=-.12, *p*=.53.

Table 9

Correlation between NDB and PAINAD Sum Total

Variable	**NDB**	**PAINAD Sum Total Weeks**
NDB	--	-.12[1]
PAINAD Sum Total		--

[1]*p*=.53 (2-tailed); *(n=28)*

Table 10 presents a Pearson's r correlation examining the relationship between MQS III Mean and APS sum total scores. The 2-tailed correlation indicated that MQS III Mean and APS sum total scores were positively correlated at a level approaching statistical significance, *r*(26)=.35, *p*<.10 (*p*=.067).

Table 10

Correlation between MQS III and APS Sum Total

Variable	**MQS III Mean**	**APS Sum Total Weeks**
MQS III Mean	--	.35†
APS Sum Total		--

†*p*<.10 (2-tailed); *(n=28)*

Table 11 presents a Pearson's r correlation examining the relationship between MQS III and PAINAD sum total scores. The 2-tailed correlation indicated that MQS and PAINAD sum total scores were not correlated at a statistically significant level, *r*(26)=.16, *p*=.43.

Table 11

Correlation between MQS III and PAINAD

Variable	MQS III Mean	PAINAD Sum Total Weeks
MQS III Mean	--	.16[1]
PAINAD Sum Total		--

[1] *p*=.43 (2-tailed); *(n=28)*

Qualitative Analysis

A total of six nurses participated in one-on-one interviews. Demographic characteristics are presented in Table 12. Participants' experiences were characterized into three core themes and sub-themes: (a) assessing PWD for pain (sub-themes: assessment techniques, know the resident, pain assessment is a process, staff knowledge / education, assessing for pain versus other need, and measurement scales), (b) facilitators and barriers to pain management (sub-themes medications, education, staff approach to pain management, and specific strategies, documentation / staff communication, staffing, resident characteristics and other comments) and (c) caring for PWD. Please see Table 13 for representative quotes.

Assessing PWD for Pain. This theme emerged as a result of nurses' comments regarding how they assess for residents' pain, necessary knowledge of the resident and the fact that assessment is an ongoing process. Nurses stated it was important to have good assessment techniques with this population, the importance of knowing the PWD, recognizing that every PWD is an individual, assessment as an ongoing process, consistent care with a good attitude, and the importance of staff education and knowledge. Two sub-themes developed from this core. Nurses' comments indicated what they consider other causes of NDBs besides pain and experience using the APS and PAINAD tools with this population. The majority of nurses preferred the APS for use in PWD.

Table 12

Demographic characteristics of nurse sample (*n* = 6)

Characteristic	n (%)	Mean	SD
Nurse Age		54	9.4
Sex			
Female	5(83.3)		
Male	1(16.7)		
Race			
Caucasian	6(100)		
Other	0		
Education Level			
LPN	2(33.3)		
ADN	2(33.3)		
BSN	2(33.3)		
Years' experience as nurse		24	15.3
Years' experience with dementia		14.8	9.2
Additional Certifications			
Yes	4(66.7)		
No	2(33.3)		

Pain Management. The second theme encompassed comments regarding pain management for PWD including factors that facilitate pain management. Participants addressed some positive ways in which they felt they were able to manage pain for residents. This included giving scheduled pain medications and having 'as needed' medications available for use, good documentation and communication from nurse to nurse, nurse to aides, and nurse to doctor. Nurses also discussed the importance of enough staff, having a kind approach to care, empowerment through education, ongoing training and practice development, knowing the residents, establishing consistent routines, and other specific strategies for pain management. Barriers to effective pain management focused on difficulties with effective pain management such as lack of time, poor or inaccurate documentation and communication, being ‘short staffed’, bad attitudes of nurses, unfamiliar float nurses caring for residents, confusion over which behaviors were for what need, and unpredictable resident characteristics.

Caring for PWD. An unexpected third theme emerged from the data. Nurses expressed difficulties in caring for a PWD and the challenges of correctly interpreting residents’ behaviors since PWD cannot adequately express their needs. Statements included the need for patience, the emotionally and physically demanding nature of the work and feeling invalidated by others. However, some nurses felt that they made residents lives better providing a feeling of satisfaction.

Table 13. Themes and Representative Quotes from Qualitative Data

Theme	Sub-Themes And Representative Quotes
Theme 1: Assessing PWD for pain	**Assessment techniques:** • Non-verbal: “facial grimaces” / “Behavior and body language” or see a clue like some blood on their pillow. • A difference in the usual way they act and you can see it • You could touch the areas so you that would give you guideline if you press like say, when they’re bending it hurts their hips or whatever, you want to touch around that area to see if the hips bothering them or Vitals **Know the resident:** • Example: “What their baseline, you know and because that’s the first thing I ask, “Well, were they able to do that yesterday? • What they came in with, their diagnosis, like they had arthritis in their knees and then you’re watching for that. • Their behavior just gets more busy, intrusive, sometimes agitated, depending on what’s normal for them as far as if that’s when they’re really hurting … so you see their behaviors change. **Pain assessment is a process:** • If we notice anything out of norm, then we do a further assessment, it’s an ongoing process • Sometimes I think they think, “Oh, he’s having pain, give him something.” But is that because you want him to sit down and be quiet? You know, because he’s being so

	intrusive or he’s acting up and, “Oh, he’s gotta have pain, give him something.” And then they’re quieter, but is that fair? We need to assess why is he constantly having behaviors? You know, not just give him a pill. **Staff knowledge / education:** • “Somebody that ideally would be educated enough, trained enough to be able to pick on what might be an indicator of pain.” **Assessing PWD for pain versus other need:** • Is it because you’re hungry? Do you need to go to the bathroom? • There’s too many people around. • Bowel list – constipated? • Psychotic-type behaviors, neurological issues • Thirst • Bad mood • They just want your company • Rule out other physical problem: Make sure that if they have a respiratory, breathing heavy and stuff and they don’t have any respiratory diagnosis or they’re not having respiratory issues, it’s usually pain. **Measurement scales for PWD including Abbey Pain Scale & PAINAD scale:** **Abbey Pain Scale:** • I think it is maybe a little bit more, more appropriate for dementia, including the facial expressions, body language, and behavior changes. I like it a little bit more for dementia in particular for some of those nonverbal signs. • I really liked the physical changes of Abbey. Makes you think, “Okay, skin tears, pressure areas.” Those are good points to keep in mind. • I think that with dementia that I think the Abbey works a little better in the dementia because it gives you a little more play as far as where, what you’re looking at to kind of assess – what’s the norm and how is it different? **PAINAD** • I think it’s adequate and again, just because each individual will really display pain differently. There’s no such thing as a perfect tool. But for a one-size-all, I felt it was adequate. I feel it is adequate. • PAINAD would probably be better for EMPs or whatnot or better for somebody who floats the unit.

Table 13. Themes and Representative Quotes from Qualitative Data (continued)

Theme	Sub-Themes And Representative Quotes
Theme 2. Barriers and Facilitators to Pain Management	**FACILITATORS:** **Medications:** • Kept the PRN med there and we didn't use it unless we had to have it because of at some point when you need it quickly, you need it. Documentation / Communication: • Good documentation so thorough, accurate, and visible documentation for alternate caregivers to know about the resident's baseline pain that is consistently updated as residents change over time. • I passed it on to the oncoming nurse so they can keep an eye on this behavior to see what is going on. • Leave a note for the doctor saying, "Hey, we've been trying PRN around the clock to help manage this issue and it's been having a positive effect." Then see about getting a scheduled maintain dose of it and hopefully continue on the positive effect. • Having those specifically documented behaviors, if it's accurate, would be a great way to be able to communicate and keep records for future reference. • Staffing enough staff to be able to watch them. **Education:** • Some nurses that maybe work in dementia or have some type of experience or some type of extra training or a few of them are good at assessing non-verbal symptoms of pain. • Ongoing education for working nurses either within their facilities or outside. There's a lot of room to improve there, too. **Staff approach to pain management:** • A lot of the pain control with residents is sometimes only as good as your staff. • They (residents) see you on more of a personal level, equal, you know. • It's trust • Gonna have you know an individual pain and so their own individual strategies • Good pain management is to observe. Good observation before you just go ahead and medicate. • You kinda have to go in with a kind of calm approach to them. • Your attitude, they pick upon it **Specific Strategies** • Common ones that I use, either prophylactic or reactive analgesia, pharmacological pain relief. • "I always try to do that (non-pharm interventions) before I go to any of the other alternatives." • One-on-one support, you know, are they hungry, are they wet? You know. And if all that stuff, then you go on to the next step with them and then you may go with the Tylenol first.

Table 13. Themes and Representative Quotes from Qualitative Data (continued)

Theme	Sub-Themes And Representative Quotes
Theme 2. Barriers and Facilitators to Pain Management (continued)	• Some rubbing, cool washcloth on that area, cool or warm • TLC, positioning, you'd want to go with positioning • Scheduled Tylenol • You just talk to them, you talk to them in a way that, not down to them. It makes them happy. **BARRIERS** **Documentation / Staff Communication** • Documentation system lacks supportive features • More work to document everything on paper or electronically, for that matter. Some nurses want to get their documentation done, either midway, end of their shift, beginning of their shift and so they go down through and they scribble or they click or they type, "0,0,0,0,0,0,0,0,0,0,0,0," because it's expected that everyone had no pain. And maybe they think, "Alright, later I can change that if I find they have pain." Maybe they don't even do that. So I think accurate reporting is a problem **Staffing levels** • Can you realistically only have "dementia" nurses caring for dementia patients? I don't think you really can, but I think that's an important piece of controlling and assessing pain versus behaviors. • Inconsistency of caregivers • Right now, unemployment out there in the market it's under 4 percent. It's hard to find enough nursing staff or people to pump your gas or people to fold sweaters at the mall. It's not just nursing economy • there's a deeper understanding that comes with experience working with dementia or through more advanced education that not every nurse has • We don't always have adequate time / doing so many tasks that it's hard to stop. / it becomes a challenge to have enough time, frankly, to adequately assess all the residents • Not knowing the resident's baseline / how they manifest pain, what their indicators are **Resident characteristics:** • Trying to get somebody to stay still to keep a cold pack on is harder with some dementia residents. Having them tolerate therapeutic touch or massage isn't always as easy with dementia. • Communication: They can't totally tell you, "This is what hurts and that's why I'm acting that way." • Are they agitated because they're in pain? Or are they agitated because of stimuli in the environment because Sun downing is a huge factor for the dementia people and so now you have, you know, Sun downing or is it pain? Or is it both? **Other comments:** • 14 days makes it a lot harder to make sure that PRN order stays on there • (at night) I'm apt to get a covering (physician) rather than someone here that knows these folks.
Theme 3: Caring for PWD	**Caring Considerations** • It just takes special people to be able to help your patients, to take care of these people. • It really takes incredible patience. • They hear what we talk about when we're upset and they feed off our emotions, too. If we're wound up, they're wound up. • emotionally draining / emotional effort which is draining • physically draining

Table 13. Themes and Representative Quotes from Qualitative Data (continued)

Theme	Sub-Themes And Representative Quotes
Theme 3: Caring for PWD (continued)	• It takes a lot of mental effort • Emotional effort which is tiring sometimes • They react to smiles and just your acting happy. Little things, they react to it. • it's hard to shut it off and then go home • I feel satisfied when I can sing and joke and they are happy • I'm the Charge Nurse, the only one passing out the meds in the morning and a lot of time my patience starts giving out. • Most people do not understand what it takes to care for a PWD: And that their behavior totally is increased during that time frame, and people don't understand that that time change.

Discussion

Algase et al. (1996) developed the mid-range theory, NDBM, which provided the structure for this study. Pain, a proximal factor according to the NDBM, can be a precursor to NDBs which in turn might call for medication administration. The aim of this study was to examine the relationship between two OPSs and NDBs. Qualitative data were embedded into the design and provided insight into nurses' perceptions regarding barriers and facilitators to identifying pain in PWD and practicality of the two OPSs.

There is a plethora of evidence suggesting that pain management in PWD remains a challenge for nurses (Brorson et al., 2014; Burns & McIlfatrick, 2015; Dowding et al., 2015; Fry et al., 2015; Gilmore-Bykovskyi, & Bowers, 2013; Lichtner, Dowding, & Closs, 2015; Pieper et al., 2013; Tsai, Jeong, & Hunter, 2018) and that the various OPSs, while useful to assist in clinical judgement of pain, are still limited and only as good as the user (Tsai, Jeong, & Hunter, 2018). There is much less research conducted directly with PWD participants. There is also no universally accepted tool, and the inconsistency and inadequacy of current tools does not fully address the practice of poor pain assessment by nurses. Therefore, it was important to investigate not only the use of OPSs with PWD subjects, but to also look at the nurses' perceptions of the tools and pain management of PWD in general. Therefore, the first and second research questions of this study were to determine if NDBs were correlated with two OPSs (determined to be clinically relevant, valid and reliable, and easy to use). Supporting the first question, the APS was determined to be correlated to NDBs at a significant level ($p<.05$); the PAINAD did not have a significant correlation. This conflicted with a previous study examining behavior overlap between PAINAD and CMAI (Kutschar et al, 2017). However, these findings suggest that the APS is a more sensitive tool in determining pain in PWD.

