

**Pain Assessment and Management for People with  
Dementia in Long-Term Care in Ontario**

By

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## **Abstract**

Providing nursing care for people with dementia and pain has many challenges. The studies completed for this thesis explore the depths of these challenges by analyzing the concept of nurses' clinical judgment in caring for this population, as well as through the analysis of resident assessments conducted in long-term care facilities in Ontario. By understanding clinical judgment as well as patterns from resident assessment data, nurses can better understand the steps required to provide adequate pain management for people with dementia. The findings show that long term care residents with dementia who have untreated pain exhibit several behavioral indicators of pain. This supports the creation of policies and best practice guidelines that include a tailored assessment of pain using specialized knowledge and tools. These studies strive to improve the quality of life of residents living with dementia and pain by improving pain management through proper assessment and intervention.

*Keywords:* clinical judgment, pain, dementia, assessment, treatment, nurses, long-term care

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## **Chapter 1: Introduction**

### **Introduction to Nursing Care for People with Dementia and Pain**

Nursing is a dynamic and ever-changing profession that requires special consideration within many different settings and roles. By exploring specific contexts and associated challenges nurses may face, this paper can support nurses and positively impact the care they provide and improve patient outcomes. My practice has been, in part, in long-term care (LTC). During my practice, I have become increasingly interested in managing the pain of residents in LTC, especially for residents with dementia. As such, the focus of this thesis is nursing care for LTC residents with dementia and pain.

Dementia is extremely common and a significant health issue around the globe. Dementia affects over 47 million people worldwide and is projected to affect more than 100 million people by 2050 (Koo et al., 2018). In Canada, the standardized prevalence of dementia is 6.8%, and Ontario has the highest prevalence in the country at 7.3% (Canadian Institute for Health Information, 2019). Approximately 80% of LTC residents have dementia (Nakashima et al., 2019). Koo et al. (2018) estimated that between 40% and 80% of people with dementia also suffer from pain. Cognitive impairment can reduce a patient's ability to express pain (Nakashima et al., 2019). People with dementia are at high risk for poorly managed pain and can develop secondary neuropsychiatric symptoms and responsive behaviours, including agitation, psychosis, and sleep disturbances (Aasmul et al., 2016). They can also suffer from depression, anxiety, and appetite loss (Nakashima et al., 2019). Unmanaged pain also increases their risk of functional decline and falls (Lichtner et al., 2016).

Despite the high prevalence of pain and dementia, there remains little evidence about Canadian LTC residents with pain and associated behaviours. This research was conducted to

better understand the experience of pain for LTC residents with dementia. This new knowledge can inform changes in policy and nursing practice that may improve the care of such residents.

### **Definition of Terms**

A long-term care (LTC) home is a facility that provides services and care for people who require onsite nursing care, 24-hour supervision or personal support, or are unable to live independently (Ministry of Health and Long-Term Care, 2017). Those living in LTC will be referred to as residents throughout this thesis. Also included throughout this thesis is information regarding older adults with dementia, as not all people with dementia are institutionalized, thus they are not all referred to as residents in the literature. Assessment refers to the gathering of information regarding an individual physiological, psychological, and sociological needs to plan care that includes subjective and objective data (Toney-Butler & Unison-Pace, 2021). According to the World Health Organization (2020) dementia is a syndrome that involves a deterioration in cognitive functions including memory, thinking, orientation, learning capacity, language, comprehension, and judgement.

### **Literature Review: Dementia and Pain in Long-Term Care**

For older adults, dementia is a contributing factor leading to admission to LTC (Halonen et al., 2019). Consequently, cognitive impairment is prevalent in LTC (Bjork et al., 2016; Burfield et al., 2012; Kaasalainen et al., 2007; Nakashima, et al., 2019). In addition to cognitive impairment, pain is also prevalent (Bjork et al., 2016; Chow et al., 2016; Kaasalainen et al., 2007; Nakashima et al., 2019). Due to the high demand for LTC beds, long wait times, and strict qualification standards, residents are frail when admitted to LTC (Bjork et al., 2016). This means that from the point of admission, many residents have high care needs. Unfortunately, there is no current cure for dementia and care is geared toward symptom management (Koo et al., 2018). A literature review

was conducted to determine the pain management status of LTC residents with dementia and to identify gaps in the literature that point to a need for research.

For an in-depth review, the following databases were searched: PubMed, Cumulative Index of Nursing and Allied Health Literature, Scholars Portal, and ProQuest. Databases were searched using the terms: residents, seniors, long-term care, pain, cognitive impairment, and dementia. Filters were set to exclude grey literature and articles published before 1999; a total of 9,155 articles were returned (Appendix A). A large date range was included as there are a limited number of recent Canadian studies. The results were reviewed for relevance, quality, credibility, location of study, and transferability. Many studies were included for a synthesis of the literature. Five studies were included for a thematic review as they demonstrated appropriate scope, strong manageability, and relevance in that they each explored a different aspect of pain and dementia to allow for a holistic understanding of the dynamic levels of consideration required.

