Factors that Influence Nurses' Pain Management Practices in Hospitalized Older Persons Living with Dementia

by

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Abstract

Aim: To assess factors influencing nurses' beliefs and knowledge when assessing and managing pain in hospitalized older persons living with dementia (PLWD). **Background:** Hospitalized PLWD often experience unrelieved pain. Pain is common in PLWD, and undermanaged pain accelerates changes in cognition, memory loss, and functional decline, underscoring the need for proper assessment and intervention. However, limited literature has explored nurses' pain management practices in PLWD and what research is available suggests that nurses often underrecognize, underreport, misdiagnose, and undermanage pain in PLWD. Most of this research was conducted in long-term care facilities, which has left gaps in research into how nurses assess and manage pain in hospitalized PLWD. Additionally, past research has failed to determine if nurses' age, gender, years of worked experience, beliefs, and knowledge influence pain management practices in this vulnerable population. Nurses are primarily responsible for pain assessment and management decisions. Nurses' personal feelings and professional experiences with pain may lead to inaccurate knowledge and beliefs based on negative stereotypes of aging and dementia. **Methods:** This dissertation consists of three related studies and sequential papers that were theoretically informed by the concept of ageism: (1) a scoping review to assess the extent of available literature related to nurses' pain management practices in hospitalized PLWD, (2) a quantitative cross-sectional survey study using a validated tool that measured nurses' knowledge and beliefs about pain in hospitalized PLWD, and (3) a qualitative study that examined nurses' knowledge, beliefs and experiences when assessing and managing pain in hospitalized PLWD. We designed the research conducted in Paper 2 and Paper 3 as a mixed method explanatory sequential study. **Results**: In Paper 1, our review findings revealed six articles indicating that hospital nurses experience many complex challenges managing pain in

PLWD. This paper described the extent of literature available, pain assessment and management practices, the challenges that hospital nurses encountered, and knowledge – practice gaps. For Paper 2, we conducted research with a quantitative study using a validated survey tool, Knowledge and Beliefs about Pain in Elderly Patients with Dementia (KBPED). Nurses working in two hospitals located in Southern California, one of which was designated as a Nurses Improving Care for Healthsystem Elders (NICHE) site were surveyed. Results were analyzed to compare the association of the nurses' age, gender, and years of experience on their general beliefs about pain, dementia, and aging; knowledge about pain management in PLWD; and beliefs about pain in older people. A multivariate analysis of variance did not support a statistically significant association. However, testing using an analysis of variance (ANOVA) revealed that male nurses of all ages and years of experience held less favorable beliefs about pain in older people. The third study for Paper 3, reported findings from a qualitative descriptive study of 12 nurses who worked in the NICHE designated hospital and participated in individual semi-structured interviews. The findings from the quantitative study informed construction of the interview guide for data collection. A content and thematic analysis resulted in two themes: nurses improvised pain assessment, and managed pain through trial and error. The nurses did not follow standardized pain assessment and management guidelines which led to various approaches when caring for PLWD. The nurses noted barriers and challenges based on communication with the patients and health care team, and perceived lack of organizational support for extra time and resources to care for PLWD. The results also indicated that knowledge deficits negatively influenced pain management strategies based partly on nurses' experiences, negative beliefs, and stereotypes about older people and PLWD. **Conclusions:** Nurses' knowledge, beliefs, and experience influenced pain assessment and management practices, potentially contributing to underrecognized, underreported, misdiagnosed, and undermanaged pain in hospitalized PLWD. These three studies imply that educational offerings thus far have not been sufficient for building adequate knowledge, or addressed negative stereotypes associated with hospitalized PLWD. The nurses' relied on experience or tacit knowledge to inform pain management practices rather than evidence-based practice guidelines. We suggest interventional strategies using knowledge transfer and translation frameworks, to improve practice, and address negative stereotypes and improve nurses' pain management practices in this population.

Preface

This thesis is an original work by Beverley Faye Ingelson. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, title: “Factors Influencing Nurses’ Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia” Pro0012843 August 9, 2022.

Dedication

To my husband, Brian Ingelson, my sons Sean, Matthew, and William, my family Marshall, Cindy, Jody, Kevin, and Patrick Iles, Dr. John Jarrell, and my parents, Marlene and Talbot Iles; this dissertation is dedicated to you

Brian, your unwavering love, support, encouragement, and faith in our shared journey has provided the foundation for all possibilities. Thirty-three years ago, we promised "when the way is long, let us go together", we have, and I thank you. Sean, Matthew, and William, you inspire me daily; I only hope to be a worthy role model. My dearest brother and sisters, Marshall, Cindy, and Jody, without your constant support and belief through the years, I would not be who I am today. To Kevin and Patrick, you helped inform what I wanted to do, while providing the motivation to achieve. Dr. John Jarrell, you gave me the courage and support to reach for the stars. Finally, Mom and Dad, your sacrifices and vision set me on my path; I share this with you both and hope you are celebrating in your heavenly place.

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Many considerations dictate the decision to pursue a Doctorate of Philosophy. It is said that first impressions are incredibly powerful and can set the tone. This was the case as I searched for an educational institution that was the best fit for my terminal degree, the University of Alberta. Two of the people that made such an impact were Ms. Anita Green and Dr. Diane Kunyk. Anita, thank you for your steady positive support. Every time I needed assistance, had questions, and just needed a pleasant voice to speak with, you were there. Dr. Kunyk, your softspoken constant commitment to excellence was a calming influence as I began this journey and throughout.

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Chapter 1: Introduction

Pain is a complicated, complex, and subjective experience that, when left untreated, profoundly impacts all aspects of daily life. In her seminal work, Margaret McCaffery (1968) stated, “pain is whatever the experiencing persons say it is, existing whenever he/she says it does” (McCaffery et al., 2000, p. 1). In 2020, the International Association for the Study of Pain (IASP) published the definition of pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (Raja et al., 2020, p. 1977). This definition includes six key considerations that have a direct bearing on the subject of this dissertation:

1. Pain is always a personal experience influenced by biological, psychological, and social factors.
2. Pain and nociception are different phenomena; pain cannot be inferred solely from activity in sensory neurons.
3. Through their life experiences, individuals learn the concept of pain.
4. A person’s report of an experience in pain should be respected.
5. Although pain usually serves an adaptive role, it may adversely affect function and social and psychological well-being.
6. Verbal description is only one of several behaviors to express pain; the inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain. (Raja et al., 2020, p. 1977)

I have based my nursing practice on the belief that nurses have an ethical and moral obligation to adequately relieve the pain of all persons assigned to their care. My belief is consistent with the American Nurses Association (ANA), which advises that it is nurses’ ethical responsibility to provide pain relief, suggesting that the nursing process should guide nursing pain management practices (Stokes, 2018). Working as a bedside clinical nurse and nurse leader, I have cared for patients of all ages and conditions across the continuum of care. I have been exposed to many approaches nurses have taken while managing patients with persistent unresolved pain. Nurses caring for many of these patients have made comments such as “The patient is a drug-seeker,” “They are just addicted,” “I am not calling the doctor for any more pain medication; the person is faking it,” “the patient is just crazy,” and “The patient is too old for this amount of medication [*referencing medications that the person had been taking regularly*]”. It is difficult to believe that nurses intentionally leave pain unmanaged in any population; however, statements such as these indicate variations in how nurses manage pain that may lead to prolonged, unnecessary, and harmful patient discomfort. It is essential to discover the underlying issues and challenges when nurses assess and manage pain, particularly in vulnerable populations such as persons living with dementia (PLWD). Regardless of whether an individual can articulate their pain—and perhaps especially when they cannot—they should receive evidence-based care that includes pain management.

Nurses’ pain management practices ought to consist of assessments and interventions designed to relieve pain, evaluations of the effectiveness of the pain management plan, and adjustments of the intervention plan (McCaffery et al., 2000, p. 80). Pain management relies upon adequate assessment, which should be a continuous process designed to ensure the achievement of relief from pain (McCaffery et al., 2000). The assessment process is primarily subjective, as nurses rely upon an individual’s self-reported pain (Beach et al., 2015; Booker & Haedtke, 2016; Buffum et al., 2007; van der Steen et al., 2015). Pain assessment in patients who cannot self-report pain due to cognitive, developmental, or physiological issues is challenging.

One such population of patients with difficulty self-reporting pain are persons living with dementia (Coker et al., 2010; Cravello et al., 2019). Nurses still have a duty to use other appropriate techniques to assess pain, when a patient cannot self-report their pain experience.

While nurses are responsible for choosing an assessment method suited to the patient's needs, the literature suggests that nurses typically do not use alternative pain assessment methods such as observation, which results in undermanaged pain and prolonged discomfort (Peisah et al., 2014). These tools allow nurses to assess signs of pain, such as facial expressions, frowning, grimacing, grunting, moaning, restlessness, agitation, and changes in mental status (Buffum et al., 2007; Gallagher & Long, 2011; Herr et al., 2019b; Sampson et al., 2009; van der Steen et al., 2015).

Scholars have suggested that PLWD often experience unrelieved pain when hospitalized (Tsai et al., 2018; Zwakhalen et al., 2018). Pain is often underrecognized, underreported, misdiagnosed, and undermanaged in PLWD (Coker et al., 2010; Cravello et al., 2019; Kaasalainen et al., 2017; Lichtner et al., 2016). Much of the responsibility for continual pain management lies with the attending nurse (McCaffery et al., 2000). Many intrinsic and extrinsic factors influence how nurses manage pain (Coker et al., 2010). When dementia is present, factors such as pre-existing beliefs based on culture, social upbringing, age, knowledge, and experience impact nurses' practices that may manifest in ageist stereotypes, dementia stigma, and unconscious bias (Alzheimer Society of Canada, 2023; Bruneau, 2014; Coker et al., 2010). Researchers have expressed a growing concern that PLWD may be receiving suboptimal care owing to the complexity of such factors (Latina et al., 2015; Zwakhalen et al., 2018).

Pain management nursing practices are thought to be influenced by limited knowledge and inaccurate or prejudicial personal beliefs (Coker et al., 2010; Lichtner et al., 2016; Scerri et al., 2020; Tsai et al., 2018). At this time, very little literature has examined the influence of nurses' individual factors, such as age, gender, and experience, on beliefs and knowledge about how pain is assessed and managed in PLWD. It is important to focus on hospital nurses' beliefs and knowledge about pain management when a person living with dementia (PLWD) is admitted to their care.

Dementia and Pain

Dementia is defined as a "chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning" (Oxford Reference, 2023, p. para 1). Dementia is also described as "a clinical syndrome … characterized by a substantial global decline in cognitive function that is not attributable to altered consciousness [and] consists of a combination of symptoms attributable to various causes or pathological events" (Palm et al., 2016, p. 2). Symptoms correspond to the seven stages of the condition, ranging from mild (early) to moderate (middle) to advanced or severe (late) (World Health Organization, 2004). To date, there is no cure for dementia. At best, treatment methods may slow disease progression (Palm et al., 2016).

According to Alzheimer's Disease International (2019), there are over 50 million PLWD globally, estimated to reach 152 million by 2050. Age is the most significant risk factor for developing dementia (World Health Organization, 2022) . Most individuals with dementia are aged over 65, with the risk of developing dementia doubling every 5 years after age 65 (Alzheimer's Disease International, 2019). The economic impact of dementia worldwide was estimated at $818 billion in 2015, representing 1.09% of global GDP, with this economic impact attributed to the direct costs of social and health care, as well as the indirect costs associated with informal caregiving in the community (World Health Organization, 2015). Approximately 20%

of global dementia costs are direct medical or healthcare costs (World Health Organization, 2015).

The four most common types of dementia are Alzheimer's disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies (Achterberg et al., 2020; Álvaro González, 2015). People may develop mixed types of dementia, such as Alzheimer's disease and vascular dementia. Additionally, people in the end stages of other neurodegenerative diseases such as Parkinson's and Huntington's often develop associated dementia (Cravello et al., 2019). Alzheimer's disease is often specified in the literature because of its relatively high frequency and early onset (Cravello et al., 2019; van Kooten et al., 2015).

Persistent pain, both chronic and acute, is prevalent in PLWD. Studies reveal that 40% to 80% of PLWD suffer from pain (Achterberg et al., 2020; Briggs et al., 2017; Larsson et al., 2017; Molton & Terrill, 2014). Although it is clear that PLWD often have pain, there is a paucity of research focusing on differences in pain perception according to dementia type (Binnekade et al., 2017; Cravello et al., 2019; Scherder et al., 2015; van Kooten et al., 2015). Scholars who have studied this topic have found no empirical evidence that PLWD experience less pain than persons who do not have dementia, with some suggesting that pain is felt at higher levels in patients who have vascular dementia than persons who have other dementias (Achterberg et al., 2020; Álvaro González, 2015; Benedetti et al., 2004; Cravello et al., 2019; Defrin et al., 2015; van Kooten et al., 2015). However, it should be noted that literature on this topic is often contradictory, with few straightforward guidelines. More research is needed to inform best nursing practice guidelines for pain assessment and management. Until such guidelines are developed, nurses caring for PLWD must be mindful of potential differences in pain perception and limitations that PLWD have with self-reporting abilities.

Dementia is estimated to be present in 29–72% of hospitalized adults over 70 years of age, with pain prevalent in 46–57% (Achterberg et al., 2020; Briggs et al., 2017; Fogg et al., 2019; Sampson et al., 2009; van Kooten et al., 2015). These patients often have multiple comorbidities, such as "musculoskeletal, gastrointestinal, and cardiac conditions" (Achterberg et al., 2020, p. 2), that contribute to chronic or persistent pain (Briggs et al., 2017; Shepherd et al., 2019). Achterberg et al. (2013) suggested that "50% of PLWD also experience pain" (p. 1471). When PLWD are hospitalized, the primary concern for healthcare professionals is the acute condition, not necessarily considering management of pain from comorbid conditions, leading to inadequately managed pain (Scerri et al., 2020).

Effective pain management is vital to PLWD's quality of life (Lichtner et al., 2016). The deleterious consequences of persistent unrelieved pain can devastate PLWD (Fogg et al., 2019). Pain accelerates changes in cognition, memory loss, and functional decline, underscoring the need for adequate pain assessment and management in PLWD (Achterberg et al., 2020; Achterberg, 2019; Husebo et al., 2012; Lichtner et al., 2016). In hospitalized PLWD, much of the responsibility for continual pain management lies in the hands of the attending nurse, thereby placing nurses in the pivotal role of performing pain assessment and management (McCaffery et al., 2000).

The Influence of Ageism, Unconscious Bias, and Dementia Stigma on Nurses' Pain Management Practices for PLWD

Pain management for PLWD requires that nurses use a combination of complex skills (Bernhofer, 2012; Briggs, 2002). Nurses must assess whether PLWD are experiencing pain, establish whether the pain is severe enough to be managed, select the best intervention, administer the intervention both safely and effectively, and then evaluate the effectiveness of the intervention in relieving the patient’s pain (McCaffery et al., 2000). The nurse makes many decisions when caring for these patients that may be influenced by their beliefs about older people, beliefs about dementia, knowledge about pain assessment and management, and their past experiences.

Nurses’ beliefs that are based on ageist stereotypes may result in unconscious bias and dementia stigma, contributing to pain in hospitalized PLWD that is not assessed or managed (Ben-Harush et al., 2017; Bruneau, 2014; Coker et al., 2010). Ageism is “discrimination against older people because of negative and inaccurate stereotypes that are “so ingrained in our culture that we often do not even notice,” perpetuating unconscious biases. (Weir, 2023, p. 36). Ageism can be manifested through actions and policies, interpersonal or social interactions, and internalized as beliefs. Ageism also exists at institutional levels (Castiello & Villines, 2021; Weir, 2023; World Health Organization, 2021).

Dementia stigma refers to “any negative attitude or discriminatory behavior against people living with dementia, just based on having the disease” (Harper et al., 2018). When ageist stereotypes, unconscious bias, and dementia stigma are present, nursing care can become task-oriented and superficial, demonstrated by patronizing speech patterns and/or excluding the person from decisions about the care plan (Ben-Harush et al., 2017). In addition, other scholars have suggested that unconscious biases can lead to care that is rationed in a fast-paced hospital environment (Hunter & Dahlke, 2023). Nurses’ pain management practices require communication appropriate to the stage of dementia to assess, intervene, and evaluate pain. Yet, pain may not be assessed and managed if the nurse has unconscious bias about age, dementia, or stigma (Ben-Harush et al., 2017; Bruneau, 2014; Coker et al., 2010).

The Influence of Knowledge on Nurses Pain Management Practices for PLWD

Knowledge is a familiarity, awareness, or understanding of facts or skills associated with life experiences and clinical situations (Lin et al., 2020). Nurses' knowledge is based on formal education and tacit experiential knowledge in meeting the complex care needs of PLWD (Graham et al., 2022; Samarkandi, 2021). Knowledge deficits, such as a fear of overmedication, also often lead to undermanagement of pain in PLWD (Ernstmeyer, 2020; Fang et al., 2017; Lee & Kang, 2020; Lichtner et al., 2016; Martorella et al., 2019; Youngcharoen et al., 2017). Other common knowledge deficits concern use of alternative pain assessment methods to manage pain, the possibility that PLWD may have multiple sources of pain, and the contemporaneous overuse of psychotropic medications to treat pain (Kaasalainen et al., 2017; Knopp-Sihota et al., 2019). Scholars suggest that other knowledge gaps related to insufficient education about care of older PLWD, policies and procedures based on evidence-based practice guidelines impact nurses’ pain assessment and management (Jonsdottir & Gunnarsson, 2021; Lin et a., 2020).

Study Aim

Nurses’ knowledge and beliefs influence their pain management practices. However, what is not known is the impact that a dementia diagnosis has on nursing pain assessment and management practices for hospitalized PLWD. Therefore, the primary aim of this dissertation was to advance an understanding of how nurses’ knowledge and beliefs influence their pain assessment and management practices when caring for hospitalized PLWD. This dissertation is informed by the concept of ageism and the potential it might play in nurses’ practice with hospitalized PLWD. The following objectives met this aim:

1. Identify research that describes how nurses who care for hospitalized PLWD (1) assess and manage pain, (2) define “adequate pain relief”, (3) assess the effectiveness of pain management, and (4) describes barriers to pain assessment and management.
2. Investigate the influence that gender, age, and experience have on nurses’ knowledge and beliefs when managing pain in hospitalized PLWD.
3. Understand the influence of nurses’ experiences, knowledge, and beliefs on their pain assessment and management in hospitalized PLWD.

Dissertation Papers

The objectives were answered through three studies reported in three papers (Chapters 2, 3, and 4). The second and third paper (chapters 3 and 4) were designed using an explanatory sequential mixed method (Creswell, 2015; Fetters et al., 2013). Integration of data collection and analysis used a building approach, with the quantitative results (chapter 3) followed by the qualitative data collection (chapter 4) (Fetters et al., 2013). Taken together, the studies investigated hospital nurses’ knowledge, beliefs and experience on pain management practices with hospitalized PLWD.

The first paper (Chapter 2), "*A Scoping Review on Nurses' Pain Management of Older Patients With Dementia in a Hospital Environment*," identified research that describes how nurses who care for hospitalized PLWD (1) assess and manage pain, (2) define "adequate pain relief", (3) assess the effectiveness of pain management, and (4) describe barriers to pain assessment and management (Objective 1). This work highlights the current research gaps in nurses' pain assessment and management practices for hospitalized PLWD. Findings revealed that when pain management practices among the nurses lacked consistency and standardization, it was unclear if adequate levels of comfort were achieved in hospitalized PLWD. The literature failed to identify how the effectiveness of nurses' pain management practice was measured. Barriers were identified that included communication difficulties with the patient and inconsistent information shared within the care team. Other barriers such as time constraints, and a perceived lack of organizational support, contributed to increased nurse stress. The nurses also described knowledge deficits resulting in practice gaps that when combined with barriers and challenges resulted in underrecognized and undermanaged pain.

The second paper (Chapter 3), "*Hospital Nurses' Knowledge and Beliefs About Pain Management Among Older Persons Living With Dementia: A Cross-Sectional Survey Study,*" explored nurses' self-reported knowledge and beliefs (Objective 2). Nurses working in two hospitals in Southern California responded to a validated survey that measured their knowledge and beliefs when managing pain in hospitalized older PLWD. The study explored whether there were nurse-specific factors such as age, gender, and experience that influenced knowledge and beliefs when assessing and managing pain in hospitalized PLWD. A multivariate analysis of variance revealed no significant differences based on the nurses' age, experience, or gender, in terms of their general beliefs about pain, aging, and dementia; knowledge about pain management in PLWD; and beliefs about pain in older people. However, testing using an analysis of variance (ANOVA), revealed that male nurses of all ages and years of experience held less favorable beliefs about pain in older people, than their female counterparts. These findings informed a more in-depth examination in Paper 3 by increasing focus on the nurses' experience, using qualitative research methodology.

Paper 3 (Chapter 4), "*Nurses' Knowledge and Beliefs About Pain Management in Hospitalized Persons Living With Dementia: A Qualitative Descriptive Study,*" addressed the third objective. A purposive sampling technique was used to explore potential differences in registered nurses' knowledge, beliefs, and experience building on and informed by data collected in the quantitative research paper (Chapter 3). The nurses who participated in this study worked in the hospital that was a Nurses Improving Care for Healthsystem Elders (NICHE) designated organization. The study's findings were consistent with the information discovered in the scoping review. Nurses were not using standardized procedures to manage pain when caring for hospitalized PLWD. There were: significant gaps in knowledge; beliefs that indicated stereotypes about aging and dementia; and complexities when managing pain related to communication challenges with the patient, fellow nurse team members, and external facilities. Qualitative data revealed that nurses' experience influenced pain management practices, a finding that was different from Paper 2. Nurses used knowledge gained through work experiences, described as tacit knowledge, rather than evidence-based clinical guidelines, or explicit knowledge, when assessing and managing pain.

Key Terms

The researcher has identified some key terms to provide context and clarity for key concepts found in this proposal.

Ageism refers to stereotypical thoughts (how we think), feelings or prejudices, that lead to discrimination (actions) (World Health Organization, 2021). The World Health Organization (2022) further defines ageism in three categories which are institutional, interpersonal, and internalized. *Institutional ageism* is described through actions and policies that perpetuate ageism. *Interpersonal ageism* refers to social interactions, and internalized are those beliefs that are applied to oneself and will apply to the nurses (Castiello & Villines, 2021). *Benevolent ageism*, is described as patronizing beliefs towards people based on their age (Cary et al., 2017).

Biases can be unconscious and/or conscious and be evidenced by negative views about aging and dementia. *Unconscious biases* are described as “associations or attitudes that affect behaviors, interactions and decision-making (Marcelin et al., 2019). *Conscious bias* are attitudes or stereotypes about certain people that we are aware of Jaskulski and Schneider (2020, July 21).

Communities of practice refers to how “learning occurs among groups of people within a place of work” and are relied upon heavily in healthcare practice (Terry et al., 2020, p. 370).

Data saturation refers to the point when analyzed qualitative data becomes repetitive with no new information discovered using an inductive thematic saturation model. Data saturation was conceptualized in consultation with the supervisor, reviewing coding reliability, and reflexive thinking by the first author, to ensure consistency for codes and themes. In doing so, data saturation was not predetermined by an arbitrary number of interviews (Braun & Clarke, 2021; Saunders et al., 2018; Walker, 2012)

Dementia is used as a global term that includes all types of dementias such as Alzheimer’s disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies (Achterberg et al., 2020).

Effective pain management refers to the nurses’ pain management practice that involves assessment, intervention, and re-assessment of the comfort level of the individual following the intervention (Cox, 2022)**.**

Integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) refers to an implementation science framework that supports implementation of complex interventions in healthcare, prioritizing the role of a facilitator and the context of the environment (Harvey & Kitson, 2016; Roberts et al., 2021).

Knowledge Translation Complexity Network (KTCN) refers to a “network that optimizes the effective, appropriate and timely creation and movement of knowledge to those who need it in order to improve what they do” (Boyes, 2023; Kitson et al., 2018). The KTCN framework is particularly effective in health care environments, in particular, hospitals, because it emphasizes the importance of individuals, and their influence within networks when implementing sustained change in practice. As it pertains to this study, it is recommended for facilitating changes related to policy and practice.

Mind lines refer to internalized tacit knowledge that was formed in early education, experience and colleagues such as opinion leaders (Gabbay & le May, 2016).

Older patients are persons 65 years of age and older who are admitted to a hospital for care (Orimo et al., 2006).

Pain assessment is a continuous process of subjective or objective measurements of pain that uses a published standardized measurement tool for the purpose of providing adequate relief from pain (McCaffery et al., 2000; Zwakhalen et al., 2018).

Nurses' pain management practices consist of assessments and interventions designed to relieve pain, evaluations of the effectiveness of the pain management plan, and adjustments of the intervention plan accordingly (McCaffery et al., 2000, p. 80).

Nursing Interventions are considered to be any “actions that a nurse takes to implement their patient care plan” that may be classified “independent (does not require a prescription) or dependent (requires prescriptions or authorization by a provider)”. This study refers to both types of interventions when describing the methods that nurses use when managing pain. (Ernstmeyer, 2020, p. Chapter 4).

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Chapter 2: A Scoping Review on Nurses' Pain Management of Older Patients with Dementia in a Hospital Environment

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Abstract

Aims and Objectives: Hospitalized persons living with dementia often experience unrelieved pain. Unmanaged pain during hospitalization has a significant negative impact on quality of life for persons living with dementia. Despite the central role of nurses in pain management, little is known about how nurses manage pain in this patient population in the hospital environment. Therefore, a scoping review was conducted to identify research that described how nurses who care for hospitalized PLWD (1) assess and manage pain, (2) defined "adequate pain relief", (3) assessed the effectiveness of pain management, and (4) described barriers to pain assessment and management.