The third question addressed whether using the OPS would prompt the nurse to administer pain medication. This was done by measuring the quantification of medication given by amount, pharmacological class, and the amount of detriment to the PWD using the MQS III scale. Neither the APS nor PAINAD showed significant correlation with medication administration; however, the APS showed a trend approaching significance ($p = .067$) meaning that PWD were given more medication during the APS control condition. This was the first known study to examine relationships between variables; however, a previous study compared APS and PAINAD instruments in PWD to a cognitively intact control group and reported both scales were beneficial to recognize the presence/absence of pain in PWD (Lukas et al., 2013).

The full scope of the pain management for PWD would not be complete without inquiry into the nurses who used the OPSs. The fourth research question addressed nurses' perceptions regarding barriers and practicality of the scales. All of these themes were consistent with current qualitative and mixed methods research studies such as difficulty in assessing pain (Coker et al, 2010), relying on experience for assessments (Dowding et al., 2015), poor communication, lack of pain recognition, workload pressures, not knowing residents, , poor staffing, and inadequate training/education (Brorson et al., 2014; Burns & McIlfatrick, 2015; Corbett et al., 2014; Coker et al., 2010; Dowding et al., 2015; Gilmore-Bykovskyi & Bowers, 2013; Monroe, Parish, & Mion, 2015; Lichtner et al., 2016). Nurses in this study reported a preference for the APS. However, one theme not intrinsically related to pain that emerged unexpectedly was caring for PWD. Nurses' reported feeling emotionally, mentally, and physically drained, impatient, frustrated, and invalidated by others in the organization as well as resident families. While lack of satisfaction and not meeting resident needs has been reported (Brorson et al, 2014), some nurses did express feeling satisfied that they made the residents lives better.

Qualitative themes provided a richer context in which to view the quantitative findings. While the study may identify the most appropriate pain assessment tool for PWD, it was necessary to provide a first-hand description of the experiences working with the OPSs and providing pain management. Nurses also described using a process similar to the ADD protocol. Merging results provided some clarity of nurses' experiences, thought processes, barriers, and attitudes in caring for this population. Interestingly, quantitative findings revealed that the APS was more correlated with NDBs and qualitative data revealed that nurses actually preferred the APS tool over the PAINAD. During qualitative interviews, the nurses described a lack of time, appropriate staff, education, and confidence in providing effective pain management. They expressed confusion in understanding which behaviors belong to which need, responding to NDBs, and the burden placed on the nurses. The themes extracted validated important issues regarding facilitators, barriers, OPS preference, and attitudes in providing care for PWD.

Strengths and Limitations

This study has several notable strengths including an embedded mixed methods and prospective design, use of validated instruments and testing a theoretical model for identified gaps in the literature. This research presented a unique blend of variables that can be translated into the nursing home setting. It provides strong evidence for clinical utility, adds to nursing knowledge and examined the effect of a systematic, consistent way of observing pain-related behaviors, treatment of pain, and the correlation with NDBs.

Limitations of this study include threats to both internal and external validity. Threats to internal validity include attrition and instrumentation. Attrition was a threat to internal validity because three participants dropped out of the study due to death. To decrease the threat of attrition oversampling was done and the final participant number ($N = 28$) was satisfactory for statistical conclusion validity. Instrumentation was also considered a threat to internal validity due to data collected by observation and different data collectors. To decrease this threat, independent pain observers (nursing staff) were trained by the researcher. The staff also practiced the OPSs using clinical videos and an acceptable inter-rater reliability was established by comparing staff-rated practice pain with other staff and that of the researcher. The researcher followed up with nurses every two weeks during the study data collection period to ensure accuracy and consistency with the instruments.

Threats to external validity include Hawthorne effect, effects of selection, and generalizability. The Hawthorne effect posed a threat as the nurses are aware they are participating in a study about pain. However, since implementation is within the same population (for both patients and nurses), it is thought that this effect would be equal for both the experimental and control conditions. In addition, the PI was careful not to bias the nurses toward either scale during the workshop session. Because pain intensity can vary according to the type and variations of participant's pain, the sample of PWD is fairly heterogeneous impacting the effect of selection. Finally, the participants are PWD and nurses located in one region; findings might not be generalized to other geographic areas.

Recommendations

Recommendations for future research were identified. Due to the numerous barriers attributed to pain assessment, research to develop alternate assessment methods is needed. How assessment outcomes are translated into clinical decisions and the effect on NDBs is warranted. However, even research that purports to detect pain in PWD should be approached cautiously as there are many variables such as situational factors that affect NDB. An individualized approach to assessment may be recommended and observation of PWD behaviors that deviate from their baseline.

More research should be conducted in clinical practice to assess the feasibility and clinical utility of OPSs and their potential for use in everyday practice. In addition, research on pain protocols that incorporate the use of OPS such as the ADD is warranted. Further studies on types and degrees of dementia and pain, as well as, types of pain should be explored. Qualitative findings indicated that nursing home nurses experience many challenges in managing pain for people with advanced dementia. More in-depth research on these barriers are indicated as well as caregiver burden, compassion fatigue, and social support.

Clinical implications from this study suggest the need for a systematic, consistent method of observing pain-related behaviors which are essential to decoding the meanings behind expressed behaviors. Incorporating an OPS such as the Abbey Pain Scale into the electronic medical record (EMR) and MAR might prompt nurses to recognize behaviors and treat pain and help overcome barriers such as lack of time. Nurses also need to understand study findings to improve patient outcomes.

More critically, it is important to establish an institutional philosophy of dementia care. Using the NDBM was empowering for the nurse participants as it helped to validate and give structure to the care they intuitively provide. A theoretical structure might address other barriers such as education and communication and ultimately serve as a model which can be transferred to other facilities.

Summary

Appropriate treatment of pain in PWD is needed. PWD receive approximately one-third less pain medication than cognitively intact patients for the same conditions (Rantala, Kankkunen, Kvist, & Hartikainen, 2014; Reynolds et al., 2008). Twenty-five percent of PWD are inappropriately treated for pain with the use of antipsychotic medications or physical restraints (Pratt, Roughead, Salter, & Ryan, 2012).

Due to the physiological, chemical, and anatomical changes that occur with dementia, there is a clear association between NDBs and pain. Nurses' recognition of pain behaviors, historically, has been subjective and challenging resulting in suboptimal pain management. Exploring the validity of instruments as well as existing barriers is crucial to ensure accurate assessment, treatment, positive health outcomes, and quality of life.

This embedded mixed methods study examined the effects of implementing APS and PAINAD in the assessment and treatment of pain and correlation to need-driven behaviors. This theory-based, mixed-methods, quasi-experimental study hopefully illustrated the importance of regular, systematic observational pain assessment. The qualitative strand revealed barriers, facilitators, and utility of these pain tools. Nurses can be sensitized to need-driven behaviors and it is important to recognize behaviors as symptoms of pain or other unmet needs.

Raising awareness of pain in PWD is a high priority. The goal of providing comfort and care for this vulnerable population is pervasive and ongoing. Additional research in the area of pain management and associated NDBs is necessary for a more accurate differential assessment, and consequently, relief from pain.

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Chapter 5

Summary and Conclusion

During the last decade, much effort has been expended to improve the quality of pain assessment in the persons with dementia (PWD). However, many gaps still remain, such as misinterpretation of pain behaviors, subjectivity of measurement scales, knowledge and attitudinal deficits of nurses, unwillingness of nurses to use a scale, ethical challenges, lack of systematic pain protocols, and inappropriate treatment of pain in PWD. As the evidence reveals, there is a complex relationship between pain, need-driven behaviors, and the nurse's perceptions of those behaviors including what they mean and how to manage the PWD exhibiting them. Current evidence lacks replication and may be difficult to reproduce. Further studies are needed which delve into the complex relationship and provide insight into which interventions and outcomes are most effective.

This portfolio includes three manuscripts. The first manuscript, entitled *Comparison of Pain Assessment Tools Used for Persons with Dementia,* summarized current evidence of existing tools for pain assessment in PWD using the American Geriatrics Society (AGS) guideline for persistent pain. The purpose was to find OPSs which encompassed all three of the comparison criteria and to incorporate them into the study presented in the third manuscript.

The second manuscript: *In the Eyes of the Beholder: The Historical Basis for an Integrated Model of Pain Management,* is a non-traditional concept analysis based on a series of previous pain-related concept analyses. This manuscript was instrumental in providing insight into creative ways of studying new pain management measures.

Based on findings from Chapters 1 and 2, the researcher conducted the study entitled, *Pain, Need-Driven Behaviors in Dementia, and Nurses' Perceptions: An Embedded Mixed Methods Study*. This study was a comparison of two OPS, their correlation to NDB and pain medication administration as well as nurses' perceptions of pain and the PWD. The study involved a cohort of in-patient PWD and a cohort of the nurses' who cared for and assessed pain. The theoretical framework used was Algase's Need-driven Behavior Model (NDBM). An embedded mixed methods design was used and qualitative data was embedded within a major quantitative design. The initial quantitative phase was a quasi-experimental design in which the protocols were counter-balanced to minimize the effect of outside factors on study outcomes. Findings revealed that the Abbey Pain Scale (APS) was significantly correlated to NDBs and approaching significance with medication administration while the Pain Assessment in Advanced Dementia (PAINAD) was not significantly correlated to NDBs or medication administration. The qualitative strand revealed three major themes (assessing PWD for pain, facilitators and barriers to pain management, and caring for PWD) and two sub-themes (assessing for pain versus another need, measurement scales for PWD including APS and PAINAD scale). Nurses preferred the APS over the PAINAD scale. The third theme of caring for PWD emerged unexpectedly from the data revealing the struggled nurses experienced in caring for PWD. In completing this dissertation, the researcher filled a gap in professional knowledge by exploring the complexities associated with pain assessment in PWD and NDBs while relating to the issue of the subjective nurses' experience.

Conclusion

The study of persons with dementia is difficult for the same reasons that pain management is difficult. Gaining permission and understanding from patients, families, and nurses are challenging. This study was no different. Attrition was 9% with this vulnerable population; nevertheless, the researcher concluded that the value of gaining insight into best practices for care of PWD was worth the effort. The unique measurements of this study may yield information that could advise practice. Comparing two scales and using the subjects as their own control was fruitful in that the residents' typical behaviors were consistent for both conditions. The APS appeared better than the PAINAD for assessing pain in PWD. The organization decided to incorporate the results of this study into their electronic assessment system based on both the quantitative as well as qualitative findings.

The educational workshops with the nurses and nurses' aides were a positive experience for most, particularly as they pertained to application of the NDBM. Many of the attendees gave feedback that the model helped to articulate what they do on a daily basis because their actions previously were thought intuitive in nature. Nurses were interested in participating in this project and excited to contribute to nursing research.

There was value in working with actual subjects. Much of the literature surrounding pain and PWD have been various types of reviews around a few studies with patients. Although it was challenging getting IRB approval and proxy consents, the whole process helped engage families, nurses, nurses' aides, facility administration, and researcher to work together in a resident-centered collaboration. Research was previously seen as an intimidating, futile activity; however, now the organization and employees appreciate and understand the value of research by incorporating evidence and meaning into their work. The mixed methods approach added another dimension to this study that helped give meaning to the quantitative data. This process would not have the depth and breadth without first investigating the OPS currently in use (Chapter 2). It was helpful to start this journey with a concept analysis to help define parameters of the research.

More research should be conducted in clinical practice to assess the feasibility and clinical utility of OPS and their potential for use in everyday practice. In addition, research is needed on pain protocols that incorporate the use of OPS. Further studies on types and degrees of dementia and pain should be explored in this population.

Clinical practice research that includes engagement and education of the nursing staff has dual benefits of ensuring the reliability of data collected, affirming the staff and demonstrating the benefits of participating in evidence based practice. The qualitative findings from this study indicate that nursing home nurses experience many challenges in managing pain for people with advanced dementia. More in-depth research on these barriers would be indicated, as well as, caregiver burden, compassion fatigue, and social support.

Long-term care nurse professional development programs to increase knowledge of pharmacology, dementia knowledge, pain assessment, and a compassionate approach to NDBs is beneficial. A post-doctoral opportunity related to this area of research is being considered. In the near future, smaller grants will be sought in order to help offset the cost of statistical software needed to analyze large datasets and for dissemination of research nationally.

Appendix A. Eligibility Checklist

Information will be obtained via chart review except for 3MS which will be administered by PI

Subject # _____________

Criteria	**Yes/No**	**Eligible/Not Eligible**
1. ≥65 years		
2. Diagnosis of dementia according to Diagnostic Statistical Manual IV		
3. Score of <48 on the 3MS	Score:	
4. Pain related diagnoses (minimum of one such as osteoarthritis, cancer, injury, etc.).	List total # and type:	
5. Admitted to hospital ≥ 2 times in past 2 months (diagnosis of CHF or exacerbations of chronic diseases)		
6. Comorbid psychiatric disorder (schizophrenia or bipolar disorder)		
7. Recent distressing social circumstances (death of a spouse or child)		
8. Life expectancy greater than 3-6 months. Not under palliative care.		

Appendix B. Permissions

CITY OF PORTLAND
HEALTH & HUMAN SERVICES DEPARTMENT • BARRON CENTER

July 17, 2017

Suzanne E. Parkman, PhD(c), MSN, RN
Assistant Professor
Department of Nursing
Saint Joseph's College of Maine
278 Whites Bridge Rd
Standish, ME 04084

Dear Ms. Parkman,

We are pleased to participate in and grant permission for your research project, "Comparison of Observational Pain Scales for use in Persons with Dementia and Nurses Perceptions: A Mixed Method Embedded Design, pending IRB approval from the University of Texas at Tyler.

We are excited about this project and are looking forward to our collaboration with St. Joseph's and, of course, with you.
Sincerely,
Edward Latham, RN, FNGNA
ACTING ADMINISTRATOR

Edward Latham, RN, FNGNA
Acting Administrator
BARRON CENTER
1145 Brighton Avenue
Portland, ME 04102
207-541-6500

Appendix B (Continued)

MARION E. YOUNG, PHD

CHAIR, INSTIUTIONAL REVIEW BOARD

ASSISTANT PROFESSOR OF PSYCHOLOGY

SAINT JOSEPH'S COLLEGE OF MAINE

STANDISH, ME 04084

Re: Suzanne Parkman

Nursing Department

Saint Joseph's College of Maine

278 Whites Bridge Road

SEPTEMBER 28, 2017

Standish, ME 04084

Dear Suzanne:

Your research proposal entitled Pain, Dementia, and Nurse's Perceptions: An Embedded Mixed Methods Study submitted August 2017, has been approved as EXPEDITED Review by the SJC Institutional Review Board. The approval is valid for one year from the date of this letter. If you wish to continue collecting data beyond that time, you will need to request continuing approval. Note that any deviations from the procedures described in the approved research proposal must be approved by the IRB prior to implementation.

Best wishes for completion of your project. Please feel free to contact me with any questions.

Sincerely,

Dr. Marion E. Young

Chair, Institutional Review Board

Appendix B (Continued)

THE UNIVERSITY OF TEXAS AT TYLER
3900 University Blvd. • Tyler, TX 75799 • 903.565.5774
Office of Research and Technology Transfer
Institutional Review Board

November 28, 2017

Dear Ms. Parkman,

Your request to conduct the study: Pain, Need-Driven Behaviors in Dementia, and Nurses' Perceptions: An Embedded Mixed Methods Study, IRB #F2017-43 has been approved by The University of Texas at Tyler Institutional Review Board under expedited review. This is an approval with informed signed consent and your assurance of participant knowledge of the following prior to study participation: this is a research study; participation is completely voluntary with no obligations to continue participating, and with no adverse consequences for non-participation; and assurance of confidentiality of their data. In addition, please ensure that any research assistants are knowledgeable about research ethics and confidentiality, and any co-investigators have completed human protection training within the past three years, and have forwarded their certificates to the IRB office (G. Duke). Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:

- This approval is for one year, as of the date of the approval letter
- The Progress Report form must be completed for projects extending past one year
- Your protocol will automatically expire on the one year anniversary of this letter if a Progress Report is not submitted, per HHS Regulations prior to that date (45 CFR 46.108(b) and 109(e): http://www.hhs.gov/ohrp/policy/contrev0107.html
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.
- Approval with signed consent

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely, Danita Alfred, PhD, RN Delegated Reviewer, UT Tyler IRB

Appendix C. Letter to Proxy

CITY OF PORTLAND
HEALTH & HUMAN SERVICES DEPARTMENT • BARRON CENTER

November 1, 2017

Edward Latham, RN, FNGNA
Barron Center-Director of Nursing Services
1145 Brighton Avenue
Portland, ME 04102

RE: Permission to participate in nursing home research study

Suzanne Parkman, a PhD nursing student from The University of Texas at Tyler is conducting a study about nurses caring for nursing home residents with dementia. Suzanne worked for the Barron Center for over 3 years as our educator and is an expert in geriatric nursing. I would like to invite your loved one to join this research. The ultimate goal of this study is to improve nursing care of nursing home residents.

In this study, Suzanne will review your loved one's chart for pain scores, behaviors, and amount of pain medication administered. She will also review the chart in particular the nurse's notes and medications about your loved one's health, the nursing care provided, and effects of that care.

The results of the study will help us to understand how to care for nursing home residents with dementia, and to improve comfort and care for residents.

Please read the enclosed consent form carefully. If you have any questions, please call myself at 207-541-6500 or Suzanne at 207-228-3207. If you agree to have your loved one participate in this study, please sign the attached consent form and return it to the nurse researcher in the stamped envelope included with this letter.

Thank you in advance,

Edward Latham, RN, FNGNA
Director of Nursing Services
Barron Center
Suzanne Parkman, PhD(c), MSN, RN

Appendix D. Informed Consent

THE UNIVERSITY OF TEXAS AT TYLER
Informed Consent to Participate in Research: Proxy Consent
Institutional Review Board # F2017-43
Approval Date:

1. Title of study: *Pain, Need-Driven Behaviors in Dementia, and Nurses' Perceptions: An Embedded Mixed Methods Study*
2. Principal investigator: Suzanne Parkman, PhD-c
3. Participant's name:

To the Participant:

You are being asked permission on behalf of _____________, to take part in this study by a doctoral student and nurse from The University of Texas at Tyler (UT Tyler). This permission form explains:

- Why this research study is being done.
- What the person you represent will be doing if they take part in the study.
- Any risks and benefits expected if they take part in this study.

After reading this consent, you should be able to:

- Understand what the study is about.
- Choose to agree that the person you represent take part in this study because you understand what will happen.

4. Description of Project

This study will help nurses to recognize and treat pain in people with dementia or memory loss.

Research Procedures

In this study, the nurse taking care of the person you represent will:

- Watch for pain and behaviors using two different ways every 8 hours
- If the nurse thinks there is pain, medicine will be given according to what has been already ordered.
- The researcher will look at the chart for evidence of pain, the medication given, and what happened.

6. Side Effects/Risks

There is very small risk for the person you represent to join the study, however, a loss of privacy could happen. The researcher will not use their name but a number. The list with the name and number will be double locked in an office and will be shredded once everything is collected. The person you represent will never be identified by name. This study may help us to see how pain and behaviors are related to dementia, the best ways to recognize pain, and help your loved one be more comfortable.

Understanding of Proxy giving Permission:

8. I have been given a chance to ask any questions about this research study. The researcher has answered my questions.
9. If I sign this consent form I know it means that:

Appendix D. Informed Consent (Continued)

- The person I represent is taking part in this study because I have given permission. I chose to allow this person to take part in this study after having been told about the study and how it will affect them.
- I can refuse to allow the person I represent to be involved in this study. If I choose that they not take part in the study, then nothing will happen to them as a result of my choice.
- I can ask that they not be involved in this study at any time. If I ask that they stop being a part of the study, then nothing will happen to them.
- I will be told about any new information that may affect my wanting them to continue to be part of this study.
- The study may be changed or stopped at any time by the researcher or by The University of Texas at Tyler.
- The researcher will get my written permission for any changes that may affect the person I represent.

10. I have been promised that the name of the person I represent will not be in any reports about this study unless I give my permission.
11. I also understand that any information collected during this study may be shared as long as no identifying information such as name, address, or other contact information is provided. This information can include health information. Information may be shared with:

- Organization granting permission to conduct this study
- Other researchers interested in putting together your information with information from other studies
- Information shared through presentations or publications

12. I understand The UT Tyler Institutional Review Board (the group that makes sure that research is done correctly and that procedures are in place to protect the safety of research participants) may look at the research documents. These documents may have information that identifies the person I represent on them. This is a part of their monitoring procedure. I also understand that this personal information will not be shared with anyone.
13. I have been told about any possible risks that can happen while taking part in this research project.
14. I also understand that I will not be given money for any patents or discoveries that may result from taking part in this research.
15. If I have any questions concerning participation in this project, I will contact the principal researcher: (Suzanne Parkman) at (207-228-3207) or email (sparkman@patriots.uttyler.edu).

Appendix D. Informed Consent (Continued)

16. If I have any questions concerning the rights of the person I represent as a research subject, I will contact Dr. Gloria Duke, Chair of the IRB, at (903) 566-7023, gduke@uttyler.edu, or the University's Office of Sponsored Research:
The University of Texas at Tyler
c/o Office of Sponsored Research
3900 University Blvd
Tyler, TX 75799
I understand that I may contact Dr. Duke with questions about research-related injuries.
17. CONSENT/PERMISSION ON BEHALF OF THE PERSON I REPRESENT FOR PARTICIPATION IN THIS RESEARCH STUDY
I have read and understood what has been explained to me. As the legal representative of the person I represent, I give my permission for them to take part in this study as it is explained to me. I give the study researcher permission to register the person I represent in this study. I have received a signed copy of this consent form.

____ ________________________
Signature of Proxy of Participant Date

____
____
Printed name of Person Responsible (e.g., legal guardian) Relationship to Participant

____
Witness to Signature

18. I have discussed this project with the participant (proxy), using language that is understandable and appropriate. I believe that I have fully informed this participant (proxy) of the nature of this study and its possible benefits and risks. I believe the participant (proxy) understood this explanation.

_________________________________ _______________
Researcher/Principal Investigator Date

Appendix E. Authorization to Use Personal Health Information

The University of Texas at Tyler
Institutional Review Board# F2017-43 —Approved, 2017

RESEARCH PARTICIPANT AUTHORIZATION TO USE PROTECTED HEALTH INFORMATION

This form is to be signed by you to allow me to audit Personal Health Information (PHI) of your loved one for the purposes outlined in this study. All PHI will be treated as confidential. This information is protected by a federal law (HIPAA), and I will not release any information without your written permission.

The information I am referring to is information such as age, gender, medical diagnoses, pain assessment, medication administration, and behavior that might be caused by pain all of which is located in your loved one's chart. All of this information collected will be given a unique code and any identifying factors will be removed such as name, birthdate, and other personal information, however, the outcome of the study and in particular which type of assessment tool works best for a person with dementia (not any individual information) may be published in a nursing journal. Individual information will not be shared outside of nursing/medical staff at facility.

♦You may cancel your permission at any time.

This permission to use and disclose your loved one's Health Information will only be used for the study outlined in the letter. You may cancel your authorization at any time by calling or emailing Suzanne Parkman at 207-228-3207, or by sending a written notice to the following address:

The University of Texas at Tyler
Institutional Review Board
c/o Office of Sponsored Research
3900 University Blvd
Tyler, TX 75799

If you cancel your authorization, Suzanne Parkman will no longer use or disclose your Health Information for this Study.

I understand the above with regard to my privacy rights.

Participant's Proxy Signature	Date

Print Name

Witness

Appendix F. Application for Use of Personal Health Information

THE UNIVERSITY OF TEXAS AT TYLER
INSTITUTIONAL REVIEW BOARD
APPLICATION FOR PROTECTED HEALTH INFORMATION USE
Principal Investigator: Suzanne Parkman
Email address: sparkman@patriots.uttyler.edu
Phone number: 207-228-3207
Research Staff needing access to protected health information (must also be listed in IRB review application): n/a

Study Title: Pain, Dementia-Compromised Behaviors, and Nurses' Perceptions: An Embedded Mixed Methods Study

TYPE OF HEALTH INFORMATION REQUESTED

Which of the following categories of health information is being requested for use in this study (check all that apply)

☒ Category 1: Health information that is protected, with authorization from participants
Health information, as defined by the HIPAA Privacy Act can be protected or it can be de-identified. Protected health information (PHI) includes the following:
"…as individually identifiable health information, held or maintained by a covered entity or its business associates acting for the covered entity, that is transmitted or maintained in any form or medium (including the individually identifiable health information of non-U.S. citizens). This includes identifiable demographic and other information relating to the past, present, or future physical or mental health or condition of an individual, or the provision or payment of health care to an individual that is created or received by a health care provider, health plan, employer, or health care clearinghouse. For purposes of the Privacy Rule, genetic PHI Use Application IRB Approved information is considered to be health information." [http://privacyruleandresearch.nih.gov/pr_07.asp]

☐ Category 2: Health information that is a limited data set
Limited data sets include that all identifiers have been removed except:

☐ Admission, discharge, or service dates
☐ Dates of birth, death
☐ Age (including age 90 or over)
☐ Five-digit zip code or any other geographic subdivision, such as state, county, city, precinct and their equivalent geocodes (except street address).