Data Sources and Review Methods: The scoping review utilized Arksey and O'Malley's methodological framework. Eight electronic databases were searched for studies using key search terms that focused on hospitalized dementia patients and nurse's pain assessment and treatment or intervention practices. Included was any literature related to policies and procedures as well as grey literature. Data was extracted based on the types of research designs used, the methods nurses use to assess and manage pain, descriptions of adequate pain relief measures, effectiveness of nurses' pain management practices, and barriers that nurses encountered when assessing and managing pain. A descriptive content analysis was used to synthesize data from qualitative studies.

Results: Six articles published between 2016 and 2021 met the inclusion criteria; four utilized qualitative methods, and the others used either mixed-methods or quantitative study designs. The review found that pain management practices among the nurses lacked consistency and standardization, making assessment, interventions, and reassessment of adequate pain relief difficult. Adequate pain relief was not described in four out of six articles. The effectiveness of nurses’ pain management practices that included assessment, intervention, and evaluation of pain following the intervention, was not addressed in any of the articles. The nurses described knowledge deficits for assessment and interventions with PLWD, resulting in practice gaps. Barriers included communication from nurse to patient, nurse to nurse with inconsistent information shared, and outside facilities. Other barriers noted were time constraints, and a perceived lack of organizational support which contributed to increased nurse stress.

Conclusion: The results of this scoping review illuminate the paucity of current literature available on how pain is assessed and managed by nurses when PLWD are admitted to the hospitals. Studies included in this review indicated that even in hospital wards that specialize in acute geriatric care and used a person-centered care model, pain is underassessed and undermanaged in PLWD. There was evidence that using methods found in knowledge translation framework, was effective in improving pain assessment and management.

Nursing Practice Implications: Managing pain in this population is complex and lacks organizational support. Implementing evidence-based practice standards, educational support, and organizational activities using knowledge translation frameworks would improve pain management practices in hospitalized PLWD, improve communication, and potentially reduce nurses’ stress. Organizational leaders should assess a person-centered care model that would provide extra time nurses require to effectively manage pain. Based on these findings, we suggest examining nurse factors, knowledge and beliefs to understand why hospitalized PLWD have pain that is unrelieved.

Key words

dementia, hospitalized, nurse, pain management, pain assessment, intervention

A Scoping Review on Nurses' Pain Management of Older Patients with Dementia in a Hospital Environment

One of the significant challenges that nurses working in hospitals face is managing pain adequately in persons living with dementia (PLWD). Current literature suggests that nurses often underrecognize, underreport, misdiagnose, and undertreat pain in hospitalized PLWD (Cravello et al., 2019; Lichtner et al., 2016; Savvas & Gibson, 2016; Zwakhalen et al., 2018). PLWD are more likely to be admitted to hospitals and experience longer hospital stays than persons without dementia (Möllers et al., 2019; Shepherd et al., 2019). The Alzheimer's Disease International (2019) has estimated that approximately 40% of persons admitted to hospitals have dementia, which is two to three times higher than for persons without dementia. Moreover, pain is the most common reason that PLWD are admitted to acute care institutions, which makes pain management a priority for nurses (Boltz et al., 2021).

Chronic or persistent unrelieved pain has many deleterious consequences, such as delirium superimposed on dementia and behavioral and psychological symptoms of dementia (Fogg et al., 2019; Paulson et al., 2014; Yous et al., 2019). Behavioral responses and psychological symptoms of dementia, also referred to as responsive behaviors, are closely related to unrelieved pain (Yous et al., 2019). Common responsive behaviors include agitation, sleep disturbances, depression, sleeplessness, aggression, anxiety, and motor disturbances (Dobbs et al., 2008; Kales et al., 2015). Characteristics of acute care environments, such as constant changes, noise, unfamiliar caregivers and different surroundings, can enhance confusion and result in behavioral responses and anxiety among PLWD (Digby et al., 2017; Toot et al., 2013). Unrelieved pain may further exacerbate responsive behaviors (Digby et al., 2017; Hynninen et al., 2016; Toot et al., 2013). Prolonged pain also accelerates changes in cognition as well as memory loss and functional decline, which often negatively impact the quality of life of PLWD after they are discharged from the hospital (Achterberg et al., 2020; Achterberg, 2019; Sampson et al., 2015).

Background

Dementia is a progressive clinical syndrome caused by neurodegenerative processes that damage the brain (World Health Organization, 2004). Characteristics of dementia include impairments in memory, reasoning, cognitive function, ability to communicate, and judgment and may also include changes in personality, moods, and behavior (Palm et al., 2016; Timmons et al., 2016). PLWD are often co-diagnosed with age-related chronic conditions, wherein the most significant symptom is chronic pain (Cravello et al., 2019; Larsson et al., 2017). Approximately 40% to 80% of older PLWD suffer from persistent pain (Briggs et al., 2017; Lichtner et al., 2016; van Kooten et al., 2015). The combination of dementia and pain can lead to unique care challenges during hospitalization.

When hospitalized, PLWD often experience unrelieved pain (Tsai et al., 2018; Zwakhalen et al., 2018). Pain is a complicated, complex, and subjective experience that, when left untreated, profoundly impacts all aspects of daily life. In her seminal work in 1968, Margaret McCaffery stated, “pain is whatever the experiencing persons say it is, existing whenever he/she says it does” (2000, p. 1).

In 2011 and again in 2021, the International Association for the Study of Pain (IASP) asserted that all patients have the right to pain management (Cousins & Lynch, 2011; Raja et al., 2020). The IASP expanded on McCaffery et al.’s (2000) definition of pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (Raja et al., 2020, p. 1977). This definition includes six key considerations: (1) pain is always a personal experience influenced by biological, psychological, and social factors, (2) pain and nociception are different phenomena; pain cannot be inferred solely from activity in sensory neurons, (3) through their life experiences, individuals learn the concept of pain, (4) a person's report of an experience in pain should be respected, (5) although pain usually serves an adaptive role, it may adversely affect function and social and psychological well-being, and (6) verbal description is only one of several behaviors to express pain; the inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain (Raja et al., 2020, p. 1977).

Nurses play a central role in pain management of hospitalized patients. McCaffery et al. (2000) suggested that nurses assess the patient for pain, establish whether the pain is severe enough to be managed, select the best intervention based on the patient's assessed pain, administer the intervention both safely and effectively, and evaluate the effectiveness of the intervention. When managing pain with medication, the nurse must determine the drug, the dose, and the method of administration, while adhering to hospital unit pain protocols or physician and nurse practitioner orders (McCaffery et al., 2000).

In their 2018 position paper, the American Nurses Association (ANA) provided ethical guidelines intended to support nurses' pain management practices (Stokes, 2019). The ANA argued that it is the nurses' ethical responsibility to provide pain relief and that the nursing process should guide and improve nursing pain management practices (Stokes, 2018). The ANA also suggested that:

> nurses provide individualized nursing interventions, pain management is multimodal and interprofessional approaches are necessary to achieve pain relief, pain management modalities should be informed by evidence, nurses must advocate for policies to assure

> access to all effective modalities, and the nurse leadership is necessary for society to appropriately address the opioid epidemic (Stokes, 2018, p. 1).

As noted by McCaffery et al. (2000), pain management relies upon adequate assessment, a continuous process designed to ensure the achievement of relief from pain (McCaffery et al., 2000). The process is primarily subjective, as nurses rely upon an individual's self-reported pain (Beach et al., 2015; Booker & Haedtke, 2016; Buffum et al., 2007; van der Steen et al., 2015). Pain assessment in patients who cannot self-report pain due to cognitive, developmental, or physiological issues is challenging. However, as noted by the IASP (Raja et al., 2020) and ANA (Stokes, 2018), nurses still have a duty to use other appropriate techniques to assess pain, when a patient cannot self-report their pain experience.

One such population of patients who have difficulty self-reporting pain is those diagnosed with dementia. PLWD will eventually lose the ability to communicate verbally. If a person cannot express their pain level and intensity verbally, pain assessment methods that rely on the persons' identification of a numerical pain intensity value is not adequate. In these instances, alternative pain assessment methods such as observation should be utilized (Coker et al., 2010; Cravello et al., 2019). These methods allow nurses to assess signs of pain, such as facial expressions, frowning, grimacing, grunting, moaning, restlessness, agitation, and changes in mental status (Buffum et al., 2007; Gallagher & Long, 2011; Herr et al., 2019b; Sampson et al., 2009; van der Steen et al., 2015).

In 2019, the American Society for Pain Management Nursing (ASPMN) updated their 2011 position statement for patients such as PLWD, who are unable to self-report pain (Herr et al., 2019a, 2019b; McCaffery & Pasero, 2011) endorsing updated clinical practice recommendations for a hierarchical framework to guide pain assessment. These best practice evidence-based guidelines reinforce nurses' role in assessing and reassessing pain following interventions (Herr et al., 2019b). Pain management begins with assessment, which may then be followed with interventions designed to provide comfort.

Nurses are responsible for choosing an assessment method suited to the patient's needs. The literature suggests that nurses typically do not use alternative pain assessment methods such as observation, or a hierarchical framework for cognitively impaired PLWD which results in undermanaged pain and prolonged discomfort (Peisah et al., 2014; Tsai et al., 2018). Pain assessment and management practices in hospitalized PLWD, challenges, and barriers is not well understood, therefore, a review of the available literature is indicated.

A scoping review is a systematic, structured, and comprehensive approach to searching and mapping a broad body of published literature to:

> identify types of evidence available . . ., identify and analyze knowledge gaps, clarify key concepts and definitions in the literature, examine how research is conducted in a certain topic or field, and identify key characteristics or factors related to a concept" (Peters et al., 2020, p. 5), thereby providing information for future research (Arksey & O'Malley, 2005; Peters et al., 2020).

Most of the published literature about pain management in PLWD is based in long-term care facilities (Jonsdottir, 2021). Therefore, a scoping review was conducted to identify research that describes how nurses who care for hospitalized PLWD: (1) assess and manage pain; (2) define "adequate pain relief"; (3) assess the effectiveness of pain management; and (4) describe barriers to pain assessment and management.

Methods

This review followed Arksey and O’Malley’s (2005) 5-stage scoping review framework. The five stages are to (a) develop one or more research questions, (b) identify all relevant studies, (c) select studies, (d) chart the data, and (e) collate the results. The inclusion criteria comprised original research published in international peer reviewed journals. Articles were included if (1) the study participants were nurses who provided direct patient care in ambulatory and inpatient units located in a hospital on hospitalized patients older than 65 years of age who have any stage or type of dementia and are experiencing any type of pain. We limited the publication time period from January 2016 through January 2021 to capture the most recently published literature. Also included were current and national standards for assessing pain among older hospital patients with dementia in English-speaking countries that were published as research articles. Findings are presented in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for Scoping Reviews (PRISMA-SCR) (Figure 2.1) (Tricco et al., 2018). Review articles (identified as excluded in study design on the PRISMA diagram), pain tool validation articles, and non-English publications were excluded.

Search Strategy

We developed a comprehensive search strategy, which we used to conduct a systematic literature review. To define our search strategy, we used key concepts based on nurses’ pain assessment and management practices for hospitalized PLWD. In collaboration with a Health Sciences librarian, key search terms and database-specific subheadings included: ‘patient with dementias in hospital,’ AND ‘nurses’ AND ‘pain assessment or treatment’ (see Table 2.3). Two researchers pilot tested and refined our search strategy using MeSH terms on the Medline and CINAHL databases. We then applied the search strategy to Embase, PsycINFO, Medline, Cochrane Database, Scopus, the Directory of Open Access, Journals ProQuest Dissertations and Thesis, and Google Scholar. Our search included current international standards of practice, policies, procedures (Peters et al., 2021), and grey literature such as reports, white paper, and government documents (National Institutes of Health, n.d.).

Evidence Screening and Selection

The research team used Covidence (2021) electronic software to screen and select articles that met the inclusion criteria. An initial review of the first 50 titles and abstracts was completed by the first and second authors to ensure agreement and consistency. Any differences were resolved through discussion until a consensus was reached. A review of all titles and abstracts was then conducted to screen articles for full text review and study inclusion.

Data Extraction

Prior to the full-text article review, we developed detailed definitions and guidelines (see Table 2.4) as well as two charting forms to ensure consistency with data extraction. The charting forms were designed to extract descriptions of pain assessment and treatment strategies, and of study characteristics. Pain assessment and treatment strategies data was extracted to the headings: author, year published and country, target population (patient), target population (nurses), intervention, adequate pain relief (type or nature of pain), pain assessment details, name of treatment, treatment components and activities, treatment mode of delivery. Study characteristics were extracted to the headings: overall study purpose, study population characteristics, study methods, outcome measures result (quantitative), outcome measure results (qualitative), effectiveness, and comments. The definitions and guidelines provided comprehensive instructions about the data elements to be extracted, where to find the information, and how to capture the data on the charting forms (O'Rourke et al., 2018; Peters et al., 2020). Amendments to the forms were made after two researchers piloted the tools. Characteristics and concepts were extracted, coded, categorized, and subcategorized according to the authors' descriptions of pain assessment, management, adequate pain relief, effectiveness of pain management practices, and identified barriers. Surface-level words, characteristics, and concepts were extracted, coded, categorized, and subcategorized according to the author's descriptions of pain assessment, management, adequate pain relief, effectiveness of pain management practices, and identified barriers

Data Charting and Analysis

Frequencies were calculated using Statistical Package for the Social Sciences (v 28.0) (2021) on participant and context data that included country, types of research designs, setting, participant age, gender, professional experience, and educational level, and types of research designs. We then conducted a content analysis on the data by extracting words such as such as adequate pain relief, nurse assessment and management, challenges or barriers to pain assessment and management, and whether pain assessment and management practices were effective. Words, characteristics, and concepts, which were coded, grouped into similar categories, and mapped to the research questions (Peters et al., 2020; Vaismoradi et al., 2013). Data from the mixed methods and qualitative studies were synthesized across all studies using definitions and guidelines developed prior to data extraction (see Table 2.4).

Results

The initial search yielded 935 articles from 8 electronic databases. After 129 duplicates were removed, 806 article titles and abstracts were screened for inclusion. Eligibility criteria were applied after which 757 articles were excluded based on the study setting, design if it was a review, and outcomes. A total of 49 articles were reviewed by reading the full text. Forty-three articles were then excluded, resulting in six studies that met the inclusion criteria of the review (see Figure 1 for exclusion details).

Characteristics of Sources of Evidence

Characteristics of the population, concept, and context of the included articles are described narratively and summarized in Table 2.1 according to pre-defined elements (see Table 2.4). Articles included in this scoping review were published in Sweden (*n*=3) (Krupic et al., 2020; Krupić et al., 2018; Seffo et al., 2020), Ireland (*n*=1) (McCorkell et al., 2017), and Spain (*n*=2) (Minaya-Freire et al., 2020; Minaya-Freire et al., 2021). The types of research methods used were primarily qualitative (*n*=4) (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020). Among the two others, one used a quantitative method (Minaya-Freire et al., 2021) and the other, a mixed-method action cycle research study design (McCorkell et al., 2017). All studies were conducted in acute care hospitals, among which 66.7% (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Seffo et al., 2020) were academic teaching organizations. The unit or ward types are summarized in Table 2.1.

Both nurses (working in a hospital or hospital based ambulatory care setting) and patients (older than 65 years with dementia and pain) formed the study populations. Five of six articles included a total of 105 nurse participants. The average age of nurse participants was 40.5 years, with 73.3% being female and 27.7%, male. None of the studies noted ethnicity. The education levels of the registered nurses were reported for 72 participants, among which 38.9% (*n*=28) had a master's degree and 16.7% (*n*=12) were doctoral candidates. The authors did not specify the education level of the remaining 55.5% (*n*=40) nurses, which suggests that the nurses' education level was baccalaureate or lower. A total of 93 participants reported how many years they had practiced as nurses. None of the nurses had received any specific training in caring for the older person with dementia except for those who worked in the acute care geriatric unit (Minaya-Freire et al., 2021). Two nurses working the acute care geriatric unit had received additional education on care of older persons and pain (Minaya-Freire et al., 2021).

The patients described in all studies were older PLWD. The reason for admission in four articles was post-operative repair of hip fractures or other orthopedic needs (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020). The patients in the studies by Minaya-Frieire et al. (2021) and McCorkell et al. (2017) were admitted for medical conditions. The population characteristics are summarized in Table 2.1.

Study Findings

Characteristics and concepts that were extracted, coded, categorized, and subcategorized according to the authors' descriptions of pain assessment, management, adequate pain relief, effectiveness of pain management practices, and identified barriers are summarized in the following section.

Pain Assessment

Nurses used alternative pain assessment methods based on their inferences of patients' pain when patients had difficulties communicating. Pain assessment methods were inconsistent, varied according to nurse, and lacked standardization or measurement. The nurses described that when assessing pain, they used signs and gestures and observed changes in the patient's body language and behavior as well as any verbal expression of pain (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020).

Only two of the studies used a standardized tool such as the Numerical Rating Scale (NRS) (Farrar et al., 2001), Pain Assessment in Advanced Dementia (PAINAD) (Warden et al., 2003) or Cognitive Impairment Pain Assessment scale adapted from the Bolton Assessment Tool

(Gregory, 2017; McCorkell et al., 2017). McCorkell et al. (2017) used action cycle research methodology to implement the Cognitive Impairment Pain Assessment scale. A total of 20 patient records were assessed to track improvement. Pain assessment improved from the baseline measure *n*=0 to *n*=19 during the course of the study (McCorkell et al., 2017). Minaya-Freire et al. (2021) noted that nurses used the NRS and PAINAD assessment tools, however, the frequency or compliance was not noted and that 88% of hospitalized PLWD were assessed for pain on admission, followed by 80% during the hospital stay.

Nurses expressed that they valued the information provided by family members about the person's pain behavior. However, family members and caregivers were often absent and therefore not able to provide nurses with information on their loved one's pain indicators (Krupic et al., 2020; Krupić et al., 2018; Seffo et al., 2020).

Pain Management

Three of the six articles described nurses' pain management choices (McCorkell et al., 2017; Minaya-Freire et al., 2021; Seffo et al., 2020**.** In McCorkell et al. (2017), nurses used analgesic medications that were scheduled and as needed, for which the frequency of administration improved from 30% (N=6) to 90% (N=18) following implementation of the Cognitive Impairment Pain Assessment scale.

In Minaya-Freire et al. (2021), nurses used analgesic medication scheduled and as needed, as well as complementary and alternative interventions such as ice repositioning, and end of life care comfort care measures. The authors found that PLWD received one third less pain medication when compared to other post-operative patients in this review (Minaya-Freire et al., 2021).

In Seffo et al. (2020), nurses provided analgesics as needed with the primary initial intervention being physician administered nerve blocks related to the diagnosis of hip fracture. Pain interventions may have been provided in the other three studies; however, the type and method were not identified (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020).

Adequate Pain Relief

Adequate pain relief is described as an assessment of the effect that the intervention (medication or alternate comfort measures) had on reducing the patient's perceived pain intensity. As indicators of adequate pain relief were not explicitly described, the authors of this review inferred that nurses in all qualitative studies used body language and other non-verbal behavior to assess comfort if verbal feedback was absent (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020). Nurses used the Cognitive Impairment Pain Assessment Scale to assess pain and pain relief from medication in McCorkell et al. (2017) (McCorkell et al., 2017) and the NRS and PAINAD in Minaya-Freire et al. (2021) to assess for adequate pain relief. Nurses used a combination of the Numeric Pain Scale and Pain Assessment in Advanced Dementia Scale in Minaya-Freire et al. (2020).

Effectiveness of Pain Management Practices

Effectiveness of pain management practices refers to the nurses' pain management practice that included assessment, intervention, and evaluation of adequacy of pain relief. Effectiveness of pain management practices that include nurses' assessment, intervention, and evaluation of pain management were not measured in any of the articles included in this review. Nurses did however, note barriers to pain assessment and management in PLWD.

Barriers

Nurses noted many barriers that hampered their pain assessment and management when caring for PLWD. These barriers included communication challenges (nurse to patient), information sharing (nurse to nurse), knowledge, time constraints, and nursing stressors.

Communication challenges (nurse to patient). The most challenging factor impacting pain assessment and the administration of pain interventions was the inability of patients to communicate verbally (Krupic et al., 2020; Krupić et al., 2018; Seffo et al., 2020). Nurses described the use of different communication patterns when assessing patients' pain. For example, nurses stated that they often used simple language, short sentences, and speech patterns that were intentionally kind and attentive combined with touch (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020). They also assumed that the patients did not understand and thus communication was one way, i.e., nurse to patient (Krupic et al., 2020; Krupić et al., 2018). Additionally, nurses presumed that communication was absent when patients did not respond verbally (Krupic et al., 2020; Krupić et al., 2018).

Information sharing (nurse to nurse). Nurses expressed that information was often not shared between staff and other wards, limiting their capacity to provide seamless care for PLWD (Krupic et al., 2020; Krupić et al., 2018; Seffo et al., 2020). They stated that they often lacked relevant information about the person's dementia type and the patient's communication patterns prior to their admission or transfer within the hospital (Krupic et al., 2020; Krupić et al., 2018; Seffo et al., 2020).

Knowledge. Nurses recognized that they had knowledge deficits related to pain assessment and management. Nurses described an absence of education about pain assessment and management for PLWD in their initial educational programs and a lack of organizational education on specific pain assessment and communication methods (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Seffo et al., 2020). They expressed the need for education on psychotropic medications, analgesics, doses, and the potential impacts of these medications on PLWD (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Seffo et al., 2020).

Time constraints. Nurses expressed that caring for hospitalized PLWD is time-consuming. The authors described nurses' feelings that the extra time required to provide the elements of dementia-specific person-centered care was not supported by their organization. Dementia-specific person-centered care elements include an individualized pain management care plan for assessing and managing pain. The nurses felt that the inability to devote enough time to these patients led to less optimal care, especially when managing pain (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Seffo et al., 2020). For example, the nurses in Minaya-Freire et al, (2020) expressed the view that time constraints limited the ability to conduct proper pain assessments and provide non-pharmacological interventions.

Nurses also expressed the view that handoffs and care transitions were complex and time-consuming. Thus, when short on time, the sharing of information was sub-optimal, which often resulted in delays in care and missing information (Krupic et al., 2020; Seffo et al., 2020).

Nursing Stressors. Nurses reported that caring for hospitalized PLWD was stressful (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Seffo et al., 2020). Nurses related that stress increased when the person could not verbally communicate. They also suggested that additional factors such as knowledge deficits about general care, pain management, and the lack of time and organizational support needed to provide care were significant stressors (Krupic et al., 2020; Krupić et al., 2018; Seffo et al., 2020). Additionally, the nurses identified the Emergency Department was a high stress area and were concerned for the PLWD safety, due to time constraints (Seffo et al., 2020).

Discussion

During this scoping review, we conducted an extensive search for peer reviewed research on how nurses manage pain in hospitalized PLWD published from January 2016 through January 2021. Our review was specific to nurses who provided direct care for older PLWD who had pain in a hospital inpatient or in hospital ambulatory area such as the Emergency Department. It is important to note that the studies included in this review reflected small sample sizes, two to fifty-one nurses, and twenty to one hundred eleven patients, which may have limited our outcome findings. However, there was consistency in the extracted data.

We discovered a wide variation not only in the methods for assessing pain, but also in interventions to manage pain and how nurses defined adequate pain relief. None of the articles contained any information about how the effectiveness of nurses' pain management practices was measured.

Similar to the findings of other researchers, our review revealed that nurses did not use standardized tools to assess pain intensity or the effectiveness of their pain management (Digby et al., 2017; Peisah et al., 2014). Minaya-Friere et al. (2021) found that even when standardized pain assessment tools were available (the NRS and the PAINAD), nurses did not use them consistently.

Pain interventions were impacted by knowledge deficits. Nurses in this review noted knowledge deficits, which included information on psychotropic medications, analgesics, pain assessment, and the complexities of pain management in PLWD. All nurse participants requested increased education on these topics (Krupic et al., 2018; Krupic et al., 2020; McCorkell et al., 2017; Seffo et al., 2020). Moreover, pain management interventions that are provided as needed indicate nurses' knowledge deficits. Best practice guidelines suggest that persons who cannot self-report pain should be carefully considered to have regular pain intervention instead of as needed (Herr et al., 2019b).

Nurses in this review reported barriers that influenced pain management assessment and intervention. Nurse-to-patient communication challenges was the most frequently cited barrier (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Minaya-Freire et al., 2020; Seffo et al., 2020). Nurse to patient communication difficulties occurred when the patient was not able to articulate pain intensity (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020).

There was also incomplete and inconsistent information sharing from nurse to nurse, which includes external facilities. Nurses rely upon information transferred during admissions and nurse handoffs, as they do not have knowledge regarding the individual's habits and personality patterns, and how pain is to be managed effectively for that individual (Cohen-Mansfield & Parpura-Gill, 2007). Other scholars suggest that when nurses receive comprehensive information about the PLWD in advance, they may be able to prevent the development of responsive behaviors caused by underlying pain (Yous et al., 2019). Some nurse participants in the included studies expressed that having information about how the PLWD communicates might enable them to manage patients’ pain better and in a timely manner (Krupic et al., 2020; Krupić et al., 2018; Seffo et al., 2020).

When caring for hospitalized PLWD, nurses expressed feeling unsupported by their organizations when extra time is required for care for hospitalized PLWD (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Minaya-Freire et al., 2020; Seffo et al., 2020). Other scholars agree, noting that budgetary constraints result in less time spent with patients (Catananti & Gambassi, 2010). Time constraints contribute to nurses’ stress levels (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020). Nurses noted that stress leads to decisions regarding assessment and management being made for the sake of efficiency rather than effective pain management practices for PLWD, again noting an overall lack of organizational support (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020).

Limitations

The authors chose to conduct a scoping review to determine the types and amount of research that was published in a recent, narrowly defined period of time. This may have resulted in the elimination of some information that is pertinent to nurse’ pain management in hospitalized PLWD. Only three countries, all located in Europe, were represented, which indicates the need for global research to determine potential differences dictated by culture and ethnicities.