Appendix F. Application for Use of Personal Health Information (Continued)

Refer to the IRB Handbook for additional information on limited data sets and required information from covered entities.
☐ Category 3: Health Information that is de-identified, none of the identifiers will be linked to the health information.
De-Identified Health Information: Health information that cannot be linked to an individual and has none of the following identifiers with it:
☐ Names
☐ All geographic subdivisions smaller than a state, including street address, city, county, precinct, zip code and their equivalent geocodes
☐ All elements of dates (except year) for dates directly related to an individual, including birth date, admission date, discharge date, date of death
☐ Telephone numbers
☐ Fax numbers
☐ Electronic mail addresses
☐ Social security numbers
☐ Medical record numbers
☐ Health plan beneficiary numbers
☐ Account numbers
☐ Certificate/license numbers
☐ Vehicle identifiers & serial number, including license plate numbers
☐ Device identifiers & serial numbers
☐ Web universal resource locators (URLs)
☐ Internet protocol (IP) address numbers
☐ Biometric identifiers, including finger and voice prints
☐ Full face photographic images and any comparable images
☐ Any other unique identifying number, characteristic or code.
PHI Use Application IRB Approved July 2007

Any code used to link de-identified data to identifiers must be held by the investigator in a secure manner. The code must not be derived from or related to information about the individual, and may not be otherwise capable of being translated so as to identify the research subject. The mechanism for re-identification must not be disclosed to any person outside of UT Tyler or the research setting.

DATA AND/OR RECORDS NEEDED FOR RESEARCH PROTOCOL

1. Selection Criteria (e.g.: all hypertensive children seen in Pediatric Clinic)

Residents of Barron Center II in Portland, ME who are enrolled in the study.
2. Dates of required records:

Begin: 11/1/2017
End: 3/31/2018
3. Data fields required (list fields required from an electronic data base, or list fields to be recorded from the paper record by the researcher)

Age, gender, medical diagnoses, medication record, CMAI, APS, PAINAD
4. Anticipated sources of information (check all that apply)

☒ Paper medical records
☐ Electronic files
☐ Other: Face-to-face interviews
5. I certify that the use or disclosure of protected health information involves no more than minimal risk to the privacy of individuals based on at least the following elements:
a. An adequate plan is in place to protect the identifiers from improper use and disclosure. The plan is as follows (select all that apply):
☒ All electronic study data will be password protected
☒ Passwords will be changed on a regular basis PHI Use Application IRB Approved
☒ Access to study data will be restricted to the following authorized personnel only:
☒ All paper study records will be kept in locked file cabinets and access limited to authorized study personnel only.
☒ Other: If the participant experiences excessive discomfort or a catastrophic event the research nurse will verbally report in person to the Nurse Manager, Ann Marie Guevins and Director of Nursing, Edward Latham at Barron Center, on the day the tool was administered or as soon as possible.
b. An adequate plan is in place to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law.
The plan is as follows: At no time will scores be identifiable. When entered into SPSS, a unique identifier will be assigned. All identifiable data will be destroyed after data entry is complete.

Appendix F. Application for Use of Personal Health Information (Continued)

By submitting this form with the IRB research review application, the PI attests to the following:

I declare that the requested information constitutes the minimum necessary data to accomplish the goals of the research.

I agree that the protected health information that I am requesting will remain secure and will be accessible only to authorized persons for all categories, and will remain de-identified for Category 3 information.

I attest that the above statements are correct and complete to the best of my knowledge.

SIGNATURE OF PRINCIPAL INVESTIGATOR: Principal Investigator Signature (Acceptable signatures: Electronic submission from PIs mailbox or electronic signature)	Date

Appendix G. Informed Consent - Qualitative

UNIVERSITY OF TEXAS AT TYLER
Informed Consent to Participate in Research: Qualitative Strand
Institutional Review Board
Approval Date:

Project Title: Pain, Need-driven Behaviors in Dementia, and Nurse's Perceptions: An Embedded Mixed Methods Study

1. **Principal Investigator:** Suzanne Parkman, PhD(c)

2. **Participant's Name:**

To the Participant:

You are being asked to take part in this study at The University of Texas at Tyler (UT Tyler). This permission form explains:

- Why this research study is being done.
- What you will be doing if you take part in the study.
- Any risks and benefits you can expect if you take part in this study.

After talking with the person who asks you to take part in the study, you should be able to:

- Understand what the study is about.
- Choose to take part in this study because you understand what will happen

4. Description of Project

The purpose of this study is to learn about assessing and treating pain in people with dementia. During an interview, you will be asked questions about your experiences using two pain assessment tools for use in persons with dementia.

5. Research Procedures

If you agree to be in this study, we will ask you to do the following things:

- You will meet with research nurse for about an hour to share your experiences assessing and treating pain in persons with dementia.
- You may be asked to meet again if more information is needed.

Appendix G. Informed Consent – Qualitative (Continued)

6. Side Effects/Risks

A potential risk is loss of privacy. The researcher will make every effort to keep all of your information private: a code number will be used to identify your answers not your name, your answers are entered into a computer that is password protected and the paper

copies will be double locked in a file cabinet only accessible to researcher. You will not be identified by name.

7. Potential Benefits

There is no direct benefit to you. Participation might help nurses and doctors understand pain and how to manage it persons with dementia

<u>Understanding of Participants</u>

8. I have been given a chance to ask any questions about this research study. The researcher has answered my questions.

9. If I sign this consent form I know it means that:

- I am taking part in this study because I want to. I chose to take part in this study after having been told about the study and how it will affect me.
- I know that I am free to not be in this study. If I choose to not take part in the study, then nothing will happen to me as a result of my choice.
- I know that I have been told that if I choose to be in the study, then I can stop at any time. I know that if I do stop being a part of the study, then nothing will happen to me.
- I will be told about any new information that may affect my wanting to continue to be part of this study.
- The study may be changed or stopped at any time by the researcher or by The University of Texas at Tyler.
- The researcher will get my written permission for any changes that may affect me.

10. I have been promised that that my name will not be in any reports about this study unless I give my permission.

Appendix G. Informed Consent – Qualitative (Continued)

11. I also understand that any information collected during this study may be shared as long as no identifying information such as my name, address, or other contact information is provided). This information can include health information. Information may be shared with:

- Organization giving money to be able to conduct this study
- Other researchers interested in putting together your information with information from other studies
- Information shared through presentations or publications

12. I understand The UT Tyler Institutional Review Board (the group that makes sure that research is done correctly and that procedures are in place to protect the safety of research participants) may look at the research documents. These documents may have information that identifies me on them. This is a part of their monitoring procedure. I also understand that my personal information will not be shared with anyone.

13. I have been told about any possible risks that can happen with my taking part in this research project.

14. I also understand that I will not be given money for any patents or discoveries that may result from my taking part in this research.

15. If I have any questions concerning my participation in this project, I will contact the principal researcher: (Suzanne Parkman) at (207-228-3207) or email (sparkman@patriots.uttyler.edu).

16. If I have any questions concerning my rights as a research subject, I will contact Dr. Gloria Duke, Chair of the IRB, at (903) 566-7023, gduke@uttyler.edu, or the University's Office of Sponsored Research:

The University of Texas at Tyler
c/o Office of Sponsored Research
3900 University Blvd
Tyler, TX 75799

I understand that I may contact Dr. Duke with questions about research-related injuries.

17. CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY

I have read and understood what has been explained to me. I give my permission to take part in this study as it is explained to me. I give the study researcher permission to register me in this study. I have received a signed copy of this consent form.

________________________________ ____________________

Signature of Participant Date

____

Witness to Signature

18. I have discussed this project with the participant, using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks. I believe the participant understood this explanation.

________________________________ ________________

Appendix H. Demographic Information Form (Residents)

Age (in years): ___________

Gender: 1) Male 2) Female

Race: 1) Caucasian 2) Hispanic 3) African-American 4) Other

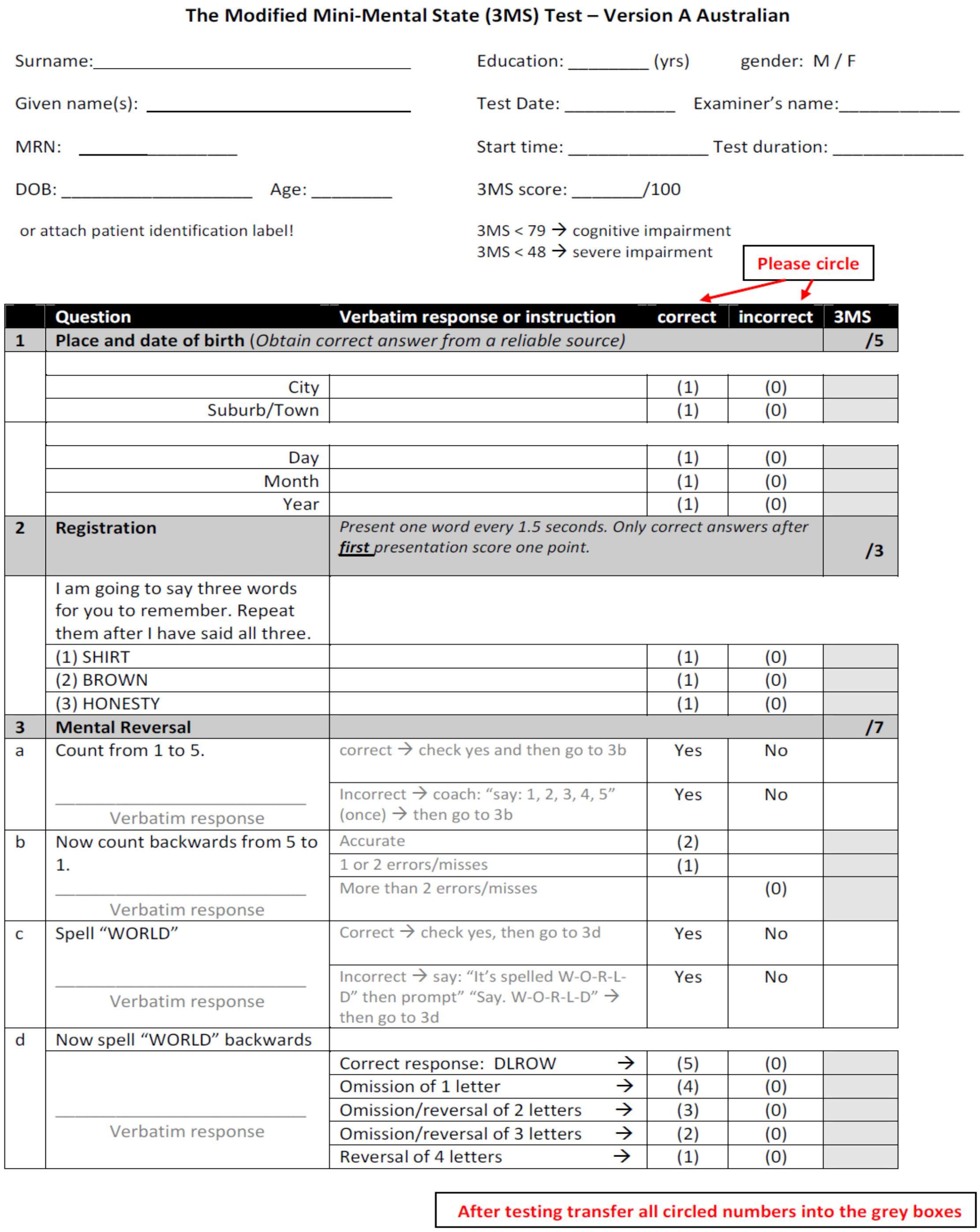
Number of comorbidities___________

Education level 1) some high school, 2) high school diploma, 3) some college, 4) college graduate, 5) graduate school, 6) other ____________

Marital status: 1) married, 2) single, 3) divorced, 4) widowed, 5) other __________

Occupation___________________

Appendix I. Mini-Mental State Test



The Modified Mini-Mental State (3MS) Test – Version A Australian

Surname:__________________________________

Given name(s): ___________________________

MRN: __________________

DOB: ____________________ Age: ________

or attach patient identification label!

Education: ________ (yrs) gender: M / F

Test Date: ____________ Examiner's name:____________

Start time: _______________ Test duration: _____________

3MS score: _______/100

3MS < 79 → cognitive impairment
3MS < 48 → severe impairment

Please circle

	Question	**Verbatim response or instruction**	**correct**	**incorrect**	**3MS**
1	**Place and date of birth** (*Obtain correct answer from a reliable source*)				**/5**
	City		(1)	(0)	
	Suburb/Town		(1)	(0)	
	Day		(1)	(0)	
	Month		(1)	(0)	
	Year		(1)	(0)	
2	**Registration**	*Present one word every 1.5 seconds. Only correct answers after **first** presentation score one point.*			**/3**
	I am going to say three words for you to remember. Repeat them after I have said all three.				
	(1) SHIRT		(1)	(0)	
	(2) BROWN		(1)	(0)	
	(3) HONESTY		(1)	(0)	
3	**Mental Reversal**				**/7**
a	Count from 1 to 5. ____________________ Verbatim response	correct → check yes and then go to 3b	Yes	No	
		Incorrect → coach: "say: 1, 2, 3, 4, 5" (once) → then go to 3b	Yes	No	
b	Now count backwards from 5 to 1. ____________________ Verbatim response	Accurate	(2)		
		1 or 2 errors/misses	(1)		
		More than 2 errors/misses		(0)	
c	Spell "WORLD" ____________________ Verbatim response	Correct → check yes, then go to 3d	Yes	No	
		Incorrect → say: "It's spelled W-O-R-L-D" then prompt" "Say. W-O-R-L-D" → then go to 3d	Yes	No	
d	Now spell "WORLD" backwards				
	____________________ Verbatim response	Correct response: DLROW →	(5)	(0)	
		Omission of 1 letter →	(4)	(0)	
		Omission/reversal of 2 letters →	(3)	(0)	
		Omission/reversal of 3 letters →	(2)	(0)	
		Reversal of 4 letters →	(1)	(0)	

After testing transfer all circled numbers into the grey boxes

Appendix I. Mini-Mental State Test (Continued)

	Question	Verbatim response or instruction	correct	incorrect	3MS
4	First Recall	*If patient unable to spontaneously recall words give* ***category cue first*** *then →offer* ***multiple choices****. If still incorrect, score 0.*			/9
	What three words did I ask you to remember earlier?				
	SHIRT ______________________ Verbatim response	Spontaneously correct	(3)	(0)	
		After cue "something to wear"	(2)	(0)	
		After cue "Shoe, shirt, sock"	(1)	(0)	
		Still incorrect		(0)	
	BROWN ______________________ Verbatim response	Spontaneously correct	(3)	(0)	
		After cue "A colour"	(2)	(0)	
		After cue "blue, black, brown"	(1)	(0)	
		Still incorrect		(0)	
	HONESTY ______________________ Verbatim response	Spontaneously correct	(3)	(0)	
		After cue "a good personal quality"	(2)	(0)	
		After cue "Honesty, charity, modesty"	(1)	(0)	
		Still incorrect		(0)	
5	**Temporal Orientation**				**/15**
	What is today's date?				
	Year ______________________ Verbatim response	Accurate	(8)		
		Missed by 1 year	(4)		
		Missed by 2-5 years	(2)		
		Missed by >5 years		(0)	
	Month ______________________ Verbatim response	Accurate or within 5 days	(2)		
		Missed by 6 days to 1 month	(1)		
		Missed by > 1 month		(0)	
	Date (of the month) ______________________ Verbatim response	Accurate	(3)		
		Missed 1-2 days	(2)		
		Missed 3-5 days	(1)		
		Missed > 5 days		(0)	
	Day (of the week): must be exact		(1)	(0)	
	Season (within 30 days)		(1)	(0)	
6	**Spatial Orientation**				**/5**
	What state are we in?		(2)	(0)	
	Which city are we in?		(1)	(0)	
	What suburb are we in?		(1)	(0)	
	Are we in a shop, a hospital (/medical clinic), or a home? ______________________ Verbatim response	*Always present the correct choice in the middle, if correct answer is not among the choices use it to replace the middle choice*	(1)	(0)	
7	**Naming**				**/7**
	What is this?				
	Pencil		(1)	(0)	
	Watch		(1)	(0)	
	What do you call this part of the face/body/hand?				
	Forehead		(1)	(0)	
	Chin		(1)	(0)	
	Shoulder		(1)	(0)	
	Elbow		(1)	(0)	
	Knuckle		(1)	(0)	

After testing transfer all circled numbers into the grey boxes

Appendix I. Mini-Mental State Test (Continued)

	Question	Verbatim response or instruction	Correct	Incorrect	3MS
8	**Four-legged animals**				**/10**
	What animals have four legs? Tell me as many as you can.				
	1		(1)	(0)	
	2		(1)	(0)	
	3		(1)	(0)	
	4		(1)	(0)	
	5		(1)	(0)	
	6		(1)	(0)	
	7		(1)	(0)	
	8		(1)	(0)	
	9		(1)	(0)	
	10		(1)	(0)	
9	**Similarities**	*To introduce this item say "An apple and a banana are **alike** in that they are **both** fruit." Then go to the actual task. Only coach with the first sub-item if necessary.*			**/6**
	In what way are .... and ... alike?				
	Arm – Leg	Body parts; limbs; extremities	(2)		
	______________________	Other correct answer	(1)		
	Verbatim response	Incorrect or tells difference, DK		(0)	
	Laughing – Crying	Feelings, emotions	(2)		
	______________________	Other correct answer	(1)		
	Verbatim response	Incorrect; tells difference; DK		(0)	
	Eating – Sleeping	Essential for life	(2)		
	______________________	Other correct answer	(1)		
	Verbatim response	Incorrect; tells difference; DK		(0)	
10	**Repetition**	***Tell the subject: "Repeat exactly what I say..."***			**/5**
	"He would like to go home"	Correct	(2)		
		One or 2 missed or wrong words	(1)		
		> 2 missed or wrong words		(0)	
	Now repeat "No ifs, ands, or buts"				
	No ifs	*Give no credit if "s" is missed;*	(1)	(0)	
	ands	*Give no credit if "s" is missed;*	(1)	(0)	
	or buts	*Give no credit if "s" is missed;*	(1)	(0)	
11	**Read and Obey**		**Correct**	**Incorrect**	**/3**
	"CLOSE YOUR EYES"				
		Obeys without prompting	(3)		
		Obeys after prompting	(2)		
		Reads only	(1)		
		Neither reads nor obeys		(0)	
12	**Writing** → use attached sheet	*OK to dictate word by word if necessary; score 1 point for each word. For each word score (0), if there is a spelling error or incorrect mixed capitalisation. No penalty for printing all letters in upper case.*			**/5**
	I would like to have a sample of your handwriting. Write "He would like to go home"				
	(He/I) would		(1)	(0)	
	like		(1)	(0)	
	to		(1)	(0)	
	go		(1)	(0)	
	home		(1)	(0)	

Appendix I. Mini-Mental State Test (Continued)

	Question	***Verbatim response or instruction***	***Correct***	***Incorrect***	***3MS***
13	**Copying 2 pentagons**	**Allow up to 1 minute for response. If patient wants to try again do not re-start timing. Score for the better product completed in 1 minute.**			**/10**
	Can you copy this?	***MMSE only**: correct (1) or incorrect (2) →*			
	Pentagon 1	5 approx equal sides	(4)		
		5 but un-equal (>2:1) sides	(3)		
		Other enclosed figure	(2)		
		2 or more lines	(1)		
		Less than 2 lines		(0)	
	Pentagon 2	5 approx equal sides	(4)		
		5 but un-equal (>2:1) sides	(3)		
		Other enclosed figure	(2)		
		2 or more lines	(1)		
		Less than 2 lines		(0)	
	Intersection	4-cornered enclosure	(2)		
		Not 4-cornered enclosure	(1)		
		No enclosure		(0)	
14	**Three-stage command**	**Use the patients non-dominant hand for this task**			**/3**
	Take this paper with your L/R hand,		(1)	(0)	
	Fold it in half, and		(1)	(0)	
	Hand it back to me		(1)	(0)	
15	**Second Recall**	***If patient unable to spontaneously recall words give category cue first then offer multiple choices. If still incorrect, score 0.***			**/9**
	What three words did I ask you to remember earlier?				
	SHIRT	Spontaneously correct	(3)	(0)	
		After cue "something to wear"	(2)	(0)	
	______________________________	After cue "Shoe, shirt, sock"	(1)	(0)	
	Verbatim response	Still incorrect		(0)	
	BROWN	Spontaneously correct	(3)	(0)	
		After cue "A colour"	(2)	(0)	
	______________________________	After cue "blue, black, brown "	(1)	(0)	
	Verbatim response	Still incorrect		(0)	
	HONESTY	Spontaneously correct	(3)	(0)	
		After cue "a good personal quality"	(2)	(0)	
	______________________________	After cue "honesty, charity, modesty"	(1)	(0)	
	Verbatim response	Still incorrect		(0)	

After testing transfer all circled numbers into the grey

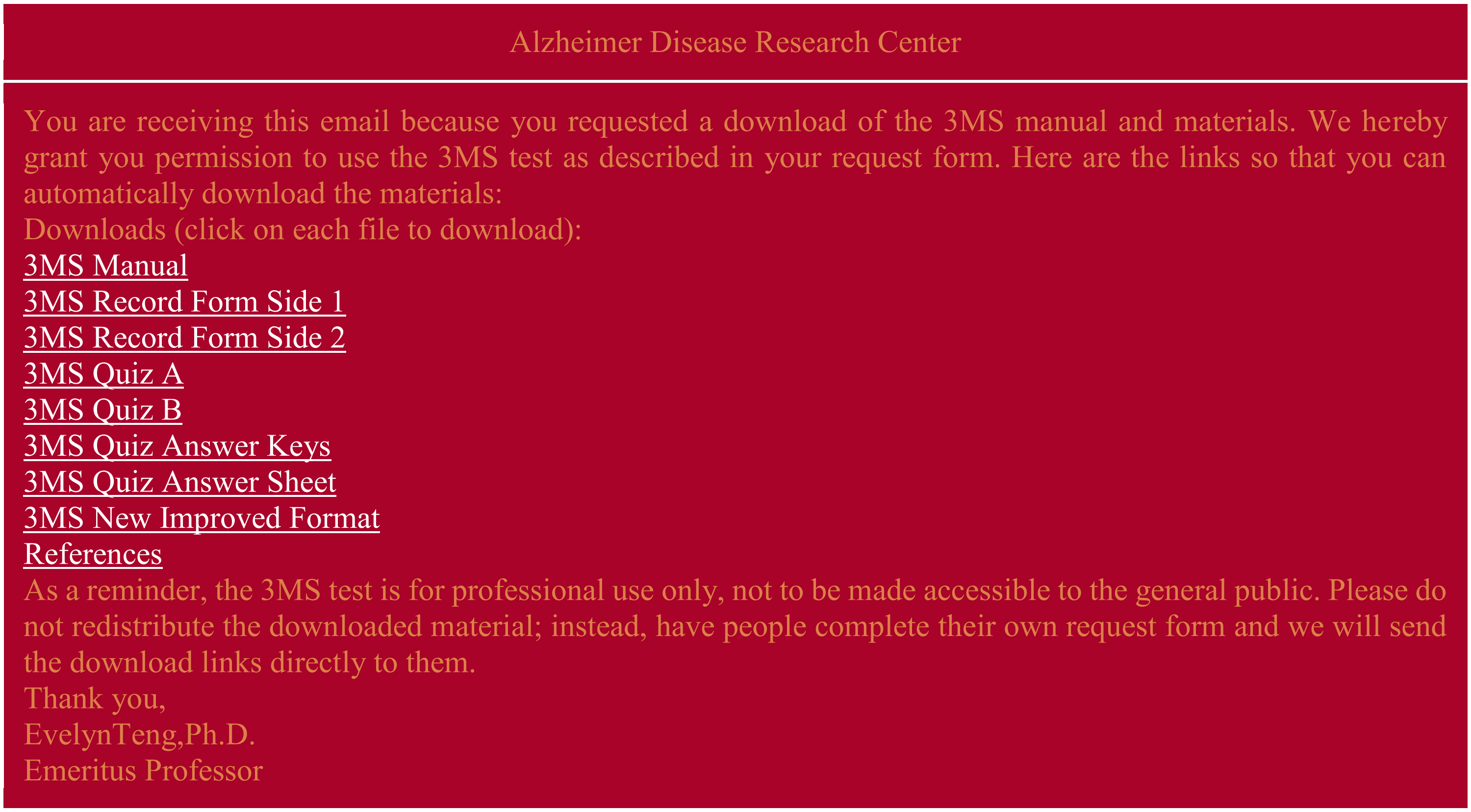
Cut-off scores:

3MS total score ranges from 0 – 100, with higher numbers indicating less impairment

3MS total score < 79: cognitive impairment

3MS total score < 48: severe impairment

Appendix J. Permission to Use 3MS Manual and Materials



Alzheimer Disease Research Center

You are receiving this email because you requested a download of the 3MS manual and materials. We hereby grant you permission to use the 3MS test as described in your request form. Here are the links so that you can automatically download the materials:

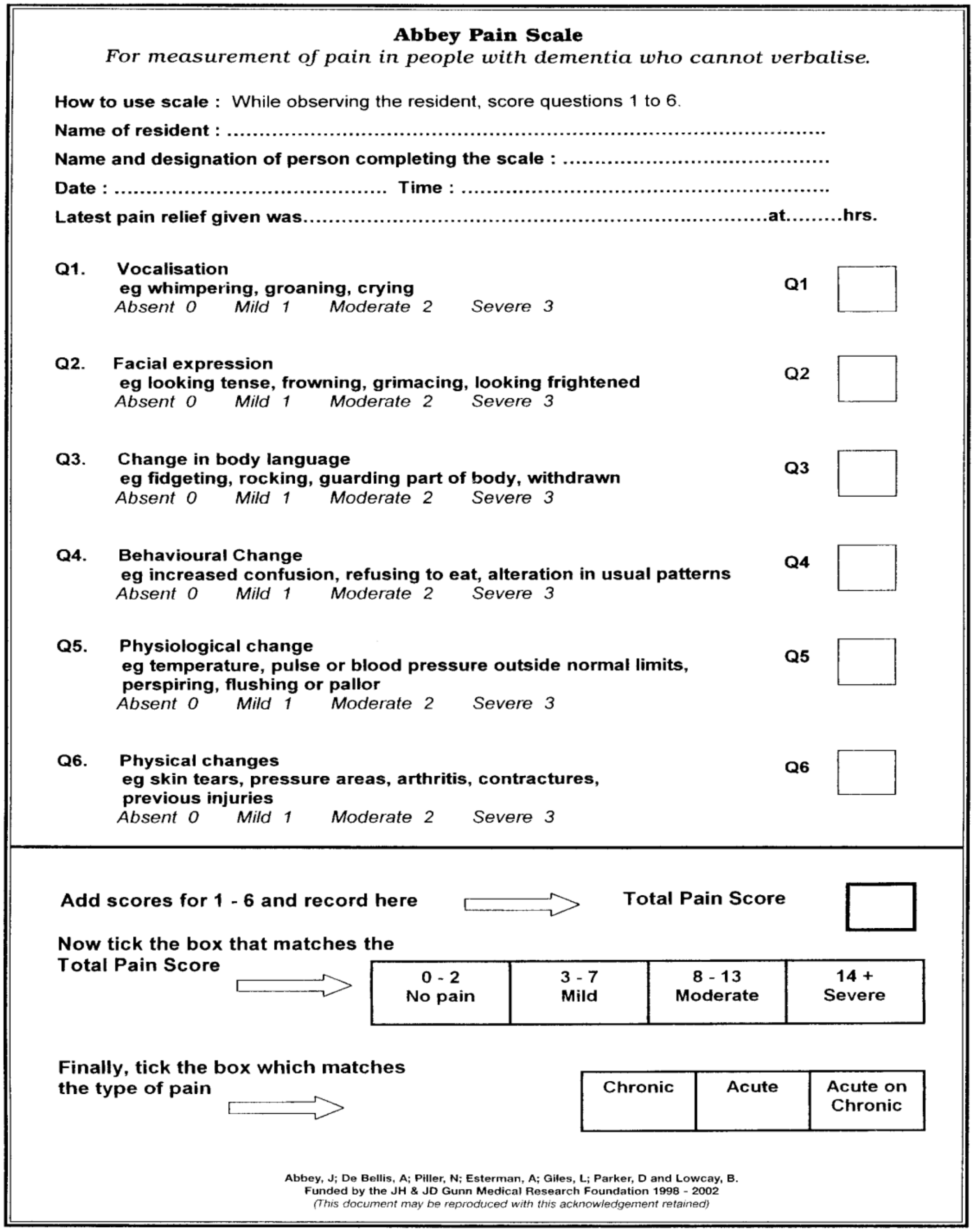
Downloads (click on each file to download):

3MS Manual
3MS Record Form Side 1
3MS Record Form Side 2
3MS Quiz A
3MS Quiz B
3MS Quiz Answer Keys
3MS Quiz Answer Sheet
3MS New Improved Format
References

As a reminder, the 3MS test is for professional use only, not to be made accessible to the general public. Please do not redistribute the downloaded material; instead, have people complete their own request form and we will send the download links directly to them.

Thank you,
EvelynTeng,Ph.D.
Emeritus Professor

Appendix K. Abbey Pain Scale



Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale : While observing the resident, score questions 1 to 6.

Name of resident : ....

Name and designation of person completing the scale : ....

Date : .... **Time :** ....

Latest pain relief given was..**at**.........**hrs.**

Q1. Vocalisation
eg whimpering, groaning, crying
Absent 0 Mild 1 Moderate 2 Severe 3

Q1 ☐

Q2. Facial expression
eg looking tense, frowning, grimacing, looking frightened
Absent 0 Mild 1 Moderate 2 Severe 3

Q2 ☐

Q3. Change in body language
eg fidgeting, rocking, guarding part of body, withdrawn
Absent 0 Mild 1 Moderate 2 Severe 3

Q3 ☐

Q4. Behavioural Change
eg increased confusion, refusing to eat, alteration in usual patterns
Absent 0 Mild 1 Moderate 2 Severe 3

Q4 ☐

Q5. Physiological change
eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor
Absent 0 Mild 1 Moderate 2 Severe 3

Q5 ☐

Q6. Physical changes
eg skin tears, pressure areas, arthritis, contractures, previous injuries
Absent 0 Mild 1 Moderate 2 Severe 3

Q6 ☐

Add scores for 1 - 6 and record here ⇨ **Total Pain Score** ☐

Now tick the box that matches the Total Pain Score ⇨

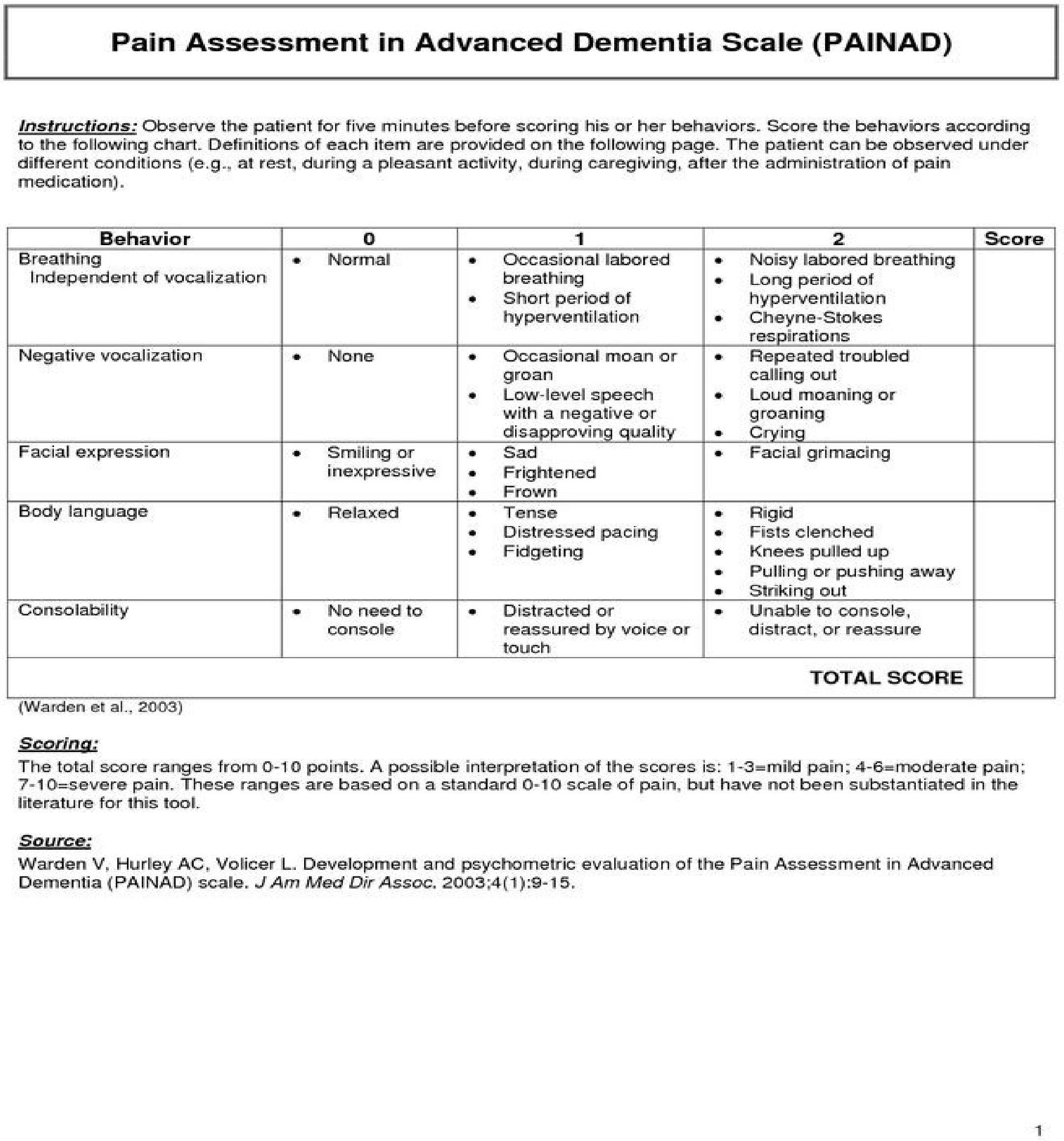
0 - 2 **No pain**	**3 - 7** **Mild**	**8 - 13** **Moderate**	**14 +** **Severe**

Finally, tick the box which matches the type of pain ⇨

Chronic	**Acute**	**Acute on Chronic**

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 - 2002
(This document may be reproduced with this acknowledgement retained)

Appendix L. Pain Assessment in Advanced Dementia Scale



Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	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 SCORE	

(Warden et al., 2003)

Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.

Appendix M. Cohen-Mansfield Agitation Inventory

Cohen-Mansfield Agitation Inventory (CMAI)[1] – Short

Instructions: For each of the behaviors below, check the rating that indicates the average frequency of occurrence ***during this shift***.

Physical / Aggressive	Never 1	Once 2	Twice 3	Three to four 4	Five times 5	Several times /shift 6	Several times an hour 7
1. Hitting (including self)	**1**	**2**	**3**	**4**	**5**	**6**	**7**
2. Kicking	**1**	**2**	**3**	**4**	**5**	**6**	**7**
3. Grabbing onto people	**1**	**2**	**3**	**4**	**5**	**6**	**7**
4. Pushing	**1**	**2**	**3**	**4**	**5**	**6**	**7**
5. Throwing things	**1**	**2**	**3**	**4**	**5**	**6**	**7**
6. Biting	**1**	**2**	**3**	**4**	**5**	**6**	**7**
7. Scratching	**1**	**2**	**3**	**4**	**5**	**6**	**7**
8. Spitting	**1**	**2**	**3**	**4**	**5**	**6**	**7**
9. Hurting self or others	**1**	**2**	**3**	**4**	**5**	**6**	**7**
10. Tearing things or destroying property	**1**	**2**	**3**	**4**	**5**	**6**	**7**
11. Making physical sexual advances	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Appendix M. Cohen-Mansfield Agitation Inventory (Continued)

Physical / Non-Aggressive

12. Pace, aimless wandering	**1**	**2**	**3**	**4**	**5**	**6**	**7**
13. Inappropriate dress or disrobing	**1**	**2**	**3**	**4**	**5**	**6**	**7**
14. Trying to get to a different place	**1**	**2**	**3**	**4**	**5**	**6**	**7**
15. Intentional falling	**1**	**2**	**3**	**4**	**5**	**6**	**7**
16. Eating / drinking inappropriate substance	**1**	**2**	**3**	**4**	**5**	**6**	**7**
17. Handling things inappropriately	**1**	**2**	**3**	**4**	**5**	**6**	**7**
18. Hiding things	**1**	**2**	**3**	**4**	**5**	**6**	**7**
19. Hoarding things	**1**	**2**	**3**	**4**	**5**	**6**	**7**
20. Performing repetitive mannerisms	**1**	**2**	**3**	**4**	**5**	**6**	**7**
21. General restlessness	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Verbal / Aggressive

22. Screaming	**1**	**2**	**3**	**4**	**5**	**6**	**7**
23. Making verbal sexual advances	**1**	**2**	**3**	**4**	**5**	**6**	**7**
24. Cursing or verbal aggression	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Verbal / Non-aggressive

25. Repetitive sentences or questions	**1**	**2**	**3**	**4**	**5**	**6**	**7**
26. Strange noises (weird laughter or crying)	**1**	**2**	**3**	**4**	**5**	**6**	**7**
27. Complaining	**1**	**2**	**3**	**4**	**5**	**6**	**7**
28. Negativism	**1**	**2**	**3**	**4**	**5**	**6**	**7**
29. Constant unwarranted request for attention or help	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Appendix N. Permission to Use CMAI Alterations

June 22, 2017 9:33 a.m.