Other limitations are the exclusion of non-English articles that may be relevant. Additionally, the selection of databases may not have provided all possible literature in other sources that were not searched or included. However, the review results are consistent with the findings of authors who have studied pain management in long-term care facilities and therefore should not be negated (Kaasalainen et al., 2017).

Implications

The authors of all the included articles indicated that institutional policies and procedures were not designed to provide person-centered care for PLWD, which has been suggested and endorsed by the World Health Organization (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017; Minaya-Freire et al., 2020; Minaya-Freire et al., 2021; Seffo et al., 2020) Pain management was even noted to be suboptimal in the study situated in an acute care geriatric unit that had implemented a persons centered care model (Minaya-Freire et al., 2021).

These findings suggest that a multimodal approach that includes an assessment of current policies and procedures for pain assessment and intervention should be conducted. Organizational policies and procedures that use current clinical guidelines, such as assessment methods endorsed by the IASP (Herr et al., 2019b) and interventions such as those suggested by Achterberg et al. (2020) and Zwakhalen et al. (2018) should be incorporated into practice. Standardizing pain management practices would also help alleviate some of the communication issues associated with information sharing between staff, and across all care transitions from community dwellings and the hospital.

Pain management in a hospital environment is complex (Bruneau, 2014). Therefore, a multimodal approach that uses knowledge translation frameworks that involve the clinical nurses to assess and implement best practice is suggested. Use of knowledge translation frameworks that includes education for best practice clinical guidelines for pain assessment and intervention in hospitalized PLWD, may improve comfort and engage interprofessional teams, and individualized care plans consistent with the ANA’s position statement (Stokes, 2018). Solutions also need to include the community to improve communication and transitions of care. One of the studies in this review demonstrated success improving pain assessment and intervention using a knowledge translation framework called action cycle research (McCorkell et al., 2017) demonstrating the value of such frameworks.

Leadership needs to be involved in methods to improve pain management among nurses for hospitalized PLWD. Time constraints contributing to nurses' stress may result in burnout and should be addressed at an organization leadership level to prevent nurses from leaving the workplace (Kang & Hur, 2021). These actions would improve patient care and quality of life for PLWD, as well as nurses' feelings of well-being.

Dementia-specific education, including pain assessment, pain management, standardized pain assessment, and organizational policies and procedures, combined with better information sharing in all care transitions, would support nurses as they strive to improve pain management practices.

Conclusion

It was clear in the studies included in the review, that nurses working in hospital wards and the emergency department did not follow evidence based best practice clinical guidelines for pain assessment and intervention, particularly when the PLWD had difficulty communicating. It is interesting that theses deficits exist even in the gerontology hospital wards (Krupić et al., 2018; Minaya-Freire et al., 2020; Minaya-Freire et al., 2021) where the nurses cite educational deficits.

The results of this scoping review illuminate the paucity of current literature available on how pain is assessed and managed by nurses when PLWD are admitted to the hospitals. The ANA, ASPMN, and ISPM have worked diligently to provide best practice evidence-based guidelines to improve the management of pain for over 50 years (Herr et al., 2019b; Raja et al., 2020; Stokes, 2018). These include tools designed to assess pain in vulnerable populations such as PLWD who are not able to communicate verbally (Herr et al., 2019b). Other scholars have provided practice guidelines for pain interventions in PLWD (Achterberg et al., 2020; Zwakhalen et al., 2018). However, reviews such as this one identifies a significant practice gap based on a failure to use evidence-based practice guidelines.

Organizational support and resources need to be dedicated to ongoing education for nurses working on the front lines. Despite the complex care needs of PLWD who are admitted to a hospital, nurses require standardized policies, procedures, and adequate knowledge so that they can effectively assess and manage pain when hospitalized. Using implementation science frameworks that involve the clinical nurses may provide hospital leaders with the tools to improve nurses' pain management practices for hospitalized PLWD. As the prevalence of hospitalized PLWD who have painful conditions continues to increase, there is an urgency to develop solutions that address this impactful knowledge-practice gap and provide PLWD with individualized person-centered care.

It is clear that while there is a knowledge and practice gap, nurses' beliefs may contribute to undermanaged pain in PLWD. As most PLWD are older, there may be unconscious biases based on ageist stereotypical beliefs and dementia stigma (Achterberg, 2019). Beliefs are formed by culture, social upbringing, age, gender, knowledge, and experience ((Bruneau, 2014; Coker et al., 2010). The combination of such ageism, dementia stigma, knowledge gaps, challenges and barriers discovered through this review may underpin reasons nurses do not utilize standardized pain assessment and management methods to effectively manage pain in hospitalize PLWD. We suggest research examining nurse factors, beliefs, and knowledge be conducted to understand why hospitalized PLWD have pain that is unrelieved. In discovering underlying causes for suboptimal pain management practices, practice solutions may be developed.

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Table 2.5

Descriptive Summary of Articles Included in Scoping Review

Characteristic	**% (*n*)**
Country	
Sweden	50.0 (3)
Spain	33.3 (2)
Ireland	16.7 (1)
Type of research	
Qualitative	66.7 (4)
Quantitative	16.7 (1)
Mixed method	16.7 (1)
Setting: Acute care unit or ward type	
Acute care geriatric	33.3% (3)
Emergency department - orthopedic trauma	16.7% (1)
Post-operative orthopedic	16.7% (1)
Trauma intensive care	16.7% (1)
Nurse participants	*n* = 105
Age	Mean=40.5
Female	73.3 (77)
Male	26.7 (26)
Ethnicity	Not reported
Education level of registered nurses	*n* = 72

Characteristic	**% (*n*)**
Master’s degree	38.9 (28)
Candidates	16.7 (12)
Professional experience	
< 5 years	25.8 (24)
6-10 years	18.3 (17)
11- 15 years	30.1 (28)
16-20 years	15.1 (14)
> 20 years	10.8 (10)
Sample size	Range 2-51 (*n*=103)
Patients included in studies	
Sample size	Range 20 – 111, *n* =111
Age	*M* = 87 (*SD* = 5.1)
Male	44.1 (49)
Female	55.9 (62)
Primary reason for admission	*n* = 6
Hip fracture for surgical intervention	50.0 (3)
Orthopedic trauma	16.7 (1)
Medical conditions	33.3 (2)

Table 2.6

Details of included articles

Author (Year) Country	Purpose and methods	Pain assessment, frequency and intervention methods, description of adequate pain relief, and measure of effectiveness	Barriers to pain assessment and management
1. Krupic, et al. (2018) Sweden	To explore the experiences of nurses who work in a post operative geriatric ward when assessing patients with dementia and hip fractures post operatively Qualitative: 23 item questionnaires with combination of demographic data and open-ended questions on 51 nurses group interviews with 21 nurses	All nurses used a combination of visual assessment and patient feedback when possible. No formal assessment tool identified Frequency of pain assessments not described Management methods not described Adequate pain relief not described Effectiveness not described	Communication with patients very difficult Knowledge deficits related to dementia, and how to assess and treat pain Information regarding patient dementia status and communication patterns inconsistent Team information on dementia status and communication patterns lacking on handoffs between wards Extra time is required to meet demands of dementia care
2. Krupic, et al. (2020) Sweden	To explore the experiences of intensive care nurses when assessing patients with dementia and hip fractures post operatively Qualitative: five focus group interviews with 21 nurses	All nurses used a combination of visual assessment and patient feedback when possible. No formal assessment tool identified Frequency of pain assessments not described Management methods not described Adequate pain relief not described	Communication with patients very difficult Knowledge deficits related to dementia, and how to assess and treat pain Care of patient with dementia causes staff stress related to patient communication issues, lack of training and resources Care of patient with dementia requires extra time

Author (Year) Country	Purpose and methods	Pain assessment, frequency and intervention methods, description of adequate pain relief, and measure of effectiveness	Barriers to pain assessment and management
		Effectiveness not described	
3. McCorkell et al. (2017) Ireland	To increase nurse awareness of patient with dementia needs when admitted to an acute care orthopedic ward Mixed methods using three action research cycles: nurse participants were those working on an orthopedic ward	Pre and post action cycle retrospective audit was conducted on 20 patient medical records Pain assessment prior to implementation of a Cognitive Impairment Pain Assessment scale was 0%(N=0); improving to 95% (N=19) Pain medication administration was administered regularly 30% (N=6); improving to 90% (N=18) Frequency of pain assessments not described Management methods not described Adequate pain relief not described (presumed with increased administration of pain medication) Effectiveness not described	Communication is essential but very difficult when caring for patients with dementia All members of the healthcare team need to be aware of patients who have diagnosis of dementia Traditional pain assessment tools are not adequate, need to use an assessment tool that combines visual and verbal communication
4. Minaya-Freire et al. (2020) Spain	Identify barriers and facilitators for nurses who work on an acute care geriatric unit pain management in patients	All nurses used a combination of visual assessment and patient feedback when possible. No	Communication with patients very difficult Knowledge deficits related to dementia, and how to assess and treat pain

Author (Year) Country	Purpose and methods	Pain assessment, frequency and intervention methods, description of adequate pain relief, and measure of effectiveness	Barriers to pain assessment and management
	with dementia who are > 85 years of age Qualitative: combination of open-ended questionnaire and group interviews in two phases of 10 nurses	formal assessment tool identified Frequency of pain assessments not described Management methods not described Adequate pain relief not described Effectiveness not described	Time constraints limited ability to conduct proper pain assessments and provide non-pharmacological interventions
5. Minaya-Freire et al. (2021) Spain	Assess nurses' pain management practices on patient > 65 years of age who have dementia and are admitted to an acute care geriatric unit Quantitative: Retrospective descriptive study on 111 patient records. Record review was conducted in four phases of pain assessment: evaluation, intervention, and re-evaluation	Pain was assessed using the Numerical Rating Scale (NRS) or PAINAD scale Patients who were assessed using the NRS received more pain therapies Pain therapy consisted of PRN and scheduled medications Complementary Alternative Medical (CAM) therapies were offered very few times Pain interventions were provided a median of one time per day Adequate pain relief not described (presumed with pain management interventions) Effectiveness not described	There was variability noted between different nurses in the manner of pain assessment and management resulting in pts who were able to self-report pain intensity receiving more pain relief interventions Nurses require increased knowledge about which pain scales are used, and when they should be used Patients with dementia received one third less pain medication when compared to other post-operative patients
6. Seffo et al. (2020) Sweden	Describe the experiences of nurses who work in an	All nurses used a combination of visual assessment and patient	Communication with patients very difficult

Author (Year) Country	Purpose and methods	Pain assessment, frequency and intervention methods, description of adequate pain relief, and measure of effectiveness	Barriers to pain assessment and management
	emergency department when assessing pain in patients who have dementia and a fractured hip Qualitative: five focus group interviews with 21 nurses	feedback when possible. No formal assessment tool identified Pain medication was administered without formal pain assessment as it was presumed that all patients have some degree of pain Use of nerve blocks and other medications to treat pain Frequency of pain assessments not described Adequate pain relief not described Effectiveness not described	Knowledge deficits related to dementia, and how to assess and treat pain High stress area with patient requiring extra time to properly care for emergent condition Safety of patients difficult as often cannot leave patients alone Lack of resources to account for extra time required to care for patient with dementias

Table 2.7

Search Strategy for a Scoping Review on Nurses' Pain Management of Older Patients with Dementia in a Hospital

Databases:
Medline
EMBASE
CINAHL
PsycINFO
Scopus
Cochrane
DOAJ
ProQuest Dissertations and Theses

Limits:
2016 - 2017
English

Search strategy example: Medline Database

1. Patient with dementias in hospital

(dementia or alzheimer* or parkinsons or huntington) and (hospitaliz* or inpatient* or in-patient* or "acute care" or ICU or "intensive care" or "critical care")

2. Nurses

Nurs*

3. Pain assessment/treatment

Pain adj3 (assess* or measur* or treat* or intervention* or scale* or test* or manag*)
Analgesi*
opioid* or opiate*
Narcotic*
"Non-steroidal anti-inflammatory" or NSAIDS (could also list known drugs e.g., tylenol, aspirin, etc. make sure to include brand name and generic names)
Pain adj2 "non-pharmacological"
Pain adj3 (reduc* or relief or reliev* or increas* or improv*)
(dementia or alzheimer* or parkinsons or huntington) and (hospitaliz* or inpatient* or in-patient* or "acute care" or ICU or "intensive care" or "critical care")) AND Nurs*
(Pain N3 (assess* or measur* or treat* or intervention* or scale* or test* or manag*) OR
Analgesi* OR
(opioid* or opiate*) OR
Narcotic* OR
("Non-steroidal anti-inflammatory" or NSAIDS) OR
Pain N2 "non-pharmacological" OR
(Pain N3 (reduc* or relief or reliev* or increas* or improv*))

Table 2.8

Data Extraction Definitions and Instructions

Data will be extracted into two data extraction tables:
Data Extraction Table 1: Description of pain assessment and management strategies
Data Extraction Table 2: Description of study characteristics

Data Extraction Table 1: Description of pain assessment and management strategies

First author (year): refers to the first authors' last name and the year that the article was published.
Study ID: refers to the numerical study number assigned to the article from which data is extracted.
Context / Setting:

- **Country:** refers to the country in which the study was conducted.
- **Site:** refers to the site that the study participants were recruited from (all should be an acute care facility). Specifically, data should be extracted in relation to the name of the hospital? The type of unit? specify

Target population: refers to the population that the author has described as the group the study intervention will be conducted on. One summary sentence can be extracted, usually found in the background or study aim.
Pain assessment and management strategies**:** refers to the strategy the author has described for inferring the presence, amount or character of pain or for managing the pain, noted in the methods section or section entitled "intervention" or "treatment".

> **Pain assessment:** refers to an evaluation made by a nurse of the type, nature, duration, intensity and location of a patients pain. Included is the impact or effect on the patients ability to participate in normal daily activities (Medical dictionary retrieved from https://medical-dictionary.thefreedictionary.com › pain).
> **Pain management:** refers to the process of providing care that alleviates or reduces pain and encompasses pharmacological, non-pharmacological and other approaches (Medical dictionary retrieved from https://medical-dictionary.thefreedictionary.com › pain).

All details that are offered by the authors should be extracted into the following categories:

- **Name of the pain assessment:** refers to the name of the pain assessment approach that is identified in the article. This will most likely be the name of an assessment tool. The name of the tool and the reference for the tool should be extracted.
- **Assessment details:** Extract the details of the assessment tool. (e.g., list out the specific items and response options for scales, the indicators used for an observational measure, or the questions that were asked in an interview).
- **Name of the intervention:** refers to the name of the intervention that is identified in the article. If there is a reference for this approach, the reference should also be extracted.
- **Adequate pain relief definition**: Extract information to describe how the authors defined what they meant by "adequate pain relief". One or two sentences should be

taken from the background, results or discussion to show how the authors defined what was adequate and compared to inadequate pain relief (e.g., this could be a particular value on a validated scale, the self-report of participants in an interview, or change of a defined size on a scale; extract how the author operationalized this construct in their study).

- **Measuring effectiveness:** refers to how pain management effectiveness is measured. This is identified by the author's description of the end result of the management strategies. The goal may be noted in the study aim or objective, or in the background or as the author's description of the intervention.
- **Management components and activities:** is the extraction of a detailed description of the pain management strategies. These are otherwise characterized as specific elements that produce changes leading to the outcomes. In this review, these are actions taken by the nurse that relate to pain management and would be noted in the methods or intervention section. List each component (e.g., giving a medication, offering distraction, etc.), and extract specific activities that describe each component (e.g., how distraction actually offered. Be as specific as possible).
- **Mode of delivery:** refers to the format and approach for delivering or conveying the management described in the paper (e.g., for a medication, the mode of delivery could be oral, IM, SC; for distraction this could be done in-person, using technology, etc.). Whether a standardized or tailored approach was used should be extracted. A standardized approach refers to the same intervention and manner of delivery to all participants. A tailored approach changes or customizes the intervention to individuals or participating groups. If it was tailored, how it was tailored should be described (e.g., distraction was delivered in-person and using pictures of cats because the person was not familiar with the available iPad and preferred images of cats).
- **Dose:** refers to the amount of intervention that participants were exposed. Describe in actual occurrences (e.g., how many mg of a medication were given and how often; the timing, frequency and duration of distraction).

Data Extraction Table 2: Description of study characteristics

First author (year): refers to the first authors' last name and the year that the article was published.
Study ID: refers to the numerical study number assigned to the article from which data is extracted.
Sample Size: refers to the sample size for the study. If there is a control group and study group, identify the number for each.
Age: refers to the average (mean or median) age, or the percentage of the participants as described by the author. If not described in number format, note the author's description of the target population (e.g., older adults, or age range of study participants). If there are separate groups in the study, these characteristics should be described for each group and for the overall sample.
Gender / Sex: refers to the percentage of the sample that was female / women, male / men, or non-binary. If there are separate groups in the study, these characteristics should be described for each group and for the overall sample.

Ethnicity: if available, refers to the percentage of the study sample described by ethnicity. Ethnicity is defined as… If not described in number format, note the author's description of the target population (e.g., range or description of Caucasian or Hispanic, or other ethnicities). If there are separate groups in the study, these characteristics should be described for each group and for the overall sample.

Cognitive Impairment: refers to the level of dementia, or cognitive impairment in the study sample. If a tool was used to measure the level of impairment, note the name of the tool and the meaning of measurements. If noted, the numerical percentages, mean score and how these measures equate to mild, moderate or severe impairment. If there are separate groups in the study, these characteristics should be described for each group and for the overall sample.

Health Status: refers to any available data on the study participants health status and how it was measured. This includes descriptions of chronic or acute conditions by name or numerical representation. If there are separate groups in the study, these characteristics should be described for each group and for the overall sample.

Setting: refers to where the study was conducted (e.g.,). If there are separate groups in the study, these characteristics should be described for each group and for the overall sample.

Comparison Intervention / condition: refers to the way the study describes the groups that are compared. Otherwise known as a control group and experiment group that received the intervention. The groups are used to compare the effect of the intervention under evaluation. Describe what the comparison group receives instead of the intervention (e.g., usual care, a different dose of the same intervention, etc.)

Design:

- Overall study purpose: extract one or two sentences that state the aim of the overall study (e.g., the purpose of the study was to assess pain as experienced by people with dementia in a hospital setting in Alberta, Canada).
- **Study design:** refers to quantitative: experimental or RCT, quasi-experimental or cohort, non-experimental, qualitative
- If the article is Qualitative the following additional design details should be specified:
    - **Semi structured interviews:** note if these were in-depth interviewed, qualitative interviews, biographical interviews
    - **Focus groups:** note if these were group discussions, group interviews, friendship group discussions
    - **Focus groups and semi-structure interviews combined**
    - **Ethnographic methods:** note is the study was conducted by participant observation in any manner, and the manner in which they were conducted
    - **Other methods:** such as photovoice, questionnaires with open ended sections, written narrative
    - **Mixed qualitative methods:** combining interview or focus groups with questionnaires or written narrative
- **Number and timing of data collection points:** for studies that included an intervention for pain, extract the timing of pain assessment in relation to the intervention (e.g., pain assessed at pretest, posttest and follow-up)
- **Method of assigning participants to group is (random, non-random, procedure)**

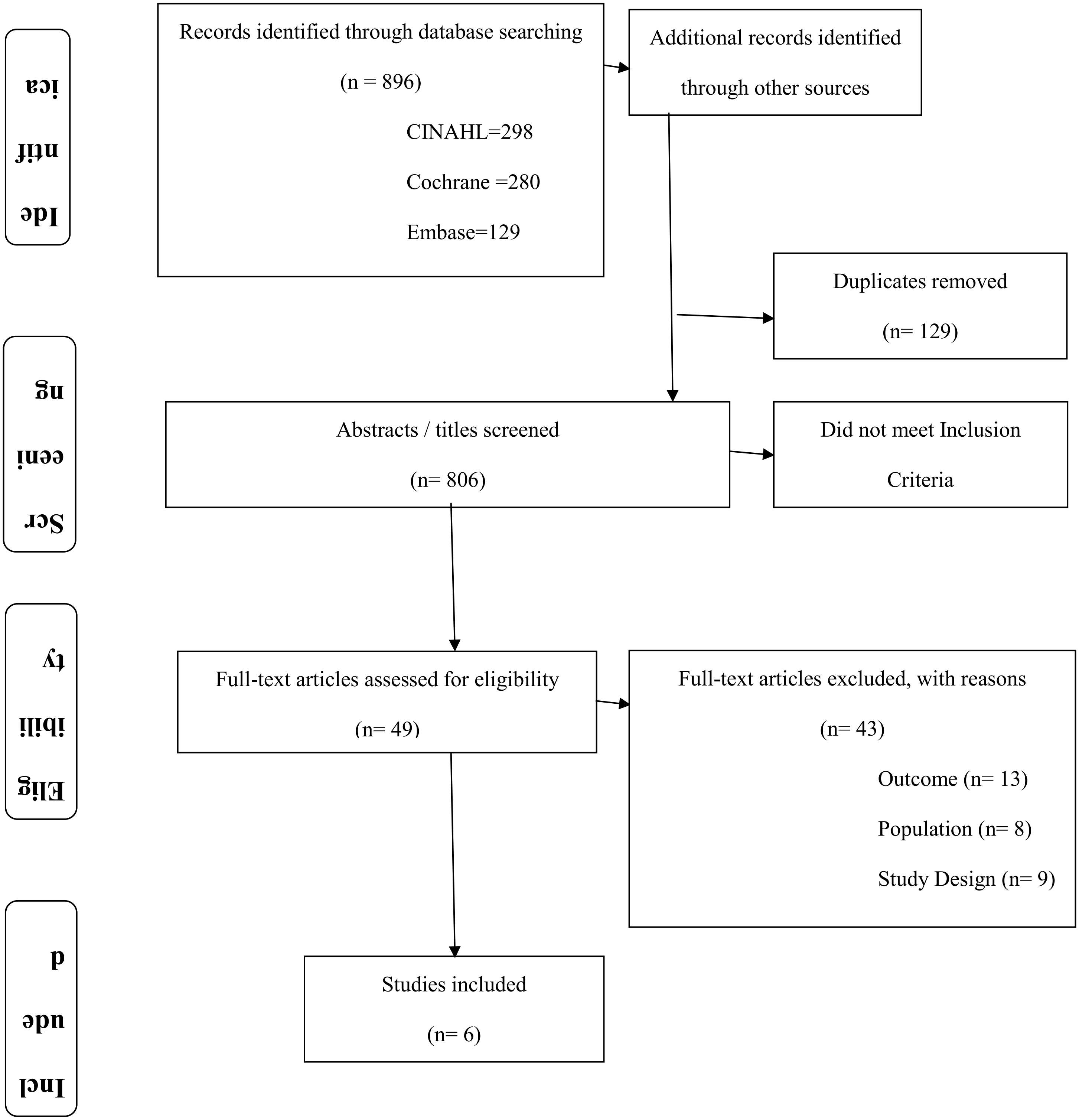
- **Confounding variables;** these are variables that are adjusted for statistically in the analysis. List each variable that is adjusted for in the analysis assessing the effects of pain management approaches upon each outcome.

Results: refers to study findings which describe either the barriers to pain assessment OR the impact of pain management on the outcome of pain .

- For results about the impact of pain interventions on the outcome of pain: Do NOT extract results of the impact of the intervention on other outcomes, but other outcomes that were assessed can be briefly noted in a list (e.g., other outcomes assessed included depression and falls).
  - For quantitative studies:
    - Note the comparison, and how the comparison was analyzed. This might mean a between group or within group comparison or changes that were measured according to the study design.
    - Effect Size: highlight the effectiveness in magnitude and significance of findings. Reported in a correlation, odds ratios, eta-square or Cohen's d. Record the direction of the finding. If it is not reported, record the number of participants in each group, the mean and standard deviation scores for before and after testing.
    - Measure of Dispersion: reported as confidence interval, standard deviation and standard error
    - Statistical significance: reported as significant relationship between variables. Report the value.
  - For qualitative studies:
    - Descriptive content analysis: Extract characteristics, codes, categories, subcategories and themes related to the impact of pain management as described by the authors. Include 1 or 2 participant quotes which support extracted data. Group will be coded data into similar categories

Figure 2. 1

Flowchart of Screening Process



Chapter 3: Hospital Nurses' Knowledge and Beliefs about Pain Management Among Older Persons Living With Dementia: A Cross-sectional Survey Study

Ingleson, B., Dahlke, S., O'Rourke, H.M., & Hunter, K.F. (in preparation) Hospital nurses' beliefs and knowledge about pain management among older persons living with dementia: A cross-sectional survey study. Target journal: *Geriatric Nursing*

Abstract

Background: Hospitalized older persons living with dementia (PLWD) often experience unrelieved pain. Nurses' personal knowledge and beliefs are strong predictors of pain management practices. Beliefs are formed by culture, social upbringing, age, gender, knowledge, and experience. Very little research has been conducted on the knowledge and beliefs about pain management of nurses working with hospitalized PLWD. Moreover, the impact of individual nurse factors such as age, gender, and experience in their pain management practices with PLWD is unknown. Therefore, the purpose of this study was to provide evidence of the influence of nurses' age, gender, age, and experience on knowledge and beliefs when managing pain in hospitalized PLWD.

Design and Methods:

An exploratory, descriptive non-experimental cross-sectional study using the Knowledge and Beliefs about Pain in Elderly Patients with Dementia survey examined Registered Nurses' beliefs and knowledge about pain management. This is the first study in an explanatory mixed method design and informed data collection in the second and qualitative study reported elsewhere. Data were collected between February and July 2022 on nurses working in two hospitals in Southern California. The hospital with the larger sample of nurse participants was designated a Nurses Improving Care for Healthsystem Elders (NICHE) facility. A standardized validated survey tool was used to measure knowledge and beliefs called the Knowledge and Beliefs and Pain in Elderly Patients (KBPED). We used three of four factors that were pertinent to our study question which were: (1) general beliefs about pain, dementia, and aging; (2) knowledge about pain management; and (3) beliefs about pain in older persons. Data were analyzed using a multivariate analysis of variance (MANOVA) to assess whether nurses' gender, age, and

experience contributed to observed differences in beliefs and knowledge about managing pain in hospitalized PLWD.