Dear Suzanne Parkman,

You have my permission to use the CMAI in the manner you described as long as 1) you instruct users to consult the manual in order to use it correctly, 2) you keep my copyright sign (c) Cohen-Mansfield on all forms, 3) you do not sell the questionnaires or their derivatives to anyone, and 4) you provide proper attribution for the assessment.

Attached please find the manual with the assessment as well as a list of publications by topic. Please note multiple papers on the assessment of pain in persons with dementia and, in particular, the paper

Cohen-Mansfield, J. & Lipson, S. (2007). The utility of pain assessment for analgesic use in persons with dementia. Pain, 134(1-2), 16-23.

I wish you success with your work,

Jiska Cohen-Mansfield, PhD
Jiska Cohen-Mansfield, PhD
Professor, Department of Health Promotion
School of Public Health, Sackler Faculty of Medicine
Director, Minerva Center for the Interdisciplinary Study of End of Life
Igor Orenstein Chair for the Study of Geriatrics
Tel-Aviv University

10/14/2017 12:47 PM
Jiska Cohen-Mansfield <jiska@post.tau.ac.il
Dear Suzanne Parkman,
You are welcome to adapt the assessment to the needs of your study. However, the same conditions apply to the adapted assessment.
Good luck on your study,
Jiska Cohen-Mansfield, PhD

Appendix O. Medication Quantification Scale

Medication Quantification Scale: Version III (MQS III)

MQS = (Topical Transdermal X1.1) + (SSRI X 1.7) +(Other Antidepressant X 1.9) + (Anticonvulsant GABA X 1.9) + (Antihypertensive X 2) + (Other Antianxiety X 2.1) + (Non-dependency Producing Muscle Relaxant X 2.2) +(Acetaminophen X 2.2) + (COX2 Inhibitor X 2.3) + (Tricyclic/tetracyclic Antidepressants X 2.3) + (Miscellaneous Analgesic X 2.3) + (Anticonvulsants-Sodium Channel Blocker X 2.8) + (Sedative Hypnotic X 3.1) + (Opioid Schedule II X 3.4) + (NSAIDS X 3.4) + (Antipsychotics X 3.6) + (Opioid Schedule IV X 3.7) + (Opioid Schedule III X 3.7) + (Dependency Producing Muscle Relaxant X 3.8) + (Benzodiazepines X 3.9) + (Steroids X 4.4) + (Barbiturates X 4.5).

Gallizzi, M., Gagnon, C., Harden, R.N., Stanos, S., & Khan, A. (2008). Medication quantification scale version III: Internal validation of detriment weights using a chronic pain population. *Pain Practice, 8*(1), 1-4.

Dear Dr. Gallizzi,

My name is Suzanne Parkman and I am a PhD student at the University of Texas at Tyler. My dissertation topic is Pain, Need-Driven Behaviors, and Nurses perceptions: An Embedded Mixed Methods Study. I would like to use the Medication Quantification Scale (MQS) III in my dissertation to quantify medication regimes. I am, therefore, requesting permission to use your MQS scale (with appropriate reference to the authors, of course). It is my hope that my dissertation will result in a publication and add to the scientific evidence supporting your scale.

Thank you for your time in considering my request. Please let me know if you have any questions, suggestions, or concerns.

Best regards,

Suzanne Parkman, PhD(c), MSN, RN

11/3/17 Friday 1:56 p.m. <michaelgallizzi@gmail.com>

I have no issue.

Michael Gallizzi, MD, MS
Minimally Invasive Spine Surgery
Porter Adventist Hospital
2535 S. Downing Street
Suite 180
Denver, CO 80210

Appendix P. Education Protocol

Education Protocol

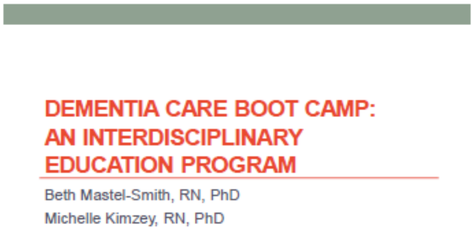
Workshop # 1 (Nurses and Nurses' Aides)

I. Need-driven Behavior Model

A. Components of the model and what they mean (Background Factors, Proximal Factors, Need-driven Behaviors).

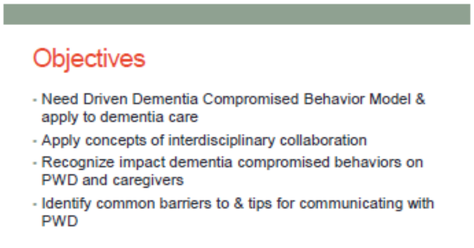
B. Difficulty in differentiating behaviors between pain and other unmet needs. Review need checklist

C. Verification of needs: History of pain or other behaviors? What does surrogate or nurse's aide report? Are residents basic needs met (hunger, thirst, toileting, loneliness, seeking attention, etc.)? Can discomfort be alleviated by a simple cause such as re-direction? If evidence shows that behaviors are likely caused by pain, nurses are required to assess and treat to relieve pain.



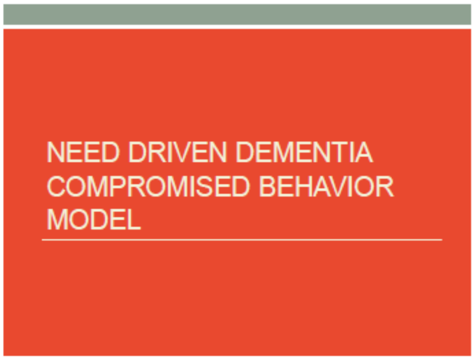
DEMENTIA CARE BOOT CAMP:
AN INTERDISCIPLINARY
EDUCATION PROGRAM

Beth Mastel-Smith, RN, PhD
Michelle Kimzey, RN, PhD



Objectives

- Need Driven Dementia Compromised Behavior Model & apply to dementia care
- Apply concepts of interdisciplinary collaboration
- Recognize impact dementia compromised behaviors on PWD and caregivers
- Identify common barriers to & tips for communicating with PWD



NEED DRIVEN DEMENTIA
COMPROMISED BEHAVIOR
MODEL

Need Driven Dementia Compromised Behavior Model

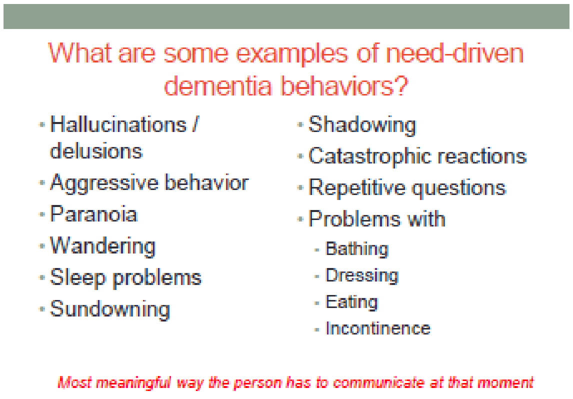
Background factors
Neurological status:
e.g. motor and cognitive abilities, language, sensory skills, imaging
Health status, demographic variables:
e.g. preexisting illnesses, gender, ethnicity, marital status, education, profession
Premorbid characteristics:
e.g. personality, reaction to stress, beliefs and thoughts

Proximal factors
Physiological needs:
e.g. hunger and thirst, excretion, pain, discomfort
Psychosocial needs:
e.g. affect, emotions (anxiety, boredom)
Physical environment:
e.g. design of environment, light, noise and warmth, daily routine
Social environment:
e.g. staffing and staff stability, atmosphere

Need-driven behavior (NDB)

Our job: assess & fulfill the need

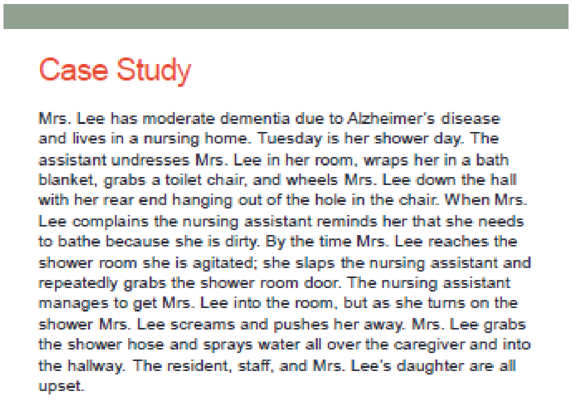
Appendix P. Education Protocol (Continued)



What are some examples of need-driven dementia behaviors?

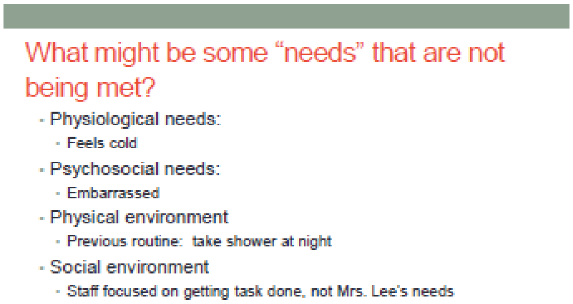
- Hallucinations / delusions
- Aggressive behavior
- Paranoia
- Wandering
- Sleep problems
- Sundowning
- Shadowing
- Catastrophic reactions
- Repetitive questions
- Problems with
  - Bathing
  - Dressing
  - Eating
  - Incontinence

Most meaningful way the person has to communicate at that moment



Case Study

Mrs. Lee has moderate dementia due to Alzheimer's disease and lives in a nursing home. Tuesday is her shower day. The assistant undresses Mrs. Lee in her room, wraps her in a bath blanket, grabs a toilet chair, and wheels Mrs. Lee down the hall with her rear end hanging out of the hole in the chair. When Mrs. Lee complains the nursing assistant reminds her that she needs to bathe because she is dirty. By the time Mrs. Lee reaches the shower room she is agitated; she slaps the nursing assistant and repeatedly grabs the shower room door. The nursing assistant manages to get Mrs. Lee into the room, but as she turns on the shower Mrs. Lee screams and pushes her away. Mrs. Lee grabs the shower hose and sprays water all over the caregiver and into the hallway. The resident, staff, and Mrs. Lee's daughter are all upset.



What might be some "needs" that are not being met?

- Physiological needs:
  - Feels cold
- Psychosocial needs:
  - Embarrassed
- Physical environment
  - Previous routine: take shower at night
- Social environment
  - Staff focused on getting task done, not Mrs. Lee's needs

Mastel-Smith, B. & Kimzey, M. (2017, October). Dementia care boot camp: an interdisciplinary education program for health professional students. In REACH 2017: People, Purpose, Passion. Symposium conducted at the meeting of East Texas Council of Governments, Longview, TX.

Workshop # 2 (Nurses only)

II. Review PAINAD

The purpose of this study is to see if use of observational pain scales such as the PAINAD and APS will help to correctly assess pain in persons with dementia and reduce problematic behavior in persons with dementia. Everyone will get a copy of the pain assessment tool and we will go over how to use the tool and I will provide a detailed description of the tool. We will start with the PAINAD tool:

a. Instructions: Rate each category from 0-2 depending on the frequency of the behavior. 0= behavior absent; 1= Occasional; 2= More frequent, occurring regularly. As you total the number for each category it reflects pain behaviors on a scale form 0-10 (0= no pain, 1-3= mild pain, 4-6 moderate pain, 7-10= severe pain). The following definitions are detailed descriptions that we will review:

A. 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, or 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).

B. 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 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.

C. Facial expression

1. Smiling is characterized by upturned corners of the 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.

D. 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 and 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.

E. Consolability

1. No need to console is characterized by a sense of well-being. 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.

Warden, V., Hurley, A.C., Volicer, L. (2003). Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *Journal of American Medical Directors Association, 4*, 9-15. DOI: dx.doi.org/10.1097/01.JAM.0000043422.31640.F7

III. Abbey Pain Scale (APS)

A. We will review each category of the APS instrument and you will rate each category from 0-3 depending on the frequency of the behavior. 0= behavior absent; 1= mild; 2= Moderate; 3= Severe. As you total the number for each category it reflects pain behaviors on a scale from 0-18 (0-2= no pain, 3-7= mild pain, 8-13= moderate pain, 14-18= severe pain). You must then specify whether pain is acute, chronic, or acute on chronic. The following definitions are detailed descriptions that we will review:

B. While observing the patients, score questions 1 to 6.

1. Vocalisation such as whimpering, groaning, crying.
2. Facial expression such as looking tense, frowning, grimacing, looking frightened.
3. Change in body language such as fidgeting, rocking, guarding part of body, withdrawn.
4. Behavioural change such as increased confusion, refusing to eat, alteration in usual patterns.
5. Physiological change such as temperature, pulse or blood pressure outside normal limits.