Results: There were 202 nurses who participated in the study, representing a response rate of 13%. The primary hospital had 190 nurse participants, whereas the secondary hospital enrolled 12 respondents. Most study participants were female (*n* = 176), males (*n* = 26). Most had a baccalaureate degree or higher (*n* = 131) and worked in an inpatient area (n = 126). Nurses who worked in the ambulatory care areas represented the emergency department, cancer infusion care, or procedural areas (*n* = 76). Results from a MANOVA analysis did not support any differences in nurses' general beliefs about pain, dementia, and aging, knowledge about pain management, and beliefs about pain in older persons, when compared across nurses' age, gender, or years of experience. However, testing conducted using an analysis of variance revealed that men had less favorable beliefs about pain in older persons than women. This finding may be the result of the small number of male participants. Overall analysis of the means and standard deviation for the three factors indicated that there were opportunities to improve nurses' knowledge deficits related to pain management, and beliefs that may indicate negative stereotypes about pain in older PLWD.

Conclusion:

The study found that even in a facility designated as a NICHE site, there are knowledge deficits and negative stereotypical beliefs that may result in pain that is underrecognized and undermanaged in hospitalized older PLWD. Study results also suggest there may be a difference in knowledge between female and male nurses in terms of knowledge and beliefs that may impact pain management practices. Further research is needed to understand this and other potential influences on nurses' understanding of this area of care.

Key words: nurses pain assessment, pain management, age, gender, experience, survey, general beliefs, dementia, knowledge, ageing

Hospital Nurses' Beliefs and Knowledge about Pain Management among Older Persons Living With Dementia: A Cross-sectional Survey Study

Hospitalized persons living with dementia (PLWD) often experience unrelieved pain. Undermanaged pain accelerates changes in cognition, memory loss, and functional decline, underscoring the need for proper assessment and intervention in older persons living with dementia (PLWD) (Achterberg et al., 2020; Achterberg, 2019; Husebo et al., 2012; Kaasalainen et al., 2017; Lichtner et al., 2016). Limited literature has explored hospitalized PLWD, but what is available suggests nurses often underrecognize, underreport, misdiagnose, and undermanage pain in hospitalized PLWD (Cravello et al., 2019; Kaasalainen et al., 2017; Lichtner et al., 2016; Savvas & Gibson, 2016; Zwakhalen et al., 2018). Moreover, negative biases towards older people and dementia stigma may also play a role in nurses' pain management (Stokes, 2018). How registered nurses (RNs) assess and manage the pain of hospitalized PLWD is poorly understood. This study examines nurse-related factors of age, gender, and years of experience to understand how they influence pain management practices in hospitalized PLWD.

Background

Dementia is a progressive clinical syndrome caused by neurodegenerative processes that damage the brain (Alzheimer's Disease International, 2019). Characteristics of dementia include impairments in memory, reasoning, cognitive function, ability to communicate, and judgment, and may also include changes in personality, moods, and behavior (Palm et al., 2016; Timmons et al., 2016). Age is the single most significant risk factor for developing dementia (Alzheimer's Disease International, 2019). Unfortunately, many older adults who have dementia also suffer from chronic pain (Briggs et al., 2017; Molton & Terrill, 2014). Approximately 40% to 80% of PLWD suffer from some chronic, acute, or a combination of chronic and acute pain daily, and with more intense or severe pain at times, such as those who are in hospital for surgical or other care (Kaasalainen et al., 2017; Larsson et al., 2017; Molton & Terrill, 2014). Multiple physical comorbidities from diseases such as osteoarthritis, cancer, and neuropathic conditions such as diabetic neuropathy, post-herpetic neuralgia, and post-stroke pain result in chronic pain and often lead to multiple hospitalizations (Cravello et al., 2019; Husebo et al., 2012; Lichtner et al., 2016; Timmons et al., 2016). Ultimately, persons with combinations of chronic pain, a diagnosis of dementia, and an acute condition requiring hospitalization present unique care challenges when hospitalized.

Registered Nurses are responsible for ongoing pain assessment and management of hospitalized PLWD. The seminal work by McCaffery et al. (2000) described the nurses' role as assessing whether the patient is experiencing pain, establishing whether the pain is severe enough to require treatment, selecting the best pain management strategy and administering it safely and effectively, and then evaluating its effectiveness. When managing pain with medication, nurses must determine the drug, the dose, and administration method, in keeping with approved hospital unit pain protocols or physician and nurse practitioner orders (Bruneau, 2014; Coker et al., 2010; McCaffery et al., 2000). The American Nurses Association position paper (Stokes, 2018) emphasized the importance of pain management and nurses' ethical responsibility to provide pain relief.

Nurses learn about pain management and their ethical responsibility to manage pain during their education programs; however, they often encounter challenges when managing pain depending on the care environment and the individual's needs, particularly when the person is living with dementia (Fry et al., 2015; Glowacki, 2015; Paulson et al., 2014). Pain management for hospitalized PLWD is time-consuming and requires nurses to use a combination of complex skills (Bail & Grealish, 2016; Bernhofer, 2012; Briggs et al., 2017). When the patient cannot verbally articulate that they are experiencing pain, which is often the case with PLWD, difficulties managing pain are compounded (Bail & Grealish, 2016; Dewing & Dijk, 2016). If a patient has difficulty communicating discomfort and an admission diagnosis is not specific to a painful condition, nurses may not prioritize pain management in their care plan (Jonsdottir & Gunnarsson, 2021).

Another challenge nurses encounter when caring for hospitalized PLWD that complicates pain assessment and management is the expression of responsive behaviors. The Alzheimer Society of Canada (2022) describes responsive behaviors as actions, words, and gestures a person with dementia uses to communicate their needs. Some examples of responsive behaviors include agitation, apathy, repetitive sentences, grabbing others, making noises, and sometimes aggressive, combative behavior (Alzheimer Society of Canada, 2022).

In PLWD, hospitalizations often increase the risk of developing responsive behaviors by as much as 70% (Hynninen et al., 2016). Characteristics of acute care environments such as constant changes, noise, unfamiliar caregivers, and different surroundings, can enhance confusion, escalating behavioral responses and anxiety among PLWD (Digby et al., 2017; Toot et al., 2013). Other overlooked factors that lead to responsive behaviors (e.g. agitation and aggression) are unmet needs such as unrelieved pain (Graham et al., 2022).

When a hospitalized PLWD becomes aggressive, nurses must assess all potential reasons for the behavior, including pain, and provide comfort to avoid escalation that could result in physical injury to the patient, nurse, or other staff (Marx et al., 2014). Psychotropic medications may become the first method for managing agitation and aggressive behavior rather than considering pain as a possible cause (Graham et al., 2022; Jonsdottir & Gunnarsson, 2021; Marx et al., 2014). The former management approach can cause prolonged hospitalization and increased cognitive decline while perpetuating pain, resulting in not meeting the needs of the hospitalized PLWD (Graham et al., 2022; Jonsdottir & Gunnarsson, 2021; Minaya-Freire et al., 2020).

Personal beliefs and knowledge are strong predictors of pain management by nurses (Alzghoul & Abdullah, 2015; Fang et al., 2017; Lichtner et al., 2016; Lin et al., 2020; Scerri et al., 2020; Tsai et al., 2018). In studies conducted primarily in long-term care facilities, some researchers have concluded that the nurses' beliefs and knowledge lead to under-managed pain in PLWD (Jonsdottir & Gunnarsson, 2021; Tsai et al., 2018). Beliefs are personal attitudes or internal feelings that an idea is true or false, even if unsupported by other forms of evidence or even if irrational or unsupported (Lin et al., 2020). An example of a common stereotypical belief among nurses is that pain is an inevitable part of a normal aging process and, therefore, not a priority in caring for hospitalized PLWD (Ben-Harush et al., 2017; Bernardes et al., 2015; Hanks-Bell et al., 2004; Higgins et al., 2007; Okbamicael, 2019, April 15; Rababa, 2018; Scerri et al., 2020; Thielke et al., 2012). Other bias about older people include the belief that older persons do not want to have pain relieved, and that nursing practice with older people is simple and basic as well as undesirable (Achterberg & Husebo, 2019; World Health Organization, 2021). These are examples of ageist stereotypes that lead to unconscious biases that may impact nurses' care for older PLWD.

Knowledge is a familiarity, awareness, or understanding of facts or skills associated with life experiences and clinical situations (Lin et al., 2020). Nurses' knowledge is based on formal and tacit experiential knowledge (Graham et al., 2022; Samarkandi, 2021). Common knowledge deficits include lack of knowledge on: alternate pain assessment methods for PLWD; potentially multiple sources of pain; contemporaneous use of psychotropic medications for responsive behaviors, and pain medication regimens specific to older adults such as using lower pain medication doses, and scheduled verses as necessary medication administration (Coker et al., 2010; Husebo et al., 2012; Minaya-Freire et al., 2020; Zwakhalen et al., 2018). Many authors have suggested that the lack of organizational and educational support contributes to unmanaged in hospitalized PLWD (Hynninen et al., 2016; McCorkell et al., 2017; Minaya-Freire et al., 2020; Scerri et al., 2020).

Scholars have suggested that nurse-specific factors such as gender, age, and experience may influence beliefs, and knowledge; however, the results to date are inconclusive (Alzghoul & Abdullah, 2015; Graham et al., 2022; Samarkandi, 2021). The literature has reported conflicting results about the influence of these nurse-specific factors on beliefs and knowledge about pain management in PLWD. For example, Zwakhalen et al. (2011) noted that novice nurses were more likely to believe PLWD required pain assessment and management, and more experienced nurses demonstrated higher levels of knowledge when managing pain in PLWD. Hweidi and Al-Hassan (2005) found a strong correlation between years of experience and positive attitudes, noting gender differences in that attitudes held by males were more positive than attitudes held by females, toward the care of hospitalized older persons. An integrative review conducted by Rush et al. (2017) assessing attitudes toward the care of hospitalized older adults discovered conflicting evidence in the literature linking nurses' ages to either positive or negative attitudes, and the study was inconclusive regarding the influence of gender. Some published evidence has supported the positive influence of years of experience on increased knowledge levels specific to managing pain in PLWD (Arsalan et al., 2016; Ben-Harush et al., 2017; Gropelli & Sharer, 2013;

Urashima et al., 2022). Other researchers have proposed that experience alone has little effect on the beliefs of nurses when caring for older persons with or without dementia (Toot et al., 2013).

Scholars have suggested that when nurses combine formal education with experiential knowledge, they engage in higher levels of critical thinking, and take a more comprehensive approach to the care of PLWD (Alzghoul & Abdullah, 2015; Dequeker et al., 2018; Samarkandi, 2021; Toot et al., 2013). However, scarce conclusive research has been conducted on how nurses' gender, age, and experience affect beliefs, attitudes, and knowledge regarding pain management in hospitalized PLWD. Instead, published literature reports on pain management with these factors only noted as potential influences. Moreover, methodological problems in quantitative studies conducted in hospitals include small sample sizes ranging from 12 to 305 nurses (Lin et al., 2020; McCorkell et al., 2017), and the use of tools that were not designed to measure nurses' beliefs and knowledge specific to older PLWD. Therefore, this study aimed to provide a robust exploratory quantitative study design to provide evidence of the influence of nurses' gender, age and experience on beliefs and knowledge when managing pain in hospitalized PLWD, inform data collection in a subsequent qualitative study and, provide a baseline for future studies. Knowledge generated with this exploratory, descriptive study can provide insights for focused education about pain management for hospitalized PLWD, which could ultimately result in improved pain relief.

Study Question

The research question was: are gender, age, and experience associated with the nurses' beliefs and knowledge regarding managing pain in hospitalized older persons who are living with dementia?

Method

Design, Setting, and Sample

This exploratory descriptive survey study used a nonexperimental cross-sectional design and was conducted in two acute care facilities in Southern California. One of the facilities was designated as a Nurses Improving Care for Health System Elders (NICHE) site. Each hospital employed between 600 and 1000 nurses, respectively. Their hospital service areas were similar, and located in the same geographical region. Convenience sampling of RNs was used. RNs were eligible to participate if they worked in the acute care or ambulatory care units in the hospital(s). The RNs employed in long-term care, rehabilitation units, or other chronic nursing care were not eligible.

Ethical Consideration

The institutional review boards of the University of Alberta and the study sites approved the study (see Appendix A). All RN participation was voluntary and anonymous; consent was implied when participants completed the survey (see Appendix F).

Methods

Participants and Procedure

Data collection occurred between February 2022 and July 2022. All RNs (n = 1600) who met the inclusion criteria were invited to participate in the study through email, posters, and the organization’s intranet (see Appendix D). An email was shared through both organizations with an information letter explaining the study, its voluntary nature, and that managers would not know they participated. Posters were posted in relevant units and on the organizations’ intranet. The survey was then sent to all RNs by an electronic link. The electronic link opened to the study consent form, which had an additional electronic link at the end of the consent advising that consent was implied by proceeding to the Knowledge and Beliefs about Pain in Elderly Patients with Dementia (KBPED) (Zwakhalen et al., 2007) survey tool (Zwakhalen et al., 2007) (see Appendix F). The survey was administered electronically using the Research Electronic Data Capture (Harris et al., 2019) software.

Measures

Descriptive variables were collected on the study participants including gender, age, number of years of experience, education level, work unit, and whether they worked full or part time (see Appendix E). The nurse related factors that formed the independent variables were gender (male or female), age (in years), and years of experience. The dependent variables for the study were based on the nurse participant's responses to the KBPED survey (Zwakhalen et al., 2007). The dependent variables included three of four possible subscales calculated from the nurse participant's responses to the KBPED survey (Zwakhalen et al., 2007).

The KBPED questionnaire is a psychometrically tested measure of knowledge levels and beliefs about pain in PLWD (Zwakhalen et al., 2007) (see Appendix B). It contains 17 items, using a five-point Likert scale from one to five (1 = completely disagrees, 2 = disagrees to some extent, 3 = no opinion, 4 = agrees to some extent, and 5 = completely agrees). A score closer to 1 indicated that nurse's beliefs and knowledge regarding pain in PLWD are positive (Zwakhalen et al., 2007). The survey has four subscales or factors: (1) general beliefs about pain, dementia, and aging (Questions 1 - 5); (2) pain management in the workplace (Questions 7 - 9); (3) knowledge about pain management (Questions 6 - 10), and beliefs about pain in older people (Questions 15 - 17) (Zwakhalen et al., 2007). This study did not include the second factor which was measured how nurses felt their workplace assessed and treated pain in our analysis because this was not the study focus.

Data was collected on the nurse participants gender, age, and years of worked experience. Data was collected on age using age ranges. The nurses' years of experience was collected in a whole number reported by the participants. To analyze the data, we collapsed age and nursing experience into three groups based on how nurses' ages were grouped and reported in the National Nursing Workforce Study when describing the current nursing workforce in the United States (Smiley et al., 2021). These categories were 20-25, 35-55, and 55 and older. Based on previous scholars' work conducted on nurses' pain management practices and the number of years worked, the categories were 0-3, 4-10, and 11 or more years (Alzghoul & Abdullah, 2015; Knopp-Sihota et al., 2019; Toot et al., 2013).

We used an a priori power analysis calculation using G*Power software (Faul et al., 2007) to estimate a minimal sample size for a global multivariate analysis of variance (MANOVA). This study was exploratory and descriptive in nature because little research that specifically assessed the influence of hospital nurses' characteristics' impact on beliefs and knowledge about PLWD; therefore, we chose a small effect size to calculate the sample size to try to prevent an underpowered study. The results indicated that for three groups to achieve 80% power with a small effect size $f(V) = 0.03$ and a significance level set at ⟨ = 0.05, the sample size should be 231 participants (Cohen, 1988) .

Data Analysis

The Statistical Package for the Social Sciences (SPSS) version 28.0 software (IBM Corp., 2021) was used to analyze the data. A multivariate analysis of variance (MANOVA) was utilized for the study analysis. We used MANOVA to mitigate a family- wise Type 1 error if a statistically significant value was found during testing as there were three independent variables (gender, age groups, and experience groups), and three dependent variables (factor 1, 3, and 4 survey responses) (Tabachnick et al., 2019) The participants' characteristics and data distribution were described using frequencies, means and standard deviations. Assumptions were tested using Box's Test of Equality of Covariance Matrices, Levene's Test of Equality of Error Variances, and the Shapiro-Wilks test, to assess the data set for a normal distribution as multivariate testing is sensitive to data that are not normally distributed (Tabachnick et al., 2019). Next, we conducted bivariate testing using a Spearman's correlation to test for the strength and direction of the association between the predictor variables and the outcome variables. Following this, we applied a three-way analysis of variance (ANOVA) to determine any statistically significant differences in general beliefs, knowledge, and beliefs about aging based on gender, age, and experience. A MANOVA was then used to identify any differences, or patterns between and within the groups to compare general beliefs, knowledge, and beliefs about aging based on gender, age, and experience. The MANOVA was analyzed for main effects only (interaction effects were removed). The small number of nurses with certain combinations of gender, age, and experience was the reason for this change.

Results

A total of 228 RNs responded to the survey (a response rate of 14%). Of these,19 were removed because it appeared that the respondents began to answer the survey, but then abandoned it prior to completion. An additional seven respondents were removed due to missing completely at random data, leaving an analytic sample of 202 participants. The primary hospital had 190 nurse participants (94.1%), whereas the secondary hospital enrolled a total of 12 (5.9%) respondents. Study participants included 176 (87.1%) female, and 26 (12.9%) males. Most respondents had a baccalaureate degree or higher (80.7%). Most nurses worked in the inpatient area (*n*= 126 or 62.4%), and the remaining (*n* = 76 or 37.6%) worked in the ambulatory procedural units, the emergency department, or the cancer infusion care area.

The respondents were in groups of 20-35 (*n* = 66 or 32.7%), 36-55 (*n* = 76 or 37.6%), or 56 years of age or older (*n* = 61 or 30.2%). The years of experience were: 0 to 3 years (*n* = 79 or 39.1%), 4 to 10 years (*n* = 63 or 31.2%), or 11 or more years (*n* = 60 or 29.7%). The majority worked full time (N=73 or 92.4%). Table 3.1 presents all the demographic data.

Table 3. 1

Demographic Characteristics of Participants Divided into Experience Groups (n = 202)

Characteristic	**0-3 years** (***n* = 79)**	**4-10 years ,** (***n* = 63)**	**11 +years** (***n* = 60)**
Female	69 (87.3)	52 (82.5)	55 (91.7)
Male	10 (12.7)	11 (17.5)	5 (8.3)
Age			
20-35 years	52 (65.8)	14 (22.2)	0 (0)
36-55 years	16 (20.3)	29 (46.0)	31 (51.7)
>55 years	11 (13.9)	20 (31.7)	30 (48.3)
Education level			
Diploma	2 (2.5)	1 (1.6)	4 (6.7)
Associate degree	16 (20.3)	5 (7.9)	11 (18.3)
Baccalaureate degree	54 (68.4)	43 (68.3)	34 (56.7)
Master's degree	7 (8.9)	11 (17.5)	9 (15.0)
Doctorate degree	0 (0)	3 (4.8)	2 (3.3)

Worked Area			
Inpatient	53 (67.1)	37 (58.7)	36 (60.0)
Ambulatory / procedural	17 (21.5)	17 (27.0)	12 (20.0)
Emergency	5 (6.3)	2 (3.2)	4 (6.7)
Cancer center / infusion	4 (5.1)	7 (11.1)	8 (13.3)
Work Status			
Full time	73 (92.4)	57 (90.5)	56 (93.3)
Part time	6 (7.6)	6 (9.5)	4 (6.7)

We analyzed the results of each KBPED survey question by calculating the percentages of responses for each scale, completely disagree, disagree to some extent, no opinion, agree to some extent, and completely agree (see Table 3.5). The nurses scored at or near the middle of the five-point Likert scale. A Cronbach's Alpha was calculated for this 17-item survey at 0.728, demonstrating adequate internal reliability.

Next, we calculated the mean composite scores of the KBPED survey subscales otherwise known as factors. There was little difference in the mean scores for each of the composite scores corresponding to each factor. Factor 1 was general beliefs about pain, aging and dementia, *M* = 2.68 (*SD* = 0.65). Factor 2 was knowledge *M* = 2.29 (*SD* = 0.57), and Factor3 was beliefs about aging *M* = 2.70 (*SD* = 0.84) (Table 3.2).

Table 3. 2

Results of KBPED Composite Scores

Name of Factor	**M**	**SD**	**Range**
General beliefs about pain, age and dementia	2.7	.65	3.4

Knowledge about pain management in older adults	2.3	.57	3.3
Beliefs about pain in older people	2.7	.84	3.7

The Shapiro-Wilk test found that the samples found in the data set were not normally distributed, indicating that there might be outliers affecting the accuracy of the results. The results of the Shapiro-Wilks test were general beliefs $W = .985$ ($p = .035$), knowledge $W = .973$ ($p < .001$), and beliefs about aging $W = .969$ ($p < .001$). Then, we assessed the data visually using a Q-Q plot to assess for outliers and their potential effect on the analysis. There were no apparent outliers; therefore, we proceeded with the bivariate and multivariate analyses.

The Spearman rank order correlation measures the strength and direction of the relationship between the independent and dependent variables. The results revealed significant relationships: (1) between experience and age (r (201) =.53, p <.001), suggesting the more experienced respondents were older; (2) between general beliefs and knowledge (r (201) = .27, p <.001), suggesting respondents who believed older persons had pain had better knowledge levels, (3) between gender and beliefs about pain aging (r (201) = .19 p <.001); (4) between gender and general beliefs about aging (r (201) = .32 p <.001), and gender and knowledge (r (201) =.34, p <.001) suggesting that gender positively related to all three survey factors. (Table 3.3).

Table 3. 3

Relationships Between Nurses' Characteristics and KPBED Subscale Results

Name of Factor	**1**	**2**	**3**	**4**	**5**	**6**
1. Gender	--					
2. Age	.11	--				
3. Experience	-.04	.53**	--			
4. General beliefs	.04	.03	.04	--		
5. Knowledge	.04	-.07	-.04	.27**	--	
6. Beliefs about aging	.19**	-.05	-.11	.32**	.34**	--

** Correlation is significant at the 0.01 level (two-tailed)

An analysis of variance (ANOVA) assessed whether any statistical differences existed (when comparing gender, age, and experience) in each dependent variable: general beliefs, knowledge, and beliefs about aging. There were no statistically significant differences between general beliefs, knowledge, and beliefs about aging when compared to age and experience. However, males had a significantly lower beliefs about pain in older people at the 0.05 significance level (F (1, 199) = 8.84, p = .003). To fully understand the differences, we examined the composite means for males and females by age and experience regarding their general beliefs, knowledge, and beliefs about aging. This analysis revealed that males (n = 26) of all ages and experience levels scored higher in their beliefs about aging (demonstrating less favorable beliefs).

The results from the MANOVA analysis revealed no statistically significant differences when comparing gender, age, and experience to general beliefs about pain, knowledge, and beliefs about aging. The results are summarized in Table 3.4. The effect size of each variable was small with partial eta^2 < 0.06 (Richardson, 2011) indicating that in this sample of respondents, their age, gender, and experience, had little association with nurses' general beliefs about pain, their knowledge about managing pain in dementia, and their specific beliefs about pain and aging.

Table 3. 4

Results of a MANOVA Comparing Nurses' Gender, Age and Experience to General Beliefs about Pain , Knowledge, and Beliefs about Aging

Predictor Variables	**Pillais Trace**	**F**	**df**	**p**	**Partial Eta2**
Gender	0.045	3.022	3,194	.031	.045
Age	0.012	.387	6, 390	.887	.006
Experience groups	0.020	.663	6, 390	.679	.010

Discussion

In this exploratory descriptive study, our findings did not support significant differences when age, gender, and experience were compared with general beliefs, knowledge, and beliefs about aging when managing pain in hospitalized PLWD when analyzed using a MANOVA model. We consider that these findings may be a result of low numbers of respondents in overall sample, and low numbers of responses when split into groups by gender, age, and experience (Tabachnick et al., 2019). We did find a statistically significant difference between gender (males) and nurses beliefs about pain and aging when analyzed with a three-way ANOVA. Further analysis revealed that males of all ages and experience levels held less favorable beliefs about aging. Thus, it would seem that the males in our sample believed that increased pain experiences with age are normal and, are less knowledgeable about pain assessment and medication administration in PLWD. We report this inference cautiously due to the number of males in this sample. However, given that differences in attitudes towards hospitalized PLWD based on gender have been identified in another study (Hweidi & Al-Hassan, 2005), further exploration and understanding of such differences in future studies would be informative to design educational interventions for hospital nurses.

Findings of this study are inconsistent with other research from long-term care settings that has suggested that inexperienced nurses do not have an adequate knowledge of assessing and managing pain with medication (Alzghoul & Abdullah, 2015; Toot et al., 2013; Tsai et al., 2018). In our study, we found no relationship between experience and knowledge of pain management. Other scholars have found that even with formal training, without the knowledge gained from experience, hospitalized PLWD who have pain do not receive appropriate pain management (Minaya-Freire et al., 2020; Scerri et al., 2020; Tsai et al., 2018). They suggested that, with experience, nurses develop critical thinking that improves their care of the complex hospitalized PLWD. As the hospital where most respondents work primarily treats older patients, providing even novice nurses with frequent opportunities for exposure to PLWD and opportunity to gain such experience, may have resulted in novice nurses' higher scores of beliefs and knowledge.

When examining the overall mean and range of scores for the three factors, general beliefs about aging, knowledge about pain management in older adults, and beliefs about pain in older people scores, we found they were not overwhelmingly positive. The widest range of scores was found in beliefs about pain in older people, which may suggest that there may be negative stereotypes based on age that may impact nurses pain assessment and management. As well, knowledge scores indicated that nurses did not have high levels of knowledge, as may be expected of a NICHE designated organization.

The organization that is NICHE designated (Capezuti et al., 2012), provides time and resources for nurses at all levels to participate in ongoing education on nursing care for older persons, including pain management. All novice nurses must complete the 12-module NICHE Geriatric Nurse (Capezuti et al., 2012) training course during their first year of employment, which includes a module about caring for PLWD. Although the relationship between nurse knowledge and experience in managing pain in PLWD is not yet well understood, this organizational support may have led to the lack of significant differences between age or years of experience in respondents' beliefs and knowledge of PLWD. There may have been leveling of specialized knowledge through the NICHE program at this site. However, as we did not compare the findings between the two participating hospitals in our study as the number of respondents from each site were vastly different (190 verses 12). Therefore, whether a difference exists remains unknown.

Limitations

This study provides information on nurses' knowledge and beliefs about pain management in the PLWD from nurses who work with a predominantly older patient population, limiting the generalizability of the results. The percentage of nurses who responded to the survey was less than 15%, which may indicate a sampling bias based on self-selection (Smith & Noble, 2014), and data that was collected primarily from one of the participating organizations, thus limiting the generalizability. As such, the survey did not accurately measure the general population of nurses’ beliefs and knowledge for managing hospitalized PLWD. The study was also conducted in-between peak periods of the COVID-19 pandemic, making study participation difficult. Nurses were working under difficult conditions, and the research was being conducted during work hours, which may have had a negative impact on study participation. A larger sample may better reflect the nurses' beliefs and knowledge, and allow interaction effects between age, gender, and years of experience to be examined. More information about nurses' educational experiences related to pain assessment and management and PLWD would enhance the results. Furthermore, this study investigated nurses' perceptions of their pain management, not their actual pain management practices.

Implications

First, given that most of the scores related to knowledge and beliefs about pain management were in the middle of the scale, our results contribute to the growing body of evidence that many nurses of all ages and experience levels who participated could benefit from ongoing education about pain management in hospitalized PLWD. Data found in Table 3.5 which provides scores for each question in the KBPED survey help identify hospital nurses' educational needs when managing pain in hospitalized PLWD. The three questions that scored the most negatively (high scores) indicated a knowledge gap about pain in aging, the fear of overmedicating PLWD, or that pain medication is overprescribed and addictive in older people. These results demonstrate that, even in an organization that serves a large population of older patients that is NICHE designated, where dementia could be present in approximately 40% of the admitted patients, nurses have knowledge and beliefs that could be improved to support better pain management in hospitalized PLWD.

It may be inferred that educational approaches taken thus far, did not translate to high level of knowledge for pain management interventions in hospitalized PLWD. Further research is suggested to compare whether nurses who work in and receive NICHE education or other specialized gerontological education, and work with predominately older populations, have different results to those without these opportunities.

One area that should garner greater attention is that nurses may have negative ageist stereotypes and dementia stigma that result in unconscious biases reflected in their knowledge and beliefs about pain management in hospitalized PLWD. Based on the nurses’ responses in questions pertaining to general beliefs about pain, dementia, and aging, and beliefs about older people in pain, it would be important to identify how nurses’ beliefs for aging and dementia were formed. Further investigations should include testing for ageism and/or dementia stigma and how it correlates to knowledge and beliefs about pain assessment and management in hospitalized PLWD. Therefore, a qualitative research project is needed to explore nurses’ knowledge, beliefs experiences, and the influence of educational methods for pain assessment and management with PLWD.

Conclusions

In this cross-sectional descriptive study, age and experience were not associated with the nurses' beliefs and knowledge regarding managing pain in hospitalized older PLWD. However, there was a statistically significant difference between gender and nurses' beliefs about pain and aging, with males having less favorable beliefs about aging. There is evidence that nurses' knowledge and beliefs may have a negative impact on how pain is assessed and managed in hospitalized PLWD. It is also clear that educational strategies have not provided a solid knowledge foundation for managing pain in these hospitals. Therefore, we suggest that hospital leadership recognize these deficits and develop a culture within the nursing workforce that emphasizes the needs of an aging population, many of whom are in pain and living with dementia when admitted to a hospital.

Assessing and managing pain in PLWD is complex, particularly in a busy hospital environment (Bruneau, 2014; Coker et al., 2010). Using multimodal strategies supported by implementation science frameworks, such as Knowledge Translation Complexity Network (KTCN) and Integrated Promoted Action on Research Implementation in Health Services (i-PARIHS) frameworks that address the complexity of pain management practices based on evidence-based practice guidelines in the context of the hospital environment, would improve nurses' pain management practices (Boyes, 2023; Harvey & Kitson, 2016). Educational strategies that use facilitators to engage clinical nurses in careful, reflective activities to explore unconscious biases based on negative stereotypes about aging and dementia stigma contextualized in the hospital environment are consistent with key elements of the i-PARIHS framework: evidence, context, and facilitation (Bucknor-Ferron & Zagaja, 2016; Dahlke & Hunter, 2021; Hunter et al., 2019; Rycroft-Malone, 2004). Therefore, educational approaches that use implementation science frameworks are suggested to improve nurses' pain management practices in hospitalized PLWD.

This data was inconsistent with the literature that suggests that both age and years of worked experience have an influence on nurses’ knowledge and beliefs. Therefore, the qualitative study semi-structured interview guide was adjusted to include more questions on experience, how knowledge was obtained, and how it is used to manage pain in PLWD.

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Table 3.5

Responses of the Nurses to the Knowledge and Beliefs About Pain in the Elderly with Dementia (KBPED) Questionnaire (n=202)

#	Question	Comple-tely Disagree (%)	Disagree to Some Extent (%)	No Opin-ion (%)	Agree to Some Extent (%)	Comple-tely Agree (%)	Mean	SD
1	Older people experience pain less intensely than younger people.	45.7	41.1	1.5	8.9	3.0	1.83	1.03
2	Pain medication works better in young people than in the elderly.	22.8	42.6	7.9	25.2	1.0	2.39	1.13
3	Pain medication works longer in the elderly than in young people.	5.9	24.3	7.4	55.4	6.4	3.32	1.01
4	Pain medication has more side effects in the elderly than in younger people.	2.0	6.4	4.0	53.0	34.2	4.11	.90
5	Dementia patients experience less pain than nondementia patients.	44.1	41.1	5.0	9.4	0.5	1.81	.94
6	Assessing pain in a dementia patient is a matter of guessing.	26.7	49.0	6.9	15.8	1.5	2.16	1.04
10	Pain medication should only be administered to patients suffering from severe pain.	45.5	46.0	1.0	4.5	2.5	1.72	.89
11	Patients are often prescribed too	5.0	43.6	17.3	24.8	9.4	2.90	1.12

#	Question	Completely Disagree (%)	Disagree to Some Extent (%)	No Opinion (%)	Agree to Some Extent (%)	Completely Agree (%)	Mean	SD
	much pain medication.							
12	It is better to administer pain medication “when necessary,” rather than according to a fixed scheduled.	6.4	38.1	7.9	38.6	8.4	3.04	1.17
13	Administering pain medication should be postponed as long as possible, because dementia patients should receive as little pain medication as possible.	39.6	51.0	6.4	2.0	1.0	1.74	.75
14	A dementia patient should first report pain before receiving the next dose of pain medication.	23.8	50.0	10.4	12.9	2.5	2.20	1.03
15	Pain is part of the aging process.	24.8	34.1	5.9	30.7	2.5	2.50	1.23
16	Older people are more likely to be affected by pain than younger people.	9.4	34.2	12.4	35.1	7.9	2.98	1.19
17	Pain medication, if administered in large quantities easily leads to addiction among the elderly.	12.4	42.1	16.8	23.3	5.0	2.66	1.12

Chapter 4: The Influence Nurses' Knowledge and Beliefs on Pain Management Practices With Hospitalized Persons Living With Dementia: A Qualitative Descriptive Study

Ingelson, B., Dahlke, S., O'Rourke, H.M, & Hunter, K.F. (in preparation). The influence of nurses' knowledge and beliefs on pain management practices with hospitalized persons living with dementia: A qualitative descriptive study. *Gerontological Nursing, or Journal of Clinical Nursing*

Abstract

Aims and Objectives: To understand nurses' perspectives on how their knowledge, beliefs, and experience influence their pain management practices in hospitalized older persons with dementia (PLWD).

Background: Hospitalized PLWD often experience unrelieved pain. Factors such as nurses' personal knowledge, beliefs, and experience are strong predictors of pain management practices. However, very little research has been conducted on how these factors influence pain management practices when PLWD are hospitalized.

Design and Methods: A qualitative descriptive design was used to explore how nurses' knowledge, beliefs, and experience impact pain management in hospitalized PLWD. This study is the second study in an explanatory mixed methods study; thus the quantitative study that is reported elsewhere informed data collection of this study.

Methods Semi-structured interviews were conducted with 12 registered nurses who worked in one acute care hospital in Southern California from October to November 2022. Data were analyzed using content and thematic analysis.

Results: Two themes were discovered: improvising pain assessment and managing pain through trial and error. Participants described assessment, management, and documentation processes inconsistent with hospital policies, procedures, and standardized tools. The findings indicate that knowledge deficits based partly on nurses' experiences and negative stereotypical beliefs, dementia stigma, and unconscious bias about older PLWD influenced nurses' pain management strategies when caring for hospitalized PLWD. Communication challenges and barriers related to perceived inadequate organizational support also negatively impacted effective pain management.

Conclusions: The study findings supported that nurses' knowledge deficits, stereotypical beliefs, and experiences contributed to suboptimal pain assessment and management practices in hospitalized PLWD. Knowledge gaps related to pain assessment and management in PLWD, organizational policies and procedures, and standardized tools led to inadequate communication about pain management with the nursing care team, the patient's family, and outside community facilities. Other knowledge deficits related to inadequate use of evidence-based guidelines for medication administration, effects of pain medications on older PLWD, and signs of delirium. Negative stereotypical beliefs and dementia stigma resulted in unconscious biases that prevented pain assessment and intervention. Utilizing knowledge translation frameworks that prioritize multimodal education methods to implement dementia-specific clinical guidelines, such as those published by the American Society for Pain Management Nursing for those unable to self-report pain, combined with a person-centered care model, would help address knowledge deficits and unconscious biases and improve care.

Keywords:

Qualitative, nurses, hospitalized persons living with dementia, knowledge, beliefs, stereotypes, pain management

The Influence of Nurses' Knowledge and Beliefs on Pain Management Practices on Hospitalized Persons Living With Dementia: A Qualitative Descriptive Study

One of the significant challenges that nurses working in a hospital encounter is managing pain adequately in older persons living with dementia (PLWD). Current literature suggests that nurses often underrecognize, underreport, misdiagnose, and undermanage pain in hospitalized PLWD (Cravello et al., 2019; Lichtner et al., 2016; Savvas & Gibson, 2016; Zwakhalen et al., 2018). PLWD are more likely to be admitted to hospitals and experience longer hospital stays (Möllers et al., 2019; Shepherd et al., 2019). Moreover, pain is the most common reason for PLWD's admission to an acute care institution, making pain management a priority for nurses (Boltz et al., 2021). Furthermore, nurses may have negative beliefs about ageing and dementia stigma influencing their pain management practices with hospitalized PLWD (Stokes, 2018). This paper reports on a qualitative study exploring the influence of nurses' knowledge, beliefs, and experience on pain management practices in hospitalized PLWD (Alzheimer's Association, 2019; Boltz et al., 2021).

Background

Pain is a complicated, complex, and subjective experience (Raja et al., 2020). Pain management relies upon adequate assessment methods. Assessment is a continuous process to ensure adequate pain management (McCaffery et al., 2000). This assessment is usually made based on an individual's self-report of pain, relying on the person's ability to describe their perceived pain level and intensity (Beach et al., 2015; Booker & Haedtke, 2016; Buffum et al., 2007; van der Steen et al., 2015; Zwakhalen et al., 2018). PLWD will eventually lose the ability to communicate verbally. If a person cannot express their pain level and intensity verbally, alternative pain assessment methods, such as observation, should be utilized (Coker et al., 2010;

Cravello et al., 2019). One example of an observation tool, the Pain Assessment in Advanced Dementia Scale (PAINAD) ((Warden et al., 2003), uses facial expressions, frowning, grimacing, grunting, moaning, restlessness, agitation, and changes in cognitive status to assess pain intensity in PLWD (Buffum et al., 2007; Gallagher & Long, 2011; Herr et al., 2019a; Sampson et al., 2015; van der Steen et al., 2015). However, research has suggested that alternative pain assessment methods based on observation are not used regularly (Achterberg et al., 2020; Bruneau, 2014; Lichtner et al., 2016; Peisah et al., 2014; Tsai et al., 2018).

Nurses play a central role in the assessment and management of pain in hospitalized patients. The American Nurses Association published a position paper citing nurses' ethical responsibility to provide pain relief, stating that the nursing process should guide and improve nursing pain management practices (Stokes, 2018). The seminal work on nurses' pain management practice by McCaffery et al. (2000) suggested the nurse assess the patient for pain, establish whether the pain is severe enough for an intervention, select the best intervention based on the patient's assessed pain, administer the intervention both safely and effectively, and evaluate its effectiveness. When the intervention is use of medication, the nurse must determine the drug, the dose, and the method of administration while adhering to hospital pain protocols or the orders of providers such as physicians and nurse practitioners (McCaffery et al., 2000).

Nurses often cite communication challenges as the reason they do not recognize pain in PLWD (Achterberg et al., 2020; Bruneau, 2014; Lichtner et al., 2016; Tsai et al., 2018; Zwakhalen et al., 2018). When dementia makes communication difficult, nurses often use subjective inferences or intuition, making decisions based on their observations, previous experiences, and knowledge (Dequeker et al., 2018; Prkachin et al., 2007). Prkachin et al. (2007) suggested that nurses base inferences on the "strength of complex and subtle evidence concerning the behavior of the patient" (p. 89). Other scholars noted that nurses report pain recognition in PLWD as a "guessing game" (Lichtner et al., 2016, p. 2). Rababa's (2018) study found that nurses managed pain in PLWD through a "trial and error" approach (p. 2). Nurses have also noted that pain assessment is a "classic case of decision-making in uncertainty," particularly when caring for PLWD (Prkachin et al., 2007, p. 89). When nurses rely on intuition and inferences, rather than utilizing validated pain assessment tools that are specific to PLWD, pain management is frequently inadequate (Dequeker et al., 2018; Lichtner et al., 2016; Prkachin et al., 2007; Rababa, 2018).

Pain management based on nurses' use of inference, intuition, and previous experiences is influenced by nurses' personal beliefs and knowledge (Alzghoul & Abdullah, 2015; Ernstmeyer, 2020; Fang et al., 2017; Lichtner et al., 2016; Tsai et al., 2018; Tsai et al., 2022; Zwakhalen et al., 2007). Research conducted in long-term care facilities, specialty nursing wards such as emergency rooms, or end-of-life care such as hospice has noted that nurses' beliefs and lack of knowledge negatively impact their pain management practices in PLWD (Jonsdottir & Gunnarsson, 2021; Youngcharoen et al., 2017).

Knowledge

Scholars have noted that overall, that nurses are less knowledgeable about ageing than other healthcare providers, which contributes to low expectations of older persons, and perceive gerontologic care to be less desirable than caring for younger persons in their profession (Achterberg, 2019; Ben-Harush et al., 2017). Knowledge is a familiarity, awareness, or understanding of facts or skills (Ernstmeyer, 2020). Nurses' knowledge about effective pain management relies on adequate education specific to various patient populations such as PLWD. Other knowledge deficits related to current clinical guidelines and best practices for the care of hospitalized PLWD can also result in ineffective pain management (Bruneau, 2014; Ernstmeyer, 2020; Fang et al., 2017; Lee & Kang, 2020; Martorella et al., 2019; Youngcharoen et al., 2017). In addition to understanding pain management in PLWD, nurses must be educated on organizational policies and procedures, which is especially relevant when managing pain for hospitalized PLWD because of patient care challenges and structural constraints (Dahlke et al., 2019; Lichtner et al., 2016). When nurses have knowledge deficits related to organizational policies, procedures, and practice standards that facilitate nurses’ consistent practice across the healthcare continuum, managing pain is often missed in PLWD (Evripidou et al., 2021).

Beliefs

Beliefs are internal feelings that an idea is true or false, even if unproven or irrational (Ernstmeyer, 2020). Nurses must believe that pain exists and needs to be managed, even when the person cannot verbally communicate that they are in pain. When nurses do not believe a patient is in pain, they will fail to assess and manage it (Catananti & Gambassi, 2010; Fitzgerald & Hurst, 2017; Latina et al., 2015; Tsai et al., 2018). For instance, they may believe that PLWD cannot feel pain, resulting in pain that is not considered, assessed, or managed.

Beliefs based on negative ageist stereotypes and dementia stigma that result in unconscious biases influence nurses' pain management practices in PLWD (Jonsdottir & Gunnarsson, 2021; Tsai et al., 2018). The World Health Organization (2021) describes ageism as prejudicial stereotypes that result in discriminatory actions taken towards a person based on their age. Ageism can be institutional (policies or rules that lead to restrictions against individuals), interpersonal (social exchanges between groups of people), or internalized or directed at oneself (World Health Organization, 2021). Scholars have suggested that ageist stereotypes are deeply ingrained in societal culture and are deemed socially acceptable (Weir, 2023).

Ageism includes negative and positive stereotypes and is manifested at the nurse and patient level (Achterberg, 2019; Cary et al., 2017; Vitou et al., 2022). For example, positive ageism may be based on a belief that all older persons are wise or have positive feelings about one's older family members (Hinchliff, 2016, October 1). The older person may feel that they do not live up to this expectation or perceive themselves this way, which may then translate to negative discriminatory beliefs manifesting in conscious or unconscious biases (Hinchliff, 2016, October 1). Another issue with positive ageist stereotypes is a paternalistic behavior by nurses that manifests in over-accommodations that assume that all older persons require assistance otherwise described as benevolent ageism (Cary et al., 2017; Hinchliff, 2016, October 1; Hunter & Dahlke, 2023; Walsh et al., 2022).

Alternatively, negative stereotypes affect nurses, older persons, and families. For example, stereotypical beliefs that pain is an inevitable part of the normal aging process and that dementia is an inevitable part of aging are prevalent among nurses (Ben-Harush et al., 2017; Bernardes et al., 2015; Hanks-Bell et al., 2004; Higgins et al., 2007; Okbamicael, 2019, April 15; Rababa, 2018; Scerri et al., 2020; Thielke et al., 2012). Other scholars note that older persons can be stoic and hesitant to complain about pain, which perpetuates negative stereotypes among nurses resulting in undermanaged pain (Achterberg, 2019; Burns & McIlfatrick, 2015; Latina et al., 2015; Topaz & Doron, 2013; Youngcharoen et al., 2017).

Ageist biases are typically unconscious based on stereotypes of which the person is unaware (Daniel-Uloa & Smith-Haghighi, 2021). Unconscious biases are "attitudes that affect behaviors, interactions, and decision making" (Marcelin et al., 2019). Nurses are expected to provide impartial care to all persons; however, if unaware or conscious of how positive or negative ageist stereotypes have created personal unconscious biases, quality of care suffers (Daniel-Uloa & Smith-Haghighi, 2021; Hunter & Dahlke, 2023).

Another factor that is prevalent among nurses that may influence pain management practices is dementia stigma. Alzheimer's Society of Canada describes dementia stigma as "any negative attitude or discriminatory behavior against people living with dementia just based on having the disease" (2023)**.** Dementia stigma is prevalent, reduces the quality of life, and extends to families of PLWD (Alzheimer Society of Canada, 2023). Dementia stigma often results in nursing practices that exclude PLWD from having a voice in their care, which includes a presumption that non-verbal PLWD does not have pain (Alzheimer Society of Canada, 2023; Dewing & Dijk, 2016; Krupic et al., 2020; Krupić et al., 2018). Other scholars have shown that when nurses have negative beliefs and dementia stigma, it is assumed that responsive behaviors or the PLWD responses to feeling ignored, often results in increased use of anxiolytic and antipsychotic medications (Digby et al., 2017; Hunter et al., 2013; Vitou et al., 2022). Ageism, dementia stigma, and unconscious biases impact nurses' pain assessment and management decisions. To what degree and if there are differences in a complex hospital environment is unknown.

Nurses' Experiences

Another factor that may influence nurses is a practice based on tacit knowledge and experience, otherwise known as mind lines. Mind lines are described as internalized tacit knowledge based on previous, usually early education, reinforced and influenced mainly by interactions with fellow colleagues, opinion leaders, and previous experience (Gabbay & le May, 2016). Nurses may use mind lines in their pain management practices as foundational knowledge.

Responsive Behaviors and Delirium Related to Pain in PLWD

Further compounding pain management in hospitalized PLWD are responsive behaviors. Characteristics of hospital environments, such as constant changes, noise, unfamiliar caregivers, and different surroundings, can enhance confusion that escalates behavioral responses and anxiety among PLWD (Digby et al., 2017; Toot et al., 2013). Responsive behaviors are described by the Alzheimer Society of Canada (2017) as actions, words, and gestures PLWD use to communicate their needs. Some examples of responsive behaviors include agitation, apathy, repetitive sentences, grabbing others, making noises, and sometimes aggressive, combative behavior (Alzheimer Society of Canada, 2017). The risk of developing responsive behaviors in hospitalized PLWD is as high as 70% (Hynninen et al., 2016; Sampson et al., 2009). Unrelieved pain is often not considered as contributing to responsive behaviors of agitation and aggression (Alzheimer Society of Canada, 2017).

Another serious, often overlooked complication of pain is delirium superimposed on dementia during hospitalization, with prevalence rates as high as 89% (Grover, 2012). Delirium in PLWD is often unrecognized and assumed to be caused by dementia (Grover, 2012). Delirium is an acute neuropsychiatric syndrome considered a clinical emergency requiring immediate treatment (Grover, 2012; Lippmann & Perugula, 2016). It is characterized by sudden changes in a person’s mental status with symptoms of disorientation, possible hallucinations, paranoia, and challenges with normal activities of daily living, such as eating (Lippmann & Perugula, 2016). The causes of delirium are multifactorial and include metabolic disorders such as hypoxia, electrolyte imbalances, post-operative anesthetic, infections, brain lesions, sensory or sleep deprivation, and fever, to name a few (Lippmann & Perugula, 2016). Some of the risk factors during hospitalization are attributed to acute illness and medications or pain that is not managed with appropriate medication choices, for example, the use of antipsychotics rather than pain medication (Han et al., 2022). When left untreated, delirium results in cognitive and functional changes with long-lasting negative impacts on the quality of life (Feast et al., 2018).

Limited research describes the hospital nurses’ knowledge, beliefs, and experiences on pain management practices in PLWD (Bruneau, 2014; Lin et al., 2020). Most of the available research exploring how nurses’ knowledge, beliefs, and experience influence pain management practices in PLWD has been conducted in long-term care facilities (Knopp-Sihota et al., 2019; Zwakhalen et al., 2018). The hospital environment poses different nursing care challenges from those in long-term care, which is related to factors such as environmental changes and the fast-paced demands of nursing care (Auerbach, 2018; Clissett et al., 2013; Dahlke et al., 2019). Understanding hospital nurses’ knowledge, beliefs, and experience about managing pain in PLWD would provide insight into improving comfort and care during hospitalization. This study is the second part of an explanatory mixed method design. Therefore, this study aimed to understand the influence that nurses’ knowledge, beliefs, and experience have on pain assessment and management in PLWD. Based on the results of the exploratory survey study where the findings indicated that there were no significant differences in nurses’ age, gender and experience when asked about their knowledge and beliefs about ageing, PLWD, and managing pain, this study made amendments to the semi structured interview guide to further explore the influence of nurses’ worked experiences on their pain management practices when caring for PLWD.

Methods

Study Design

This study is part of an explanatory sequential mixed methods study (the quantitative portion is reported elsewhere). It was conducted using a qualitative descriptive design to explore "rich, straight descriptions of an experience" (Colorafi & Evans, 2016; Neergaard et al., 2009). A qualitative descriptive method was well suited for this study, as it allowed the researchers to stay close to the data, describing a phenomenon that is not well understood. The research question was: how do nurses' knowledge, beliefs, and experience influence pain assessment and management in hospitalized older PLWD?

Study and Setting

The researcher utilized purposive sampling with a maximized variation technique to establish the study sample (Neergaard et al., 2009; Sandelowski & Leeman, 2012). Study participants were registered nurses (RNs) working on general medicine, post-operative surgery, and telemetry units from a single-site hospital located in Southern California. Patients admitted to this hospital were an average of 78 years of age. The hospital organization is recognized as a Nurses Improving Care for Healthsystem Elders (NICHE) facility since 2012 (Capezuti et al., 2012). Nurses receive extra education about the care of older people including pain management in older persons when hired as well as regular education updates on the topic during their employment. Additional educational offerings available through NICHE are offered for the nurses who voluntarily seek additional education.

Recruitment

Study recruitment consisted of information disseminated via the hospital's intranet, email, and posters placed on nursing units. Nurses who were interested in study participation were asked to contact a research assistant by email or telephone (see Appendix D). Potential participants then received information about the study, anonymity, the interview process, and the time commitment. The research assistant established an interview time that was convenient for each study participant.