6. Physical changes such as skin tears, pressure areas, arthritis, contractures, and previous injuries.

Appendix P. Education Protocol (Continued)

C. Scoring

> Add the scores for 1 - 6 for a total pain score and administer medication ordered by provider according to pain severity.

Abbey, J.A., Piller, N., DeBellis, A, Esterman, A., Parker, D., Giles, L. & Lowcay, B. (2004). The Abbey Pain Scale. A 1-minute numerical indicator for people with late-stage dementia. *International Journal of Palliative Nursing, 10*(1), 6-13. Doi: 10.12968/ijpn.2004.10.1.12013

IV. Clinical Video Vignettes

PI will do a short didactic about the PAINAD. Nurses will be shown a video of a PWD in pain. Nurses will be asked to complete the PAINAD in pairs or a small group so they have the opportunity to discuss and share answers and come up with a resolution to what is the most appropriate score. After doing individual and team work, a discussion will take place as to how they scored the items and why. Another video will be shown and the same process used with the APS.
If nurses are not in agreement with each other, the process will be repeated until consensus is consistently achieved. Individual and team hard copies will be in different colors and copies will be marked “1” for first attempt, “2” for second attempt, and so forth. Nurses will not be given the video title or description and videos will be in random order.
https://www.youtube.com/watch?v=KPtPyZWes4o

0 no pain

www.youtube.com

This is a series of 7 videos that can be used for improving pain assessment skills for persons with dementia. These videos feature a professional actress dem...

Appendix P. Education Protocol (Continued)

https://www.youtube.com/watch?v=7y798wWcu9w

1 mild pain

www.youtube.com

This is a series of 7 videos that can be used for improving pain assessment skills for persons with dementia. These videos feature a professional actress dem...

https://www.youtube.com/watch?v=h0YuIIbPUFw&t=26s

2 moderate pain - YouTube

www.youtube.com

This is a series of 7 videos that can be used for improving pain assessment skills for persons with dementia. These videos feature a professional actress ...

https://www.youtube.com/watch?v=vTOLh9pNBSQ

3 quite bad pain

www.youtube.com

This is a series of 7 videos that can be used for improving pain assessment skills for persons with dementia. These videos feature a professional actress dem

https://www.youtube.com/watch?v=yEn27Ue9bPE

4 very bad pain

www.youtube.com

This is a series of 7 videos that can be used for improving pain assessment skills for persons with dementia. These videos feature a professional actress dem...

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V. Cohen-Mansfield Agitation Inventory (CMAI)

A. Instructions: We ask that you document certain specific behaviors sometimes seen in older persons. Some are verbal, some are physical. Some are quiet behaviors and others are disruptive. We do not expect that all these behaviors will apply to the subject(s). As the behavior occurs (according to the descriptions below) please check off on the form attached to the medication administration record (MAR) The following definitions are detailed descriptions that we will review:

B. **Detailed Descriptions of Behaviors**

1. **Pacing and aimless wandering** - constantly walking back and forth, including wandering when done in a wheelchair. Does not include normal purposeful walking.
2. **Inappropriate dressing or disrobing** - putting on too many clothes, putting on clothing in a strange manner (e.g., putting pants on head), taking off clothing in public or when it is inappropriate (if only genitals are exposed, rated under sexual advances). Does not include a person’s ability to dress/undress as in ADL’s.
3. **Spitting (including while feeding)** - spitting onto floor, other people, etc.; does not include uncontrollable salivating, or spitting into tissue, toilet, or onto ground outside

4. **Cursing or verbal aggression** - only when using words; swearing, use of obscenity, profanity, unkind speech or criticism, verbal anger, verbal combativeness. Does not include unintelligible noises (rated under screaming or strange noises).
5. **Constant unwarranted request for attention or help** - verbal or nonverbal unreasonable nagging, pleading, demanding (indicate also for oriented people).
6. **Repetitive sentences or questions** - repeating the same sentence or question one right after the other, addressed to a particular person or to no one (complaining, even if oriented and possibly warranted is rated under the complaining section).
7. **Hitting (including self)** - physical abuse, striking others, pinching others, banging self/furniture.
8. **Kicking** - striking forcefully with feet at people or objects.
9. **Grabbing onto people or things inappropriately** - snatching, seizing roughly, taking firmly, or yanking.
10. **Pushing** - forcefully thrusting, shoving, moving putting pressure against another.
11. **Throwing things** - hurling objects, violently tossing objects up in air, tipping off surfaces, flinging, dumping food.
12. **Making strange noises** - including crying, weeping, moaning, weird laughter, grinding teeth, does not include intelligible words.
13. **Screaming** - shouting, piercing howl, making loud shrills.
14. **Biting** - chomping, gnashing, gnawing, either other people or self.
15. **Scratching** - clawing, scraping with fingernails either other people or self.
16. **Trying to get to a different place** - inappropriately entering or leaving a place, such as trying to get out of the building, off the property, sneaking out of room, trying to get into other resident's room or close
17. **Intentional falling** - purposefully falling onto floor, include from wheelchair, chair, or bed.
18. **Complaining** - whining, complaining about self, somatic complaints, personal gripes or complaining about physical environment or other people.
19. **Negativism** - bad attitude, doesn't like anything, nothing is right, does not include overt verbal anger, such as what can be rated as verbal aggression.
20. **Eating or drinking inappropriate substances** - putting into mouth and trying to swallow items that are inappropriate.
21. **Hurting self or other** - burning self or other, cutting self or other, touching self or other with harmful objects, etc.
22. **Handling things inappropriately**. - picking up things that don't belong to them, rummaging through drawers, moving furniture, playing with food, fecal smearing.
23. **Hiding things** - putting objects out of sight, under or behind something.
24. **Hoarding things** - putting many or inappropriate objects in purse, pockets, or drawers, keeping too many of an item. (Does not include regular collection such as collecting dolls).

25. **Tearing things or destroying property** - shredding, ripping, breaking, stomping on something.
26. **Performing repetitious mannerisms** - stereotypic movement, such as patting, tapping, rocking self, fiddling with something, twiddling with something, rubbing self or object, sucking fingers, taking shoes on and off, picking at self, clothing, or objects, picking imaginary things out of air or off floor, manipulation of nearby objects in a repetitious manner, does not include repetitious words or vocalizations.
27. **Making verbal sexual advances** - sexual propositions, sexual innuendo, or "dirty" talk.
28. **Making physical sexual advances or exposing genitals** - touching a person in an inappropriate sexual way, rubbing genital area, inappropriate masturbation (when not alone in own room or bathroom), unwanted fondling or kissing.
29. **General restlessness** - fidgeting, always moving around in seat, getting up and sitting down inability to sit still.

Cohen-Mansfield, J. (1997, May). Conceptualization of agitation: Results based on the Cohen- Mansfield agitation inventory and the agitation behaviour mapping instrument. *International Psychogeriactrics, 8,* 309-315.

Cohen-Mansfield, J. (1986). Agitated behaviors in the elderly: II. Preliminary results in the cognitively deteriorated. Journal of the American Geriatrics Society, 34(10), 722-727.

Appendix Q. Additional Data Related to Causes and Responses

Other Possible Causes & Responses to NDBs Subject #________________

Behavior	**Need**	**Date / Time**	**Action**	**Need Met? Y / N**	**Initials**
	☐ Medication effect / interaction		☐ Reviewed med list ☐ Consulted physician		
	☐ Help with hearing / vision		☐ Put glasses / hearing aid on		
	☐ Acute illness (UTI, for example)		☐ Dipped urine ☐ Focused assessment (i.e. GU) ☐ Reviewed lab results ☐ Consulted physician		
	☐ Constipated		☐ Focused assessment (GI) ☐ Bowel protocol ☐ Consulted physician		
	☐ Feeling tired		☐ Create environment of rest/nap		
	☐ Difficulty communicating		☐ Redirection/re-stating		
	☐ Emotionally upset (sad, frustrated, angry, lonely, anxious, afraid, lost)		☐ Provide comfort ☐ Redirect with props (i.e. baby doll)		
	☐ Change in routine		☐ Re-establish normal routine		
	☐ Help with a task that is too difficult		☐ Assist person or enlist help for person		
	☐ Thirsty		☐ Offer fluids		
	☐ Hungry		☐ Offer snack/meal		
	☐ Need to use bathroom		☐ Assist to Toilet		
	☐ Environment (too loud, confusing, bright, dark, hot, cold)		☐ Environmental issue corrected by____________-_______________		
	☐ Bored		☐ Redirect-activities/TV/magazines		
	☐ Other:		☐_________________		

Appendix R. Demographic for Nurses

Demographic Information Form (Nurses)

Please provide a response for each of the following questions:

What is your Age (in years)? _________

Are you? 1) Male____ 2) Female ____

What is your race? 1) Caucasian___ 2) Hispanic___ 3) African-American___ 4) Other____

How long have you been a nurse? Years______ Months _______

What degree in nursing do you hold? ADN____ BSN ____ MSN ____ LPN ____

How long have you been a nurse working with dementia patients? Years_____ Months _______

Have you had any supplementary training in dementia? Yes____ No____

Do you hold any extra certifications or advanced degrees? Yes____ No____

Appendix S. Interview Guide

Interview Guide

1. Tell me about your experiences taking care of PWD particularly as it applies to pain management.
2. Please share your experiences assessing pain in residents with dementia.
3. What facilitates pain management for your residents with dementia?
4. What poses barriers to pain management for your residents with dementia?
5. What pain management approaches seem to work the best?
6. What was your experience with the PAINAD assessment tool?
7. What was your experience with the APS assessment tool?
8. In your clinical experience what is the most effective way to assess pain in PWD?

Biosketch

BIOGRAPHICAL SKETCH			
NAME **Suzanne Parkman**	POSITION TITLE **Assistant Professor**		
EDUCATION/TRAINING			

INSTITUTION AND LOCATION	DEGREE	MM/YY	FIELD OF STUDY
University of Texas at Tyler, Tyler, Texas	Ph.D.		Nursing
Texas Women's University, Houston, Texas	MSN	12/1993	Nursing Education
University of Southern Maine, Portland, Maine	BSN	05/1988	Nursing
Central Maine Medical Center-School of Nursing	ADN	05/1984	Nursing

A. Personal Statement

The purpose of this mixed method design study was undertaken and a hypothetical model tested to determine the utility of two OPSs in clinical practice. A qualitative element was included to incorporate the nurses' perceptions of pain interpretation with PWD. Further analysis revealed the utility of the OPSs and the impact on NDB and pain medication administration. In completing this dissertation, this study contributed to the extant knowledge on pain, need-driven behavior in dementia, and nurses' perceptions. Future research should be directed towards examining pain protocols that incorporate the use of OPSs for PWD. As the population grows older, the needs of many PWD will depend on knowledgeable and skilled nurses to provide quality care.

B. Positions and Honors

Positions and Employment

2015-Present	Saint Joseph's College of Maine
2010-2015	Staff Development Coordinator for LTC-City of Portland, DHHS
1996-2010	RN Tender, Hyperbaric Cozumel, Clinica San Miguel, Mexico
1994-1996	Clinical Nursing Instructor-Texas Woman's University
1994-1996	RN Infusion Specialist-Apria, Houston, TX
1990-1994	RN Infectious Diseases-Park Plaza Hospital, Houston, TX
1988-1990	Traveling Nurse Critical Care/Ventilator
1984-1988	RN-Pulmonary Care, Mercy Hospital, Portland, ME

Other Experiences and Professional Memberships

1988- Present	Online Councilor, Sigma Theta Tau, Kappa Zeta-at-Large Chapter
2016- Present	Member, Phi Kappa Phi
2014- Present	Member, National Gerontological Nursing Association
2016- Present	Member, Western Institute of Nursing Research