Data Collection

The first author completed all interviews with guidance from the first author's supervisor, SD. Before the beginning of the interview, the consent form was reviewed and any questions were answered prior to obtaining written consent (see Appendix G). Each individual semi-structured interview was conducted face-to-face or by telephone in a private office dedicated to nursing research on the hospital site. All interviews were audio-recorded and then transcribed verbatim by the first author soon after each interview to facilitate constant comparative analysis (Vaismoradi et al., 2013). The participants' experiences, beliefs, and knowledge about assessing and managing pain in hospitalized PLWD were explored using a semi-structured interview tool (Appendix C) that consisted of questions developed from the literature and informed by the quantitative study that preceded it (Ingelson et al, 2023, in preparation). Study questions asked the participants about their experiences assessing and managing pain in hospitalized PLWD; their beliefs about aging, pain, and dementia; how pain is assessed and evaluated in nonverbal PLWD; and how they had learned to manage pain in PLWD. The participants work experience and information related to the influence that experience had on their pain management practices was also investigated to glean further information based on the quantitative study results. During each interview, the researcher asked additional questions to discover and clarify information shared by the participants. All interviews were conducted from September through November 2022. The interview times ranged from 10 to 46 minutes. Interviews continued until information saturation or no new information was raised (Walker, 2012). An inductive thematic saturation model was used to assess for data saturation during analysis (Saunders et al., 2018). Information saturation occurred when no new information was considered when codes and themes became repetitive. Reflexive thinking was utilized by the first author, and discussed with the second author, to ensure consistency of codes and themes (Braun & Clarke, 2021). The researchers determined that information redundancy began after the ninth interview but wanted to ensure that there were no new themes to be discovered, therefore a total of 12 interviews were conducted. Interviews 11 and 12 were short, as the participants did not add any new information.

Data Analysis

Data were analyzed using content and thematic analysis (Vaismoradi, 2013; Colorafi, 2016; Hsieh, 2005). Content analysis was well suited to this study as it was exploratory in nature, as there was limited research available that described the nurses' experiences, knowledge, and beliefs when managing pain in hospitalized PLWD. Two researchers (BI, SD) read the first three transcripts to get a sense of the data and identify key concepts. A coding framework was developed from the concepts that became codes. Next, the first author coded the remaining transcripts line by line, capturing key passages that reflected experiences and feelings about pain assessment and management in hospitalized PLWD. Similar codes were grouped together to form categories (Doyle et al., 2020; Graneheim et al., 2017; Kleinheksel et al., 2020; Lindgren et al., 2020; Vaismoradi et al., 2013). Categories were grouped together to form themes. The researchers met frequently to discuss and come to agreement on categories and themes. Participants were assigned non-gender-specific pseudonyms.

Rigor

Qualitative research rigor concerns the trustworthiness of the data findings (Bradshaw et al., 2017; Colorafi & Evans, 2016; Graneheim et al., 2017). Strategies to ensure trustworthiness were implemented throughout the research process (Lincoln et al., 2007). Confirmability was ensured by maintaining an audit trail of coding decisions and researcher reflexivity. Credibility was achieved through methodological triangulation, remaining open to all potential themes, careful analysis of negative cases, and independent analysis of data by members of the research team. Reduction of the data and conclusion-drawing were supported by detailed verification. When disagreements arose about coding decisions or key categories to be integrated into themes, the research team debated our interpretations until consensus was achieved (MacPhail et al., 2016). Dependability was assured through in-depth methodological description, and transferability through the inclusion of participants' demographic characteristics in the study context (Lincoln et al., 2007).

Findings

The sample included 12 registered nurses—three males and nine females. The mean years of experience were 21.2 (1–41), and all worked full-time. Three participants had 3 or fewer years of experience, three had between 4 and 20 years of experience, and six had 21–41 years of experience. Six nurses worked on a postoperative surgical ward and six on medical telemetry.

The data analysis revealed two themes: improvising pain assessment and managing pain through trial and error. The study findings are summarized in Table 4.1 by core themes,

Table 4. 1

Core themes, Categories, and Subthemes

Theme	Category	Subtheme
Improvising pain assessment	Non-standardized assessment methods	● Assessment lacks structure and standardization ● Did not assess pain if not reason for admission ● Assessment method depended on years of experience
	Inconsistent Documentation	● Did not use standardized pain level documentation for assessment and reassessment after intervention
Managing pain through trial and error	Knowledge Deficits	● Knowledge gaps about medication administration that led to administration hesitancy ● Misinterpreted medication side effects on cognitive and behavioral changes ● Responsive behaviors verses symptoms of delirium ● Education suboptimal
	Beliefs	● Stereotypical beliefs and dementia stigma perpetuate unconscious bias ● Dementia patients have altered pain perceptions ● Pain medication advances dementia
	Experience	● More experience led to a more holistic approach
	Communication Challenges	● Communication challenges – patient / family, between team members, between outside facilities and hospital

	Barriers related to Inadequate Organizational Support	● Extra resources needed to maintain patient and staff safety ● Care of older PLWD time consuming

Improvising pain assessment describes the various approaches that nurses used when assessing pain in hospitalized PLWD. Even though some assessment methods were similar, the nurses did not use standardized methods or tools to assess pain. Improvising pain assessment was described through non-standardized assessment methods, and inconsistent documentation.

Non-standardized Assessment Methods

Participants described pain assessment methods that did not include use of standardized tools or assessment methods. Instead, participants described using various methods such as verbal expressions of pain intensity and observation of body language, behaviors, and vital signs when assessing pain in PLWD that were not mapped to valid standardized tools that would provide a pain intensity level.

Most participants reported asking the PLWD to describe their pain or provide a number for their perceived pain level. They noted that in many cases, PLWD were not able to provide information. "*I will ask them how they feel the pain is. Sometimes numerically isn't possible to do" (Royal)*. Avis explained that there were other verbal expressions of pain relating "*they can still communicate if they're having pain or discomfort. . . . in the comments . . . movements . . . or the sounds that they make*" or "*sometimes they'll just say hurt, hurt, hurt".* The nurses used facial expressions as indicators of pain "*. . . you can tell by the grimacing*" (Monroe) or combinations of behaviors such as *"irritability, restlessness, facial expressions" (*Kyrie). Aspen explained that "*their level of frustration is a big indicator for me*". Some participants relied upon vital signs "*you're looking at vital signs . . . elevated blood pressure, elevated heart rate, things like that can tell you when they're in pain*" (Cleo).

Participants carefully considered if PLWD's condition would cause pain that indicated a need for assessment. "*If they have an obvious wound or injury, like a fracture, or there's something, . . . obvious that you know is going to be causing pain . . . then you know that they're going to be in pain already*" (Quinn). However, if pain was not contextualized in the reason for admission or in the admission diagnosis, participants admitted that pain was not considered. For example, "*it [pain] may not be forefront in my mind, whenever I'm assessing the patient, there may be other things . . . I kind of get blinded to the fact that they may be having pain"* (Cleo). There was also recognition that when a patient was quiet or non-verbal, they were often overlooked, especially if the admitting diagnosis did not imply a painful condition. Aspen explained: "*But I feel like when you have a quiet patient, sometimes they can fall through the cracks a little bit*".

Assessment methods varied with participants' knowledge and years of work experience when making decisions on pain assessment methods. Those with fewer than 4 years of experience relied almost entirely on vital signs to indicate pain, regardless of the unit where they worked. Alternatively, those with 20+ years of experience described using combinations of verbal and nonverbal indicators when assessing pain. For example, Zoe, who had more than 20 years of work experience, summarized: "*I assess pain [in dementia patients] . . . by their vital signs and by their nonverbal gestures, and physical gestures that they present*". Like other more experienced participants, Emory also worked to make a connection with the PLWD, explaining, "when *you come into the room again, and they say they don't remember you, . . . you can just talk to them, and then they feel like you're a familiar person. I think that helps a lot [when* *assessing pain]*” and encourages families to bring items from home such as “ *a stuffed animal to calm them [PLWD]*” (Emory) during hospitalization.

Inconsistent Documentation

Documenting the level of pain intensity during an initial assessment or following pain management interventions was not consistent, nor did it follow standardized hospital protocols. When a numerical value indicating pain intensity was documented, participants used the Faces-Revised (Hicks et al., 2001) or the Wong-Baker Faces (Wong & Baker, 2001) scale based on the PLWD’s facial expressions, or the Numerical Pain Rating Scale (Farrar et al., 2001) if the patient was able to verbally communicate. A few of the participants said that there was a dementia-specific pain assessment tool available in the electronic medical record but were not able to name it or describe how it was used. "*I like to use the faces . . . if they are having any pain and kind of get an idea of their levels" (*Ellis). Cleo explained, “*I would use ... the faces pain [scale] . . . I think there's another one that I don't recall. I think it's similar to numbers, numerical, so I don't think that it's too applicable to the situation”,* [and] “*Sometimes you can use the faces [pain scale] . . . I think we have a dementia, pain scale that we can use instead of the zero to 10*" (Kyrie). Some participants chose to describe the patients’ pain intensity in the nurses’ notes. Ellis explained, “*simply documenting in the notes that there are certain experiences that are causing pain”.*

Managing Pain Through Trial and Error

Pain was managed using a trial-and-error approach, which often led to delays in satisfactorily relieving PLWD’s pain. The trial-and-error approach was described in the following categories: knowledge deficits, beliefs, experience, communication challenges, barriers related to inadequate organization support.

Knowledge Deficits. Most of the participants described pain management practices that were based on knowledge gaps about medications that led to administration hesitancy. Some examples were misinterpreted side effects that were attributed to cognitive and behavioral changes, responsive behaviors that were attributed to medications versus symptoms of delirium, and suboptimal education.

Participants expressed a hesitancy to use pain medications. For example, when speaking about pain management in PLWD, Monroe reported: "*They [nurses] are afraid of giving them pain medication. because they're afraid of respiratory distress and more confusion"*. Monroe added *". . . older patients with dementia . . are under medicated".*

Medications were not usually scheduled but were administered as needed, thereby PLWD relied on the nurses pain assessment and decisions to provide interventions. When medications were not scheduled regularly, participants often underdosed medications. For example, participants described managing pain with medication, beginning with the lowest dose with the intent of titrating to achieve adequate levels of comfort. Unfortunately, participants only administered the lowest medication dose and did not titrate the medication. Royal noted that "*it's not going to help if you give them people more pain medicine and not determine where the foundation of the pain is coming from*" and " *if they're having severe pain and I'll get them moderate the moderate medication . . . we live in a real world . . where sometimes that [medication doses] has to be done by judgment" (Cleo)*.

When behavioral changes occurred, it was assumed that it was related to pain medication. For example, Kyrie related:

> "*You have to watch the interaction with the dementia and the medications that you're giving them. Because . . . the pain medications can make it a lot worse specifically, . . . it may make them calmer and go to sleep initially, but then it can make them more aggr*essive."

The participants did not discuss that a potential cause of behavioral changes could have reflected undermanaged pain or delirium, nor did they describe assessing for delirium. Rather, they decreased pain medication administration and administered antipsychotic medications before analgesics. For example, Royal noted, "*most times dementia patients will be severely agitated when they're hurt… you have give them medication [antipsychotic] to calm down before you can do the assessment*". Similarly, Cleo described:

Participants reported that they were not knowledgeable enough about pain management for PLWD. "*I don't think there's enough education*" (Royal). Similarly, Quinn noted that knowledge gaps about pain management were evident in the variation in nurses' approaches to medication interventions: "*Sometimes I've heard some nurses say that's not enough. They need more. I've heard other nurses saying, Oh, my God, don't give them that. . . . they're gonna go really nuts.*"

Beliefs. Many participants expressed beliefs that reflected negative ageist stereotypes, dementia-related stigma that were consistent with unconscious bias. These resulted in pain management practices whereby pain was not assessed, leading to inadequate interventions. When asked if pain management practices were different for PLWD to those who did not have dementia, Ellis stated *"If you know that they're not in the right state of mind, if they're already somewhat demented, . . . they don't act normally*".

Many of the participants expressed that they believed that pain medications made dementia worse. This belief was exacerbated by gaps in knowledge. For example, Quinn suggested, "*Some medicine, some narcotics can make their dementia even worse, so you have to be careful with that*".

Other examples related to the participants' belief that PLWD did not experience pain in the same way or extent as those without dementia. Another example was that PLWD had more side effects when receiving medication than older persons who did not have dementia. Some participants also expressed that older persons did not want to be medicated. For example, Zoe explained, "*Medications in general are just funky things . . . especially with patients with dementia and an elderly population"*, a feeling that was repeated among several participants. Royal shared "*I think sometimes older people want to be stoic with whether they have pain or not";* a feeling that Avis reiterated saying *"they don't want to be sedated*". Quinn shared that "*older people were afraid of getting forgetful*" and "*if they start getting forgetful because of the medication, . . . they behave in a more negative manner".*

Another belief expressed by many participants was that a diagnosis of dementia altered a person's pain perception. For example, Angel reported "*I medicate to help lower the pain perception, even though that's somewhat altered in Alzheimer's and dementia patients".*

When the participants spoke about managing pain in PLWD who were assigned to their care, they expressed compassion and caring. For example, Zoe summarized it expressing "*I am a nurse first, my patients are my priority . . . even if they have dementia, I always take time to make sure their needs are met*".

Experience. Participants who had more years of experience expressed that they used a more holistic approach when managing pain in older PLWD with a general feeling that all patients deserve adequate pain control. Angel summarized:

> *I just have to look at my interventions and see if there seems to be any sort of a positive impact Did their vital signs change. Do they seem quiet, or are they resting in between? What's their facial expression? Are they frowning? Are they moaning? Are they restless? Are they moving more? It's basically just looking at the overall presentation of the patient*

Communication Challenges. All participants noted that communication issues were the most challenging aspect of successful pain management in hospitalized PLWD. Communication was difficult between the nurse and patient, between the patient and family, among healthcare team members, and between outside facilities and the hospital. "*Communication is probably like the hardest part [managing pain] because most of the time if they can't tell us directly, we have to find other ways to find out how severe the pain is and what would be the best management to control their pain*" (Bryn). In situations where communication with the PLWD was challenging, it was helpful if a family member was present. Zoe explained that "*families know the patient better than I do so I ask them, Is this normal? Do you feel that they're in pain and use their guidance to tell me that they're in pain*". However, families sometimes added to the workload when they required extra reassurance because they were "*scare[d] [for their loved ones] . . . because they're so confused, you know, compared to at home or their facilities where they live"* (Quinn).

Communication between different institutions, hospital units, and shifts is crucial to continuity of care and ensuring pain is managed in PLWD. Participants relied on documentation and handoffs between shifts to determine how to assess and manage pain. Cleo noted that "*I* *think that the handoff is important because you may not be able to review all the documentation*". Ellis noted that nurse-to-nurse communication is "*really one of the biggest things, especially with being a bedside nurse"*. Nurses' communication with the nursing team regarding the level of pain was fragmented and often lacked any numerical value. "*In terms of mild, moderate, and severe pain, I try to stay as close to the situation as possible, but it's not always possible [to document pain level]*" (Cleo).

When communication relied on documentation from an outside facility, such as the patient's history, health, medication profile, responses to medications, behaviors, methods of communicating, and how the patient expressed pain, was missing, pain management was difficult. Bryn explained that "*If they're not talking a lot of times you can see one or two days where patients have been off their medicine because they couldn't tell us what they're on. . . and nobody's brought . . . the list of medications that they have*". Participants often had to call pharmacists, family members, outside facilities, and physicians' offices for medication histories, which was time-consuming. As Royal explained, "*I think one of the biggest things we need to do is make sure the medications that they are on are accurately listed so that the doctor can order them"*.

Barriers related to Inadequate Organizational Support. Participants described perceived inadequate organization support as a barrier to adequate pain management practices. They noted that extra resources were often required to keep patients and staff safe. Many participants were concerned when PLWD became impulsive, aggressive, or anxious and they did not have the staff to prevent the patient from harming themselves or others. "*It's hard to have frequent monitoring on them, when you have three or four other patients that have other issues going on that you need to address"* (Quinn*).*

They also noted that comprehensive assessment and management of pain in hospitalized PLWD was complex and time-consuming, especially when communication was difficult. Extra time was needed to gather information from various sources, which was not always supported within the organization. Zoe explained that "*It is twice as much as time . . . because you have to observe them . . .your assessment is . . . going to take a little longer*".

Discussion

The key findings from this study are that nurses' knowledge, (or lack thereof), beliefs, and experience influenced their pain assessment and management practices in hospitalized PLWD. While other studies have explored hospital nurses' knowledge about pain management in PLWD (Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020), this study is unique in that the participants were also asked about their beliefs, adding to our understanding of influences underlying practice. Participants also described how their experiences and prior education formed their knowledge base for assessing and managing pain in PLWD. The participants described knowledge deficits that contributed to or were reinforced by stereotypical stigmatizing beliefs about aging and PLWD. Taken together, the influence of inadequate knowledge, negative beliefs, and experience led to pain that was underrecognized and undermanaged, even in this hospital that provided specialized education for nurses on care of older persons through a nationally recognized program.

Pain assessment strategies were improvised even though standardized assessment tools were available at their hospital site. The result was that pain levels were inferred, which led to incomplete documentation practices, further impacting nurse-to-nurse communication about pain management in PLWD. Although participants articulated using the NPRS, Faces-R, and Wong-

Baker Faces, they could not articulate the use of the dementia-specific pain assessment tool, PAINAD (Farrar et al., 2001; Hicks et al., 2001; Warden et al., 2003).

It is unclear why the participants did not use dementia-specific pain assessment tools since they had received the hospital's standard education about pain assessment tools and documentation requirements. Other scholars noted similar findings (Krupic et al., 2020; Krupić et al., 2018; McCorkell et al., 2017). This practice may be related to the complexity of workflow and the fast pace of the hospital environment, resulting in nursing practices that often rely upon fast thinking (Hunter & Dahlke, 2023). Another potential reason for the lack of information uptake was using a single method of education, without reinforcing practice with other modalities suggested in implementation science frameworks. McCorkell et al. (2017) used an implementation science framework called action cycle research to improve nurses' pain assessment and management based on standardized tools, ultimately demonstrating a measurable improvement in PLWD comfort levels. Further research is needed to understand why nurses hesitated to use the dementia-specific pain tools that were included in their documentation record as well as studies using implementing science rather than education alone.

Although participants used best-practice medication administration interventions for managing pain in older people by starting with administering the lowest dose, medication was not titrated up to achieve comfort levels, nor was the effectiveness of the pain management assessed following interventions, which is inconsistent with pain management guidelines (Achterberg et al., 2020; Zwakhalen et al., 2018). Additionally, evidence-based guidelines suggest that pain medication administration be scheduled rather than given as necessary (Achterberg et al., 2020), which was only articulated by one participant. These findings are similar to other scholars' findings (Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al.,

2020) and may be a result of nurses' use of experience whereby they relied upon tacit knowledge that is consistent with mind lines. Mind lines are described as internalized tacit knowledge based on previous education, reinforced and influenced mainly by interactions with colleagues, opinion leaders, and previous experience (Gabbay & le May, 2016). It was unclear how much the nurses' relied on past experiences, but mind lines may have contributed to knowledge deficits perpetuated in their pain management practices.

Other knowledge deficits were noted when PLWD manifested behavioral responses, such as changes in cognition, and pain management was not a priority. None of the participants considered pain as a cause of the behavior change. Therefore, the participants prioritized managing behavior with medication and physical restraints. Walsh et al.'s (2019) study about nurses’ use of as-needed antipsychotics in hospitalized PLWD to manage responsive behaviors has similarities to this study in that the participants did not consider pain management as a first line of intervention. Rather, they relied on antipsychotic medications to control behavior without considering pain as a possible cause of the behavior. Walsh et al. (2019) did not explicitly address pain management.

Another important finding in this study was that nurses did not separate signs of delirium and dementia. Many scholars have noted that hospitalized nurses fail to distinguish delirium from dementia (Boltz et al., 2021; Paulson et al., 2014; Richardson et al., 2017). Unmanaged pain can cause episodes of delirium (Feast et al., 2018). When pain is identified and managed, and the nursing care team recognizes the risk of delirium, functional changes, and prolonged hospitalization may be prevented (Feast et al., 2018; Shrestha & Fick, 2023). Ironically, participants were aware of available delirium assessment tools, such as the Cognitive Assessment Method (CAM), relating that the tool had been implemented in the hospital setting “quite some time ago.” The CAM is the gold standard for delirium assessment and would assist nurses in differentiating between responsive behaviors and side effects from medications (Dahlke et al., 2019; Richardson et al., 2017). Unfortunately, the participants did not think the symptoms PLWD were experiencing might be because they were developing delirium from unmanaged pain, highlighting gaps in nursing knowledge about delirium, responsive behaviors, and pain in PLWD.

Respondents expressed beliefs that indicated ageist negative stereotypes, dementia stigma, and unconscious biases resulting in pain that was not assessed or managed, prolonging discomfort for PLWD. Some respondents believed pain in PLWD was different when compared to those without dementia when they expressed the view that dementia patients do not feel as much pain. There is no evidence that PLWD perceive less pain than those without dementia, suggesting that beliefs are the result of dementia stigma (Achterberg et al., 2020; Álvaro González, 2015; Alzheimer Society of Canada, 2023).

Negative stereotypical beliefs were evident in some participants' comments that older persons do not want pain medication. This led to under assessment and interventions that were not provided to ensure comfort, even when a chronic painful condition occurred. The literature notes that this behavior is prevalent and may indicate a negative ageist stereotype (Achterberg, 2019).

The participants’ experiences influenced the decisions they made in their pain management practices. Nurses with less experience relied on vital signs to assess pain, whereas more experienced nurses used a more holistic approach to assessment that combined observation with vital signs as they described the person as a whole. They also augmented pain medication with comfort measures such as ice, heat, repositioning, relaxation, and decreasing stimuli in the patient’s environment. However, experience did not result in using evidence-based practice pain management guidelines. It would seem that experienced participants relied on tacit knowledge or mind lines (Gabbay & le May, 2016).

Most participants noted significant communication challenges from nurse to patient, nurse to nurse, patient’s families, and with external facilities. These challenges had a profound impact on pain management practices, often causing significant delays in the provision of any intervention. Similar challenges have been noted by other scholars, with very little research conducted on potential solutions (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020).

The participants described barriers to effective pain management practices related to their perceived inadequate organizational support. They described concerns when a PLWD was admitted, and there was no consideration for the patient’s needs, staff safety, or extra time required to assess and manage the PLWD’s pain properly. This finding is also consistent with other scholars' findings (Krupic et al., 2020; Krupić et al., 2018; Minaya-Freire et al., 2020; Seffo et al., 2020).

In summary, participants spoke with compassion and caring, expressing a desire to dedicate time to care for PLWD; however, they did not use standardized tools to facilitate pain assessment, evaluate the intervention, and improve pain management communication challenges. Moreover, their assessment and intervention methods based on knowledge deficits and mind lines hampered their ability to manage pain in PLWD properly. Other scholars have noted similar knowledge deficits related to current clinical guidelines and best practices for the care of hospitalized PLWD (Bruneau, 2014; Ernstmeyer, 2020; Fang et al., 2017; Lee & Kang, 2020; Martorella et al., 2019; Youngcharoen et al., 2017). Compliance with standardized assessment tools and documentation would facilitate communication with patients, nurses, and outside facilities and streamline pain management practices.

Limitations

The nurses that participated in this study worked at a single hospital where the average age of patients was 78 years. We recognize that these results were collected in a unique organization in the United States and may not be transferable to other countries or organizations.

Implications

Despite the organization's designation as a NICHE facility, the study participants described inadequate pain assessment and management in hospitalized PLWD. Pain management strategies were influenced by participants' knowledge gaps, negative stereotypical beliefs, and past experiences, resulting in underrecognized and undermanaged pain. These findings indicate that educational strategies alone are ineffective in changing and sustaining nursing practice, even in an organization that supports the care of older persons with additional resources.

Changing nursing practice in a hospital environment is complex and challenging, with many barriers, as noted in this research's findings (Hunter et al., 2019). Other scholars have noted challenges such as time constraints, unpredictable workload, and strategic variations in operationalizing change (Hunter et al., 2019). The literature recognizes these challenges with solutions found in evidence-based practice guidelines to improve pain assessment and management in hospitalized PLWD (Achterberg et al., 2020; Herr et al., 2019b; Raja et al., 2020; Stokes, 2018; Zwakhalen et al., 2018).

Pain assessment and management for PLWD is a complex activity. Implementing evidence-based practice guidelines would provide structure and consistent approaches in fast-paced hospitals. Multiple strategies found in implementation science methods could be utilized that include a multimodal approach. One such framework geared to health care is the Integrated Promoting Action on Research Implementation in Health Services (i-PARIHS) framework. The framework identifies four constructs: facilitation, innovation, context, and recipients (Harvey & Kitson, 2016). Other scholars have found this framework helpful and robust for changing nurses' practice and sustaining the change (Hunter et al., 2019; Roberts et al., 2021). For example, Portela Dos Santos et al. (2022) and Hunter et al. (2019) found that education and workplace context that engage key individuals as facilitators, and involvement of unit leaders was successful in promoting improved care of older persons in a hospital environment (Hunter et al., 2019; Portela Dos Santos et al., 2022).

At a minimum, educational topics based on current evidence-based practice guidelines such as those published by the American Society for Pain Management Nursing (ASPMN) clinical practice recommendations for pain assessment in the patient unable to self-report would resolve some of the nurses' knowledge-practice gaps (Herr et al., 2019b). Other educational material should include methods for pain relief that include medication administration (type, dose, and schedule), managing responsive behaviors, and decision-making processes when managing pain in hospitalized PLWD (Achterberg et al., 2020; Scerri et al., 2020; Zwakhalen et al., 2018).

Nurses also require strategies to help them identify unconscious biases formed by negative stereotypical beliefs and dementia stigma. Some successful approaches that have been shown to have success are programs that include self-reflection exercises that lead to awareness and internalization of how to improve the care of PLWD (Bucknor-Ferron & Zagaja, 2016; Dahlke & Hunter, 2021; Veesart & Barron, 2020).

Engaging outside facilities and the surrounding community in the organization's model of care would improve communication of critical information for managing pain in PLWD when hospitalized. As well, information provided on PLWD's discharge plan of care to the family or outside community dwelling would improve recovery and functional status.

It is incumbent upon organizational leadership, which includes executives, nurse managers, and clinical nurses, to recognize the long-term impacts when pain is left undermanaged, such as extending hospital lengths of stay, and nurse stress (Kang & Hur, 2021). Implementation science that uses multimodal methods. Education and reinforcement of standardized assessment tools supported by policy and procedures would provide consistency when managing pain. If pain were managed, superimposed delirium and responsive behaviors might be avoided.

Conclusions

This study identified the influence of nurses' knowledge gaps, beliefs, and experience on pain management practices for hospitalized PLWD. These factors confirmed the negative impact of knowledge gaps based on inadequate education and experience, and beliefs that led to unconscious biases regarding pain management in PLWD. The nurses in this study did not use standardized assessment, intervention, and evaluation methods to manage pain in PLWD. They recognized knowledge deficits that impacted pain medication interventions, requesting that more education be provided. They did not acknowledge the impact that their own beliefs may have had on their pain management practices. Therefore, hospital nurses need processes supported by education and institutional policies that efficiently gather pain-related information and documentation in a centralized location that can be accessed rapidly to provide pain management practices that appropriately relieve pain. Health services implementation frameworks such as i-

PARIHS facilitate practice changes that improve nurses' pain management practices. Future research is needed to understand the complex nature of nurses' pain management in PLWD and practical strategies to implement evidence-based practice.

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Chapter 5. Summary, Implications, and Conclusions

The focus of this dissertation was to determine whether nurses’ knowledge and beliefs influence pain management practices when caring for hospitalized persons living with dementia (PLWD). There are several significant findings, implications, and recommendations to report. These are summarized in the following paragraphs.

Summary of Findings

The findings from the scoping review (Chapter 2) confirmed that little research had been conducted on nurses’ pain management practices with hospitalized PLWD, as only six publications met the inclusion criteria. This review found that nurses’ pain management practices did not utilize standardized pain assessment tools, that interventions were not based on evidence-based practice guidelines, and that barriers such as communication challenges, perceived lack of organizational support, and knowledge deficits contributed to increased nurse stress. The findings highlighted the dearth of available literature that examined nurses' pain management practices in hospitalized PLWD. It was evident that nurses' pain management practices in the six studies were inconsistent which was attributed to the patient’s diagnosis of dementia and the complexity of the hospital environment. Three of the studies were situated in acute geriatric care units, two of which had implemented a person-centered care model. We wondered if individual personal factors influenced how nurses assessed and managed pain in a hospitalized PLWD. We also wondered if negative beliefs about aging and dementia could be influencing nursing practice with hospitalized PLWD. Therefore, we conceptualized research that examined nurse factors such as knowledge, beliefs, age, gender, and experience that may have influence on pain assessment and management when the PLWD is hospitalized. The next two papers were conceptualized using an explanatory sequential mixed method design (Creswell, 2018; Fetters et al., 2013).

The second manuscript (Chapter 3) examined whether nurses' age, gender, and years of work experience influenced their knowledge and beliefs when caring for hospitalized PLWD. The study design was cross-sectional, using a validated survey (Achterberg et al., 2020) that measured nurses' self-perceived knowledge and beliefs about pain assessment and management in PLWD and the influence of age, gender, and experience. Our findings did not support the view that age, gender, and experience influenced nurses' general beliefs about pain, age, and dementia; knowledge about pain management; and beliefs about pain in older persons when analyzed. During bivariate analysis, we did find that male nurses of all ages and years of experience held less favorable beliefs about pain in older people, than female nurses. Our findings contrasted with previous scholars' work from other settings, which had suggested that age and experience improved nurses' beliefs and knowledge levels when managing pain in PLWD (Minaya-Freire et al., 2020; Samarkandi, 2021).

Most respondents in our study worked in a Nurses Improving Care for Healthsystem Elders (NICHE) organization where the primary admitted patient population consisted of adults over 65 years of age, thereby exposing nurses to care of older persons with dementia at a greater rate than in other hospitals. Moreover, all the nurses that are new to practice received additional education during the organization's yearlong transition program on caring for pain management in older adults and dementia. It would seem logical, therefore, that the scores on knowledge and beliefs would be strongly positive. However, the scores for knowledge and beliefs related to pain management, older adults, and PLWD were not strongly positive, indicating that despite continuous exposure to this population and education about pain management in older people and PLWD, overall, nurses indicated that they had gaps in knowledge when managing pain, and also held negative beliefs about aging and PLWD. Thus, there is a need for educational strategies for pain assessment and intervention, negative beliefs about aging, and dementia to help shift the culture towards one that places value on quality care for hospitalized PLWD. A robust program that uses concepts based on implementation science and knowledge translation is suggested, particularly as the results from this dissertation indicate that education provided in a NICHE-designated organization did not produce pain management practices based on best practice guidelines.

In the third qualitative paper (Chapter 4), we used results from the second paper and delved deeper into the influence of nurses' knowledge, beliefs, and experiences when assessing and managing pain in hospitalized PLWD. This research confirmed that hospital nurses often undermanage pain in hospitalized PLWD. The nurses described knowledge – practice gaps and beliefs that PLWD did not experience pain like others; and that administering analgesics would induce responsive behaviors. These findings elucidate Paper 2 (Chapter 3) results. Even though education was provided during orientation, regular in-services, and updates on assessment methods that included hospital policies and procedures, this approach did not translate into practical pain assessment and management practices.

Nurses face increasing pressure to comply with evidence-based practice guidelines deemed "best practice" based on research. Some scholars note that implementation of research is slow and not embraced by clinicians who rely on their clinical judgment, also known as mind lines (Gabbay & le May, 2016). Mind lines are "guidelines – in- the-head that have been developed from the nurse's tacit knowledge gained through experience and learning, which is then contextualized to the practice setting" (Gabbay & le May, 2016, p. 402). The qualitative research findings indicated that nurses with more experience relied on tacit rather than explicit knowledge, which perpetuated knowledge-gaps and stereotypical beliefs. A potential solution for this problem would be to use communities of practice theory to identify facilitators that could influence practice changes based on evidence. Communities of practice are a group of individuals, in this case, nurses, who work together to solve problems, generate new knowledge, and provide a foundation of learning (Terry et al., 2020). Using a multimodal approach that includes education, context, and nurse facilitators, leveraging the communities of practice would improve knowledge while identifying the impact of stereotypical beliefs that affect pain assessment and management in hospitals (Hunter et al., 2019).

Synthesis of Findings

First and foremost, the findings from all three studies were aligned with other scholars' findings and confirm that some nurses' knowledge (or lack thereof), beliefs, and experiences negatively influence how they assess and manage pain in hospitalized PLWD, resulting in underrecognized and undermanaged pain (Achterberg et al., 2020; Alzghoul & Abdullah, 2015; Fang et al., 2017; Scerri et al., 2020). What is unique about this study is that even when nurses are provided information about older adults and PLWD and the opportunity to work extensively with this population, they do not seem to retain the information they have received or put it into practice.

Taken together, the three studies build on one another. The scoping review (Chapter 2) identified the knowledge practice gaps that exist in hospital nurses pain management practices for PLWD. The review did not address the influence of nurses' beliefs or knowledge about managing pain in hospitalized PLWD, nor did it identify if there were specific nurse-related factors such as age, gender, or work experience that impacted nurse practices. However, it identified that even in an acute geriatric care unit, PLWD had pain that was undermanaged. These findings supported the next two studies that examined how nurse factors may influence pain management in PLWD. These were investigated in a mixed-method explanatory sequential study design in paper 2 (chapter 3) and paper 3 (chapter 4).

The second paper (Chapter 3) did not support statistically significant findings that may have provided some practical direction if findings suggested that age, gender or experience influenced nurses' pain management with PLWD based on their beliefs and knowledge. There were differences in the male nurses' beliefs about pain in older people. These findings suggest that there is a need to do research to further understand why and if these differences are truly present on a larger scale or if the measure was a factor of the small number of male participants. Questions emerged as to why there were no significant differences in the outcome measures by any of the participant socio demographic variables tested, which led to the qualitative investigation, Paper 3 (Chapter 4). The third study confirmed knowledge–practice gaps, while highlighting negative stereotypical beliefs about PLWD that could be reflective of unconscious and conscious biases that were consistent with survey results in Paper 2. Paper 3 also identified the differences that nurses' experience made on pain management practices on hospitalized PLWD. These findings validate the view that when education is not provided in a multimodal approach using methods that reinforce changes, such as individual facilitators and other techniques supported by implementation science, the uptake by nurses falls short. Research on methods found in implementation science that include multimodal approaches have demonstrated success in not only practice but also enculturation in hospital settings which will be described further in this chapter's implication section (Boyes, 2023; Portela Dos Santos et al., 2022).

Knowledge deficits that were noted in all three papers appeared to contribute to negative beliefs. Negative stereotypical beliefs about dementia were found in both the quantitative and qualitative research studies (Chapters 3 and 4). It was unclear if these beliefs were conscious or unconscious. Regardless, they appear to have had a negative impact on how nurses assessed and managed pain in PLWD.

There is evidence from the quantitative and qualitative papers that nurses had negative stereotypical beliefs towards older adults, consistent with ageism, exacerbated by institutional ageism. Evidence of these stereotypes was found in staffing patterns that adopted the same nurse-to-patient ratio that would be found in a clinical setting with younger patients, lack of support or extra time to care for older patients who may have had higher functional needs, and the expectation that PLWDs has the same needs as those that do not have dementia, which essentially perpetuates the perspective that caring for older people is simple, leading to nurses needing to ration their time carefully (Dahlke et al., 2015; Hunter & Dahlke, 2023).

The nurses perceived their actions as kindness, but speaking in general terms such as “they” and “them” suggests benevolent ageism, which is defined as overaccommodating behaviors that are paternalistic and undermine individual's' feelings of control (Cary et al., 2017). Benevolent ageism was noted in nurses’ paternalistic vigilance toward “safety first" prior to assessment and by not engaging the PLWD in activities to ensure they are safe (Cary et al., 2017; Scott, 2023). Instead, the nurses would discuss safety with family members and representatives from outside facilities, always assuming that the PLWD would be impulsive and display responsive behavior. Another example was found in the communication patterns that the nurses used. There was little differentiation between standard speech patterns described as best practices, such as speaking slowly when communicating with PLWD, versus patronizing language, such as “dear and sweetheart,” particularly when the person was non-verbal (although the nurses did not specify that they used these terms) (Shaw & Gordon, 2021). What is unclear is how much of the nurse participants’ biased, ageist beliefs were unconscious versus conscious.

In addition, results discovered in participant responses for survey questions specific to pain and dementia in Paper 2 (Chapter 3) and the data extracted from respondents in Paper 3 (Chapter 4) suggested that there were elements of dementia stigma that had a negative impact on how hospitalized PLWD pain was assessed and managed. These conclusions are based on pain assessments that were not conducted or based on best practice for PWLD, and assumptions that were made about the presence of pain based on the diagnosis of dementia. The result was pain that was underassessed, underreported, and undermanaged.

Based on this dissertation’s findings, the prevalence of negative stereotypes and dementia biases towards older people had a direct impact on the nurses’ decisions. The nurses relied on knowledge gained from their educational program and work experiences to determine how pain was assessed and managed in hospitalized PLWD, rather than relying on evidence-based practices and resources available to them at their institution. As such, there are many implications and recommendations derived from this research that could result in improved pain management practices for hospital nurses when caring for PLWD.

Implications

The findings from this research contribute to the understanding that current educational methods and care practices for hospitalized PLWD do not meet their pain needs. Thus, an assessment of potential changes and strategies is strongly recommended. Successful solutions must be developed with input from key stakeholders, including organizational executives, nurse leaders, members of the professional development department, and clinical nurses, to engage in careful assessment, implementation, evaluation, and a plan to sustain change (Chenoweth et al., 2019).

Translating Knowledge into Practice

Many scholars have noted that pain assessment and management in hospitalized PLWD is complex. Most implementation models of care progress in a linear or cyclical manner. These models do not wholly address the complexity of hospital environments. For example, a problem was noted by Dowding et al. (2016) when they found that a nonlinear approach that involved all healthcare team members improved pain assessment and management in PLWD by addressing the complexity of the hospital environment. It is evident that education alone, provided in a linear model, was not effective in supporting well managed pain in hospitalized PLWD that does not account for the many challenges that are inherent in the complex hospital environment. Using an implementation framework that complements the institution, the community, and the interprofessional team, while using educational interventions as one of a multi-modal approach to practice change, would improve the complex issues surrounding pain management in PLWD.

It is suggested that a specific knowledge translation framework designed for the intricacies of hospitals such as the Knowledge Translation Complexity Network (KTCN) (Kitson et al., 2018) that when combined with the implementation framework Integrated Promoting Action on Research Implementation in Health Services (i-PARISH), would be effective approaches to change practice for pain management in PLWD (Boyes, 2023; Harvey & Kitson, 2016). The KTCN optimizes timely creation and movement of knowledge in complex networks, such as hospitals (Kitson et al., 2018). This framework supports translation through sub systems that include: “problem identification, knowledge creation, knowledge synthesis, implementation, and evaluation” (Kitson et al., 2018, p. 79). The authors of the KTCN describe how sub networks or clusters account for sectors such as communities, government regulations, and education interact with the subsystems, and when activated properly, work successfully “across and between multiple systems” (Kitson et al., 2018, p. 79). The KTCN can provide structures that engage the community facilities or homes, where the families, and PLWD reside. Pain management was noted to be reliant on communication with these sectors or communities, as a contributor to effective or ineffective management (Boyes, 2023; Harvey & Kitson, 2016; Kitson et al., 2018; Roberts et al., 2021).

One of the subsystems of the KTCN is implementation. A complementary implementation framework is the i-PARIHS (Harvey & Kitson, 2016). This framework based on evidence, context, facilitation promotes multiple approaches that support leadership, clinical nurses, and the patients they serve (Roberts et al., 2021). One approach is the use of innovative educational methods to improve knowledge, and address beliefs. This novel approach to best practice implementation combines multimodal approaches that include educational techniques, leveraging mind lines and communities of change, and may provide methods that address the challenges hospital environments face

System-Level Model of Care

It is clear that the present model of care does not support adequate nurse pain management strategies for hospitalized PLWD. A persons-centered dementia model of care that encourages effective pain management strategies and incorporates a respectful holistic approach may diminish stereotypical ageist beliefs (Harper et al., 2018). Adopting a person-centered dementia model of care would also promote best-practice evidence-based policies and procedures, support environmental changes, support staffing plans with increased time and resources, and improve nurses’ pain assessment and management of PLWD (Alzheimer’s

Association, 2019; Chenoweth et al., 2019; Herr et al., 2019b Alzheimer's International). Alzheimer's Disease International, 2019 endorses person-centered dementia care as the gold standard model for organizations. A person-centered dementia care model places more emphasis on the person than a biomedical approach by focusing on PLWD's selfhood and personhood with targeted strategies (Feast et al., 2018). These strategies include prioritizing the whole person using personal knowledge, authentic relationships that honor values and beliefs, individualized care appropriate to the stage of dementia, and support for the individual and family (Feast et al., 2018). Scholars have shown that this model positively impacts PLWD's quality of life, reducing agitation, responsive behaviors, and depression (Kim & Park, 2017).

Person-centered dementia care models have been primarily implemented in long-term care facilities. Hospitals that transition toward this model of care face many challenges (Chenoweth et al., 2019). Some of these challenges include changing and sustaining a culture change, workflow changes that include appropriate allocation of nurse staffing resources according to patient acuity rather than nurse–patient ratios (Auerbach et al., 2021; Sobaski, 2018), and environmental changes (Chenoweth et al., 2019). When successfully implemented, patient outcomes improve, and hospital length of stay decreases, providing cost benefits to the organization (Feast et al., 2018). Thus, the benefits of a person-centered dementia care model outweigh the implementation challenges. However, it requires a top-down and bottom-up multi-modal approach that leverages a shared governance system to implement and sustain organizational cultural and structural changes (Chenoweth et al., 2019). Using the KTCN framework to develop a robust implementation plan for Kitwood's model (1997); the Values, Individualized approach, Perspective of the PLWD, and Social environment (VIPS) framework

(Røsvik et al., 2011); would facilitate effective implementation and sustained change (Chenoweth et al., 2019; Tay et al., 2018).

Policy and Procedure Changes

Findings from the quantitative and qualitative studies in this dissertation suggest that the policies governing care in the hospitals where this research was conducted may not have been implemented and complied with by the nurses when assessing and managing pain for hospitalized PLWD. This is particularly evident in that one of the hospitals was a NICHE site, where the nurses still had knowledge- practice gaps, and negative beliefs about aging and dementia. Therefore, it is suggested that an assessment of current policies and procedures be conducted to determine if they are based on current national and international standards and evidence-based clinical guidelines for pain assessment and management for older PLWD (Herr et al., 2019a; Raja et al., 2020). Following an assessment of current policies and procedures guiding nurses pain management practice, using implementation frameworks such as i-PARIHS would facilitate sustained practice changes (Boyes, 2023).

Other challenges nurses encountered as a result of policies and procedures that were not dementia-friendly were related to nurse–patient ratios and staffing assignments. Nurses were assigned to care for hospitalized PLWD without consideration for the additional time and workload. This practice may have led to care rationing and fast thinking that caused the nurses to use intuition and inference, thereby impacting the way that they assessed and managed pain (Hunter & Dahlke, 2023). Therefore, policies governing nurses' patient care assignments should be amended to accommodate increased time for dementia care to ensure nurses do not ration care and undermanage pain (Dahlke et al., 2015; Digby, 2016; Hunter & Dahlke, 2023). Leveraging concepts found in KTCN may facilitate solutions related to the complexities of staffing in the hospital environment.

Education

The nurse participants in this dissertation felt that education would help them improve how they manage pain in hospitalized older PLWD. Professional development departments tasked with education and re-education in hospitals face many challenges. The nursing workforce is 24 hours a day, 7 days a week. Providing education for all nurses throughout a fast-paced hospital, who work all hours of the day and night and are struggling to meet the demands of high-acuity patients, is challenging. Educational offerings should include pain management practices for hospitalized PLWD that include medication effects and interactions, best practices for medication administration methods, normal aging, dementia, and delirium. Scholars have recently published research using e-learning that demonstrates the successful uptake of new knowledge that may be used to rapidly disseminate new knowledge and reinforce current practices and policies (Dukes et al., 2022; Law et al., 2022; Portela Dos Santos et al., 2022). E-learning activities have had positive results in nurse retention of new knowledge and can be provided quickly, on the nurses' work time, and on a broad scale (Dukes et al., 2022; Kalogirou et al., 2022; Law et al., 2022). These approaches add valuable alternative modes for providing initial and ongoing education for hospital-based nurses, and are a valuable component of implementation frameworks.

While many scholars agree that education on evidence-based practices, best practices, and clinical guidelines for assessing and managing pain in hospitalized PLWD is not well supported as a standalone measure to promote practice change, and is consistent with this dissertation's findings, a multimodal combination with education as a component may be more effective in changing practice (Achterberg et al., 2020; Capezuti et al., 2012; Gkioka et al., 2020). Portela Dos Santos et al (2022) suggested that education should be paired with multimodal techniques that are consistent with implementation science to reinforce and sustain change. The i-PARIHS frameworks suggests implementation methods that are multi-modal. Some suggestions are to include facilitators such as mentors, project champions, visual reminders, discussion of new processes at shift change, and feedback from data collected on project progression (Harvey & Kitson, 2016; Portela Dos Santos et al., 2022).

Addressing Negative Stereotypes

It would seem that even when nurses have had baseline education specific to caring for older patients and PLWD, there exist significant gaps in knowledge, even in a NICHE-designated facility where the nurses have constant exposure to older PLWD. These findings suggest that beliefs may play a more prominent role in nurses' practice as compared to following best practice guidelines, as it is evident that educational methods thus far have not been effective at addressing negative stereotypes (Herr et al., 2019b).

Scholars have suggested that education that incorporates exercises that teach nurses self-reflection methods would help diminish negative dementia stereotypes that are a result of interpersonal and institutional ageist beliefs (Bucknor-Ferron & Zagaja, 2016; Dahlke & Hunter, 2021; Veesart & Barron, 2020). Promoting awareness through self-reflection helps people acknowledge negative stereotypes (Veesart & Barron, 2020). Education that includes the development of conscious empathy for patients can lead to active disengagement of negative thoughts and purposeful mindfulness that improves the care of PLWD (Bucknor-Ferron & Zagaja, 2016; Veesart & Barron, 2020). Further research is recommended on these approaches to measure their effectiveness, as there is limited information on how pain assessment and management in hospitalized PLWD are impacted by education that includes self-reflection.

Comparing Quantitative and Qualitative Findings

Findings from quantitative research (chapter 3) identified that knowledge deficits and ageist stereotypical beliefs exist even in an organization that has provided nationally endorsed resources for the care of the older PLWD. Even though the findings did not support a statistically significant association between the nurse's age, gender, and experience and general beliefs about pain, dementia, and aging; knowledge about pain management in PLWD; and beliefs about pain in older people, a bivariate analysis using one-way analysis of variance indicated that male nurses of all ages and years of experience indicated significantly lower beliefs about pain in older people than female nurses. A qualitative study allowed the researchers to delve deeper into the nurses' individual beliefs, knowledge, and experiences. The qualitative data was consistent with the survey finding that nurses had ageist stereotypical beliefs and dementia stigma that resulted in unconscious bias. In addition, the data revealed nurses’ knowledge gaps that provided insight into specific deficits and how the gaps impacted pain assessment and management practice, whereas the quantitative study provided a broad overview of knowledge gaps. The significant difference between the two studies was that the qualitative data revealed that nurses' experiences made a difference in how pain was assessed and managed in PLWD. We feel that the findings in the qualitative study may be more reflective of the influence of experience but suggest that research be conducted on a larger scale using multiple organizations and geographical areas, with an increased number of participants.

Strengths and Limitations

The uniqueness of this study is that it was positioned in Southern California and in an institution that primarily admits older patients. To our knowledge it is one of the only studies that was conducted on hospital nurses and hospitalized PLWD. Even though these nurses were exposed to large numbers of PLWD, were in a NICHE-designated hospital, and received initial and ongoing education, significant knowledge deficits in pain assessment and management existed. This information may not be generalizable, as the research was conducted primarily in a single hospital located in a retirement community. It is quite possible that similar or perhaps even more knowledge gaps exist in other nursing populations. This study was conducted during the COVID-19 pandemic, which may have had a bearing on the study findings. Based on the findings from this study, key recommendations for future studies that will advance the knowledge base include reflective activities about ageism, dementia stigma, unconscious bias and the impact on pain management practices in hospitalized PLWD, and how to provide interventions for pain that are safe and effective.

Conclusion

Nurses' knowledge, beliefs, and experience influenced pain assessment and management practices, resulting in underrecognized, underreported, misdiagnosed, and undermanaged pain in hospitalized older PLWD. Additional pain assessment and management barriers were identified that centered around communication challenges between nurses and PLWD, other nurses, family members, and outside facilities, and a perceived lack of organizational support related to a lack of resources or extra time to assess and manage pain in older PLWD. There was significant evidence of not only knowledge-practice gaps, but also that the nurses had negative stereotypical beliefs about older people, dementia, and pain that could reflect conscious and unconscious biases. These beliefs influenced their pain assessment and management. As the nurses navigated the many demands imposed by the biomedical model of care—fast-paced, high-acuity care—hospitalized PLWD did not receive adequate assessment and management of their pain.

Information gleaned from these studies completed for the dissertation identifies the complexities associated with not only pain assessment and management, but also the need to better support and address the growing issues of hospitalized older PLWD. We suggest that priority be placed on implementing, reinforcing, and supporting person-centered dementia care that addresses pain management with appropriate policies, procedures, and education. The consistency of these findings with those of other scholars who focused on long-term care facilities indicates that the problem crosses the continuum of care.

There is an urgent need to develop realistic actions and solutions as there is a growing community of PLWD, many of whom will be admitted to hospitals with some kind of pain. Pain impacts all aspects of ones' life, more so in a PLWD when unmanaged. Managing pain is an important element to maintaining the PLWD's personhood, thereby enhancing the PLWD's quality of life. The results from these studies highlight the need to improve the focus and care of pain for those who are most vulnerable. In summary, we believe these results provide us with information that reinforces the importance for health care workers, specifically nurses, to improve how we view and manage pain in PLWD.

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Appendix A: Research Ethics Board Approval

ID: Pro00112843

Title: Factors Influencing Nurses’ Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia

Study Investigator Sherry Dahlke

University of Alberta
Edmonton Alberta
Canada T6G 2E1

INSTITUTIONAL REVIEW BOARD 39000 Bob Hope Drive Rancho Mirage, CA 92270
IRB@eisenhowerhealth.org

DATE: August 10, 2021
TO: Beverley Ingelson, MSN, MSHA, RN, NE-BC
IRB # 00002040
IRBNet ID: 1791664-
PROJECT: Factors Influencing Nurses? Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia

Thank you for your submission of the above new project. This new project was reviewed using Expedited Review Procedures. It was determined that this study met 45 CFR 46.110, Expedited Categories 6 & 7, based on applicable federal regulations.

This study is design with a mixed method approach to explore nurse-related factors encompassing personal attitudes, knowledge, and beliefs that impact pain management practices in older patients with dementia who are admitted to the hospital.

The IRB expedited reviewer determined that you have justified the granting of a Waiver of Consent for the anonymous KBPED surveys, in accordance with 45 CFR 46.116 (f) which requires that 1) the research involves no more than the minimal risk to the subjects because information extracted will be recorded without identifiers and no subjects will be contacted; 2) the Waiver will not adversely affect the rights and welfare of the subjects, as the data is the survey is anonymous with no identifiers being recorded; 3) the research could not practicably be carried out without the waiver; and 4) the researcher plans to share the research results with the nursing departments within the Institution.

The expedited reviewer, on behalf of the IRB concluded that: 1) the risks have been minimized; 2) risks are reasonable in relation to anticipated generalizable knowledge that may reasonably be expected to result; 3) selection of subjects is equitable and appears to take into account the purpose of the research, and the setting in which research will be conducted; 4) A Waiver of Consent has been approved; and 5) there are adequate provisions to protect subject privacy and maintain data confidentiality. The proposed research plan was approved.

This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks, although minimal, have been minimized. All research must be conducted in accordance with this approved submission. Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Additionally, you must submit a research modification/amendment request when you are adding new researchers, students or study coordinators to the study team. Please use the appropriate revision forms in IRBNet for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported to the IRB Office within 10 working days. All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported within

10 working days. Based on the risk level, this project requires you to submit an administrative update annually.

Please use the appropriate form for this annual review. Your administrative update submission should be received three weeks prior to the expiration date of August 9, 2022.

If you have any questions, please contact [redacted], PharmD, MBA, IRB Co-Chair, at 760-340-3911 x1540 or [redacted] or [redacted], IRB Administrator at 760-837-8901 or IRB@eisenhowerhealth.org. Please include your project title and IRB number in all correspondence with this committee.

The following specific items have been reviewed and approved for use:

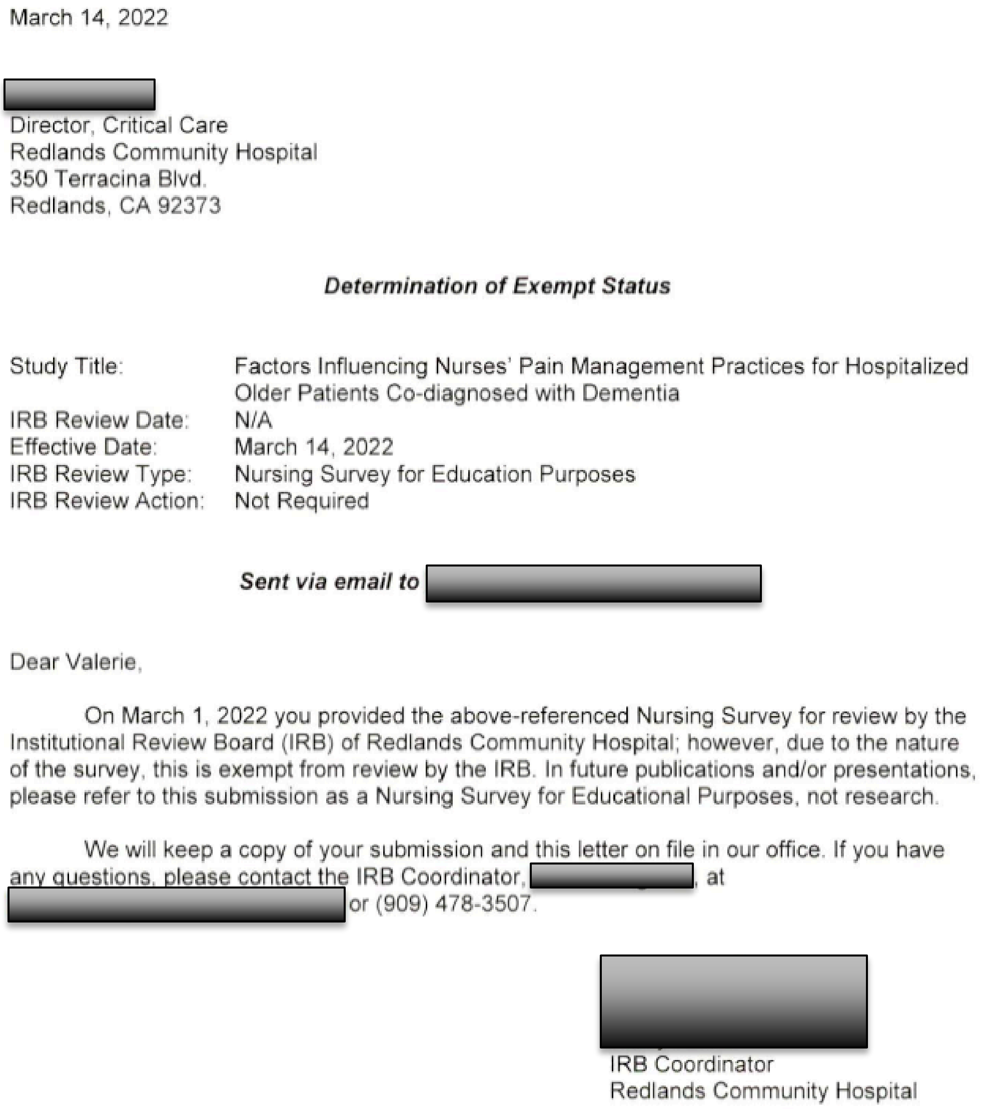
- Advertisement - Ingelson Screen Saver Poster Information Changes 08022021.pdf
- Application Form - IRB Form 1A Application Form for a Non-Clinical or Minimal Risk Protocol.pdf
- Consent Form - IRB EH Qualitative Study Consent Form B Ingelson Dissertation 08022021.pdf
- Consent Waiver - IRB EH Information Letter Implied Consent Survey Study B Ingelson Dissertation 07232021.pdf
- Investigator Agreement - IRB Form 00 Investigator Agreement to Comply with EMC Procedures B Ingelson Dissertation 07232021.pdf
- Letter - Introductory Letter for Survey Study.pdf
- Letter - Introductory letter for Qualitative Interviews.pdf
- Other - NRC Expedited Review 072921 - Ingelson.pdf
- Other - NRC01 Submission Dementia Research Protocol B Ingelson.pdf
- Other - Study Participant Demographic Information.pdf
- Other - Semi Structured Interviews Questions.pdf
- Protocol - B Ingelson Mixed Method Study Dissertation 08012021-1.pdf
- Questionnaire/Survey - Qualitative Study KBPED Survey Tool.pdf
- Study Plan - IRB Form 2A Study Plan for Non- FDA Regulated Research 08022021.pdf

Thank you for your continued support and cooperation in our shared responsibility in protecting the rights and welfare of human participants in research.

Yours truly,

EMC Institutional Review Board Co-Chair (Documentation of IRB Approval Resides in IRBNet)

Institutional Review Board – Redlands Community Hospital



March 14, 2022

[redacted]
Director, Critical Care
Redlands Community Hospital
350 Terracina Blvd.
Redlands, CA 92373

Determination of Exempt Status

Study Title:	Factors Influencing Nurses' Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia
IRB Review Date:	N/A
Effective Date:	March 14, 2022
IRB Review Type:	Nursing Survey for Education Purposes
IRB Review Action:	Not Required

Sent via email to [redacted]

Dear Valerie,

On March 1, 2022 you provided the above-referenced Nursing Survey for review by the Institutional Review Board (IRB) of Redlands Community Hospital; however, due to the nature of the survey, this is exempt from review by the IRB. In future publications and/or presentations, please refer to this submission as a Nursing Survey for Educational Purposes, not research.

We will keep a copy of your submission and this letter on file in our office. If you have any questions, please contact the IRB Coordinator, [redacted], at [redacted] or (909) 478-3507.

[redacted]
IRB Coordinator
Redlands Community Hospital

Appendix B: Knowledge and Beliefs About Pain in the Elderly Patients with Dementia Questionnaire

	1 Completely Disagree	2 Disagree	3 No Opinion	4 Agree to Some Extent	5 Completely Agree
1. Older people experience pain less than younger people.					
2. Pain medication works better in young people than in the elderly.					
3. Pain medication works longer in the elderly than in young people.					
4. Pain medication has more side effects in the elderly than in younger people.					
5. Dementia patients experience less pain than non-dementia patients.					
6. Assessing pain in a dementia patient is a matter of guessing.					
7. Where I work, pain is assessed correctly.					
8. Where I work, pain is treated correctly.					
9. Where I work, much attention is given to pain in dementia patients.					
10. Pain medication should only be administered to patients suffering from severe pain.					
11. Patients are often prescribed too much pain medication.					
12. It is better to administer pain medication “when necessary,” rather than according to a fixed schedule.					

13. Administering pain medication should be postponed as long as possible, because dementia patient should receive as little pain medication as possible.					
14. A dementia patient should first report pain before receiving the next dose of pain medication.					
15. Pain is part of the aging process.					
16. Older people are more likely to be affected by pain than younger people.					
17. Pain medication, if administered in large quantities, easily leads to addiction among the elderly.					

Source: Zwakhalen et al., (2007).

Appendix C: Qualitative Semi-Structured Interview Questions

1. What is it like to care for people with dementia
2. How would you describe your nursing practice when assessing and managing pain for elderly patients with dementia?
    a. How do you feel when a patient is confused and acting aggressively or impulsive?
    b. How do you respond when a patient is confused and acting aggressively or impulsive?
3. How do you assess pain when your older patient is not able to communicate verbally?
    a) Can you describe your process?
    b) What resources if any do you draw on to assess pain?
4. Can you describe your beliefs about aging, dementia and pain?
5. Can you describe how you have learned to care for older patients in pain?
    a. What courses or education have you taken to support your understanding about pain in older persons with dementia?
6. Please describe any barriers to pain assessment in older people with dementia? Or challenges?
7. Is there anything else you would like to tell me about pain management in older people with dementia?

Appendix D: Study Recruitment Letters, Emails, Letters of Introduction

SUBJECT LINE OF EMAIL: An Invitation to Participate in a Research Project

Letter of Introduction: Survey Research

To: Licensed Registered Nursing Staff

You are being asked to participate in this research study to help us understand how dementia impacts decisions you make when managing patients pain. This study will provide a better understanding about how nurses manage pain in older patients receiving care in your work area. The study title is Factors Influencing Nurses' Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia. The study number that has been assigned by the Research Ethics Board of the University of Alberta is Pro00112843.

As a participant in this study, you are being asked to complete a questionnaire. The survey will be distributed by an email with a comprehensive explanation of the study, called an Information Letter and Implied Consent Form. An electronic link will be embedded at the bottom of the letter. You may access the survey using the electronic link. The survey will take approximately 10 minutes to complete. After the study has concluded, the results will be shared. Your participation is confidential. Information discovered will be very helpful in the development of methods that help nurses manage pain as you provide person centered care to patients with dementia.

If you have any questions about the study or participation, please contact [redacted] by telephone at (760) 834-3510 or email at [redacted]. Your time is appreciated. Many thanks for your assistance with this project.

Sincerely,

Beverley Ingelson, MSN, MSHA, RN, NE-BC

PhD Student, University of Alberta, Faculty of Nursing

Study Recruitment Letter Reminder

SUBJECT LINE OF EMAIL: REMINDER An Invitation to Participate in a Research Project

Letter of Introduction: Survey Research

To: Licensed Registered Nursing Staff

You are being asked to participate in this research study to help us understand how dementia impacts decisions you make when managing patients pain. This study will provide a better understanding about how nurses manage pain in older patients receiving care in your work area. The study title is Factors Influencing Nurses' Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia. The study number that has been assigned by the Research Ethics Board of the University of Alberta is Pro00112843.

As a participant in this study, you are being asked to complete a questionnaire. The survey will be distributed by an email with a comprehensive explanation of the study, called an Information Letter and Implied Consent Form. An electronic link will be embedded at the bottom of the letter. You may access the survey using the electronic link. The survey will take approximately 10 minutes to complete. After the study has concluded, the results will be shared. Your participation is confidential. Information discovered will be very helpful in the development of methods that help nurses manage pain as you provide person centered care to patients with dementia.

If you have any questions about the study or participation, please contact [redacted] [redacted] by telephone at (760) 834-3510 or email at [redacted]. The study will stop participant recruitment on _________.

Your time is appreciated. Many thanks for your assistance with this project.

Sincerely,

Beverley Ingelson, MSN, MSHA, RN, NE-BC

PhD Student, University of Alberta, Faculty of Nursing

Study Recruitment Letter for Interviews

SUBJECT LINE OF EMAIL: An Invitation to Participate in a Research Project

Letter of Introduction

To: Licensed Registered Nursing Staff

You are being asked to participate in this research study to help us understand how dementia impacts decisions you make when managing patients pain. The study title is Factors Influencing Nurses' Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia. The study number that has been assigned by the Research Ethics Board of the University of Alberta is Pro00112843.

We will be conducting interviews so that you may share your experiences. Participation involves approximately ½-1 hour. The researcher will ask you questions about how you make decision, to share your experiences when managing pain for older patients admitted for care to the hospital who have dementia. Your participation is confidential and you can withdraw at any time. The interview will conducted face to face, via telephone or by ZOOM, as per your preference.

If you are interested in participating in this study, or have questions about the study, please contact [redacted] by telephone at (760) 834-3510 or email at [redacted]. The interview will be schedule at a time that is convenient to you.

Thank you for your consideration,

Beverley Ingelson, MSN, MSHA, RN, NE-BC

PhD Student, University of Alberta, Faculty of Nursing

Study Recruitment Letter for Interviews Reminder

SUBJECT LINE OF EMAIL: REMINDER An Invitation to Participate in a Research Project

Letter of Introduction

To: Licensed Registered Nursing Staff

You are being asked to participate in this research study to help us understand how dementia impacts decisions you make when managing patients pain. The study title is Factors Influencing Nurses' Pain Management Practices for Hospitalized Older Patients Co-diagnosed with Dementia. The study number that has been assigned by the Research Ethics Board of the University of Alberta is Pro00112843.

We will be conducting interviews so that you may share your experiences. Participation involves approximately ½-1 hour. The researcher will ask you questions about how you make decision, to share your experiences when managing pain for older patients admitted for care to the hospital who have dementia. Your participation is confidential and you can withdraw at any time. The interview will conducted face to face, via telephone or by ZOOM, as per your preference.

If you are interested in participating in this study or have questions about the study, please contact [redacted] by telephone at (760) 834-3510 or email at [redacted]. The interview will be schedule at a time that is convenient to you. The study will stop participant recruitment on _________.

Thank you for your consideration,

Beverley Ingelson, MSN, MSHA, RN, NE-BC
PhD Student, University of Alberta, Faculty of Nursing

Appendix E: Study Participant Demographic Information for Quantitative and Qualitative Investigation

Please answer the following questions by circling the most appropriate response or typing your response:

Age: 20-25, 26-30, 31-35, 36-40, 41-45, 46-50, 51-55, 56-60, 61-65, 65 or>

Gender: Female Male Non-Binary

Highest Education: AD RN, BSN, MSN, DNP, PhD

Years of Experience: 0-3, 4-6, 7-10, 11-14, 15-18, 19-21, 22-25, >26

Work Area: Inpatient Ambulatory Care

Primary Work Unit: Medical-Surgical Telemetry Step Down Unit Intensive Care Surgical Services Same Day Procedural Services Short Stay Observation Urgent Care Emergency Services

Number of years in current work area: ________

Do you work full time or part-time?

Appendix F: Information Letter and Implied Consent Form (Quantitative Study)

Title of the study: **Quantitative Research Using an Observational Survey Assessing Nurses' Beliefs and Knowledge about Pain Management in Older Patients with Dementia**

Principal Investigator(s) (Supervisor(s)):
Dr. Sherry Dahlke, PhD, RN
Professor, Faculty of Nursing,
University of Alberta,
Edmonton AB Canada T6G 1C9
sherry.dahlke@ualberta.ca
(780) 492-5574,

Co-investigator(s) (Student(s)):
Beverley Ingelson, MSN, RN
PhD Student, Faculty of Nursing
University of Alberta,
Edmonton AB Canada T6G 1C9
ingelson@ualberta.ca
(780) 409-6823

Invitation to Participate: You are invited to participate in this research study because you are a nurse working in an organization, who is involved with pain management in older patients who have dementia. All nurses who work in this organization will receive an invitation to participate through their email. This study is being conducted by a graduate student in the Doctorate of Philosophy of Nursing as a dissertation requirement. Caring for patients who have dementia can be very challenging. Understanding how nurses manage pain in older patients who have dementia would help develop more successful pain management practices.

Purpose of the Study: From this research we wish to learn how dementia may impact the way a nurse assesses and choses methods of pain treatment for an older patient who has dementia. There are some previously published research studies that indicate that beliefs and knowledge influence pain management practices. Exploring the impact that beliefs and knowledge have on the way a nurse manages pain in these patients will help us understand how to provide better pain relief in older patients who have dementia.

Study Procedures: This research study is being conducted by Beverley Ingelson, a student of the University of Alberta who is in a Doctorate of Philosophy in Nursing program. It will utilize a survey questionnaire called the "Knowledge and Beliefs About Pain in Elderly Patients with Dementia". The questionnaire allows you to communicate your beliefs and knowledge related to pain management in elderly patients with dementia

Participation: Your participation in this study will involve completing a survey questionnaire about your beliefs and knowledge when assessing pain in a person with dementia. If you which to participate in this study, please complete the attached survey by clicking on the electronic link found at the bottom of this page. The survey may take up to 10 minutes to complete. You do not have to answer any questions that you do not want to answer. Responses will be collected for a period of 1 month. Reminders will be sent out to all nurses every Monday for 3 weeks during the survey collection period regardless of whether you have participated. You may only participate once.

Benefits: There will be no direct benefits to you for participating. However, your participation will help us understand how to improve pain management in older people with dementia.

Risks: This research involves minimum risk. It does not include the collection of personal health information. Your identity is anonymous. It is not anticipated that there will be any risk of injuries, but if you feel any discomfort or distress, you may stop your participation by closing the electronic survey. Your answers will be deleted. If needed, you may also contact a member of the research team who will refer you to appropriate resources such as the Employee Assistance Program.

Confidentiality and Anonymity:

Your participation in this study will be private and anonymous. The researchers are the only persons who will have access to completed questionnaires and only for data analysis. In order to minimize the risk of security breaches and to help ensure your confidentiality we recommend that you use standard safety measures such as signing out of your account, closing your browser and locking your screen or device when you are no longer using them or when you have completed the study. You will be protected by all U.S.A. privacy legislation. Results will be published in pooled (aggregate) format. Anonymity is guaranteed since you are not being asked to provide your name or any personal information that can be linked to you.

Data Storage: Your responses to the survey will be stored for up to five years after the study's conclusion in a secure password protected computer electronically encrypted location on the co-investigator's secure network located at Eisenhower Medical Center, Rancho Mirage, California, for a minimum period of *5* years.

Compensation (or Reimbursement): The research is a data collection survey study. There will be no compensation to you for participating.

Voluntary Participation: Your participation in the study is voluntary. You may decide not to participate in the study. You do not have to answer any questions that you do not want to answer for any reason. Your decision will not result in any penalty or loss of benefits to which you are entitled. Should you choose to withdraw midway through the electronic survey simply close the link and no responses will be included Given the anonymous nature of the survey, once you have submitted your responses it will no longer be possible to withdraw them from the study

Information about the Study Results:

Nothing you tell us through this questionnaire will be shared with anybody; again, your identity will remain private and anonymous. The results of this study will be shared with you and the organization through small meeting presentations and electronically distributed reports. Following the dissemination of study findings within the organization, we will publish the results to learn from the research

Contact Information: If you have any questions or require more information about the study itself, you may contact the researcher, Beverley Ingelson or Dr. Sherry Dahlke at the numbers mentioned herein. You may also contact [redacted] by telephone at (760) 834-3510 or email at [redacted].

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have any questions regarding your rights as a research participant or how the research is being conducted you may contact the Research Ethics Office at 780-492-2615.

Please print a copy of this form for your records by clicking on the link to found at the bottom of this page to the pdf version.

Thank you

Completion and submission of the survey means your consent to participate.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have any questions regarding your rights as a research participant or how the research is being conducted you may contact the Research Ethics Office at 780-492-2615.

Please print a copy of this form for your records by clicking on the link to found at the bottom of this page to the pdf version.

By submitting the survey your consent to participate is implied.

Appendix G: Consent Form for Individual Interview

Title of the study:	**A Qualitative Study on Nurses Pain Management Practices in Hospitalized Older Patients with Dementia**
Principal Investigator (Supervisor):	Dr. Sherry Dahlke, PhD, RN Professor, Faculty of Nursing, University of Alberta, Edmonton AB Canada T6G 1C9 sherry.dahlke@ualberta.ca (780)492-5574
Co-investigator (Student):	Beverley Ingelson, MSN, RN PhD Student, Faculty of Nursing University of Alberta, Edmonton AB Canada T6G 1C9 ingelson@ualberta.ca (780) 409-6823

Why am I being asked to take part in this research study?

You are invited to participate in this research study because you are a nurse working in an acute care hospital, who is involved with pain management in older patients who have dementia. This study is being conducted by a graduate student in the Doctorate of Philosophy of Nursing as her dissertation requirement. Caring for patients who have dementia can be very challenging. Understanding the how nurses address challenges and experiences when managing pain in older patients who have dementia would help develop methods and processes that support clinical nurses and provide the foundation for a successful pain management program in the acute care facility. Currently, there is very little published research available which makes your contribution very meaningful.

What is the reason for doing the study?

Pain management in a fast paced health care system such as an acute care hospital has unique challenges. The patient is typically not known to the health care team which becomes problematic if communication is impaired, as is often the case in an elderly person who has dementia. The nurse's role is critical in this process assessing pain and making decisions on treatment options. Obtaining more information on how pain is managed in these patients, may assist other nurses as they navigate potential challenges in the provision of person centered care.

What will I be asked to do? This research study is being conducted by Beverley Ingelson, a student of the University of Alberta who is in a Doctorate of Philosophy in Nursing program. You have been asked to participate in this study related to your experiences in your work area, and the care you have provided for patients with and without dementia. Your participation in this study will consist of an interview that will be conducted face to face, via telephone or by ZOOM that may last approximately one hour. If the interview is face to face, it will be conducted in a quiet comfortable office. If the interview is conducted by ZOOM, you may choose to turn your video camera off. If the interview is conducted face to face, the participant and researcher will comply with any public health measures in accordance with the Riverside County Department of Health and the State of California policies and procedures pertaining to the COVID-19 pandemic such as wearing a face mask and maintaining a distance of 6 feet. The interview will be recorded so that the researcher can abstract your information that will be coded into themes. You will be asked a series of questions about your feelings, experiences and how you manage pain in patients assigned to your care who have dementia. You may pass on any questions that make you feel uncomfortable. At any time, you may notify the researcher that you would like to stop the interview and discontinue participation in the study. There is no penalty for terminating participation.

Your answers will be transcribed so that the researcher can analyze your answers and identify codes or themes. After the interview is analyzed, you may be asked to provide more information or clarifications. You will have an opportunity to read your responses to confirm the accuracy of the information or make amendments before the study is completed.

What are the risks and discomforts?
This research involves minimum risk. Your identity is confidential. Information about you (e.g., position and education, years of nursing experience, gender, age) will be collected during the interview. Identifying data will be removed and confidentiality will be maintained. Some of the questions may be personally uncomfortable; if this happens, please identify that you may wish to discontinue the interview or take a break. Your comfort is most important. You could feel distressed when discussing your experience with administering these medications. If this happens, we can refer you to appropriate resources such as the Employee and Family Assistance Program. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me? There will be no direct benefits to you for participating. You may not get any benefit from being in this research study, however, your participation will help us understand how to improve pain management in older people with dementia

Do I have to take part in the study?

Your participation in the study is voluntary. Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time. It will not affect your employment in any way. You do not have to answer any questions for any reason. Even if you agree to be in the study, you can change your mind and withdraw from the study. If you wish to withdraw, you can contact the researcher up to two weeks after you interview and your data can be removed from the study.

Will I be paid to be in the research?

You will be given a gift card worth a $10.00 to thank you for your time. You will receive the $10.00 gift card even if you decide to withdraw from the study during the interview or if you decide to withdraw your interview from the study within two weeks of completing the interview.

Will my information be kept private?
Your participation in this study will be private and anonymous. Nothing you tell us through this questionnaire will be shared with anybody; again, your identity will remain private and

anonymous. The interview will be audio-recorded; however, your name will not be recorded. You will be assigned a unique study number so that the researcher can review and confirm accurate transcription or your interview. Your name and identifying information will not be associated with any part of the written report. All of your information and interview responses will be kept confidential. Any summary interview content or direct quotations from the interview that will be added to academic publications or other presentations will be anonymized to protect your identity. All care will be taken to ensure that additional information in the interview that could identify you is not revealed.

How will the study data be used?

The results of this study will be shared with the organization through small meeting presentations and electronically distributed reports. Following the dissemination of study findings within the organization, we will publish the results so that other interested people may learn from the research.

All or part of your interview content may be used;

- in academic papers, policy papers or news articles,
- formal and informal presentations,
- and other feedback events.

If you would like to receive a final copy of the findings, you can provide your contact information (mail or email address) on the consent form. Let me know so that I can be sure to send you a copy.

How will the study data be stored?

The recording and study transcript kept for five years in an encrypted file on the co-investigator's secure network for a minimum period of *5* years in accordance with the study site requirements and University of Alberta.

What if I have questions?

If you have any questions or require more information about the study itself, you may contact the researcher, Beverley Ingelson or Dr. Sherry Dahlke at the numbers mentioned herein or [redacted] by telephone at (760) 834-3510 or email at [redacted].

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have any questions regarding your rights as a research participant or how the research is being conducted you may contact the Research Ethics Office at 780-492-2615. This office is independent of the study investigators.

Please keep a copy of this letter for reference.

How do I indicate my agreement to be in this study?

By signing below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction.
- That you will be taking part in a research study.
- That you may freely leave the research study at any time.
- That you do not waive your legal rights by being in the study
- That the legal and professional obligations of the investigators and involved institutions are not changed by your taking part in this study.

SIGNATURE OF STUDY PARTICIPANT

____
Signature of Participant

________________________________ ______________________
Name of Participant Date

SIGNATURE OF PERSON OBTAINING CONSENT

____
Signature of Person Obtaining Consent

________________________________ ______________________
Name of Person Obtaining Consent Date

A signed copy of this consent form has been given to you to keep for your records and reference.