### ***Thematic Literature Review***

A cross-sectional study done in Sweden by Bjork et al. (2016) explored the prevalence of cognitive impairment, pain, and neuropsychiatric symptoms in LTC, as well as the level of activities of daily life (ADLs) dependency. A total of 188 randomly selected LTC homes with a total of 4,831 residents were included in the study. The authors concluded that pain was more prevalent among residents who were cognitively impaired or required assistance with ADLs when compared to those who did not have cognitive impairment or require assistance for ADLs. They also found that residents with cognitive impairment had a higher rate of neuropsychiatric symptoms than residents without cognitive impairment.

Cipher et al. (2006) explored the behavioural manifestations of pain in people with dementia. Their research took place in the United States and included 16 LTC facilities and 277

residents. They conducted quantitative, cross-sectional research to explore the differences between residents with varying levels of dementia who suffer from pain to determine the influence of pain on responsive behaviors. They found higher levels of pain were associated with more frequent and more intense behaviours, and that responsive behaviors were increased in residents with more severe dementia. Their study concluded that pain should be appropriately treated to reduce responsive behaviours.

Burfield et al. (2012) completed a qualitative, cross-sectional secondary analysis of data from the Resident Assessment Instrument Minimum Data Set version 2.0 (RAI-MDS 2.0) assessment tool in selected LTC facilities in the United States to investigate the relationship between pain behaviours and cognitive status. They found that the number of assessments conducted, and number of details included in the assessment related to pain and intensity declined as cognitive status declined. This suggested that under detection of pain was more likely as cognition declined due to reduction in assessment frequency and quality. Burfield et al. (2012) encouraged the use of additional tools that incorporate behavioural manifestations to detect pain.

A Canadian study conducted in four LTC homes in Southwestern Ontario used qualitative semi-structured interviews to explore the decision-making process, attitudes, and beliefs about pain management of physicians, registered practical nurses, and registered nurses (Kaasalainen et al., 2007). This study found that many of the nurses and physicians that were interviewed felt strongly that the assessment of pain was critical as it would set the stage for how pain would be managed. Despite this, they found an overall challenge in managing pain in LTC. There was a lack of recognition of pain and ambivalence concerning pain assessment accuracy and diagnosis. The authors also found reluctance to treat pain with opioids.

Nakashima et al. (2019) studied whether there were differences in pain interventions between residents with dementia and those without. Their study was carried out in the United States and included 50,673 nursing home residents. They used quantitative, cross-sectional data from the Resident Assessment Instrument Minimum Data Set 3.0 to analyze the pain assessments and interventions received by residents with and without dementia. They found that there were fewer assessments of pain conducted for residents with dementia and that these residents received less pro re nata (PRN) analgesic and fewer non-medical pain interventions.

A common theme in the literature was the suggestion to use alternate tools and staff education to improve the assessment of pain in cognitively impaired residents (Burfield et al., 2012; Cipher et al., 2006; Kaasalainen et al., 2007; Nakashima et al., 2019). For residents with dementia, self-rated instruments for pain assessment can be impractical, and using observer-rated scales can improve assessments and patient outcomes (Chow et al., 2016). McAuliffe et al. (2009) found a lack of education and training and overall underuse of adapted pain assessment tools in LTC for residents with dementia. A holistic and comprehensive approach to pain management for this population should include behavioural evaluations, information gathered from family and caregivers, and reference to diagnoses that might result in pain (Buffum et al., 2007).

Some people with dementia may have difficulty reporting sensory and emotional responses to pain verbally; therefore, assessing external motor displays of pain is important (Monroe et al., 2012). Tools that more comprehensively consider verbal and behavioural manifestations of pain over extended periods are best suited to assess and treat pain in LTC residents with cognitive impairment (Cipher et al., 2006; Kaasalainen et al., 2007). Using observational pain scales can help healthcare workers recognize and assess pain because these scales increase awareness and prompt the process of proper pain management (Zwakhalen et al.,

2004). To improve the health and quality of life of LTC residents with dementia, it is crucial to improve the identification, monitoring, and treatment of pain (Rajkumar et al., 2017).

## Synthesis of the Literature

### *Assessment of Pain*

Evidence from the literature confirms that pain is underreported in cognitively impaired LTC residents (Andrews et al., 2019; Burfield et al., 2012; Nakashima et al., 2019). Pain is also misdiagnosed or diagnosed late in people with dementia (McAuliffe et al., 2009). Cognitive impairment increases the complexity of assessing and managing pain (Agit et al., 2018; Buffum et al., 2007; Burfield et al., 2012; Cipher et al 2006; Kaasalainen et al., 2007; Nakashima et al., 2019).

### *Consequences of Pain*

People with dementia have difficulty recognizing pain because of altered pain processing, impaired communication, and memory problems (Griffioen et al., 2019). Van Kooten et al. (2017) found that people with early-stage dementia were better able to communicate and report pain than those in more advanced stages of dementia. It is important to note that dementia does not reduce the threshold for pain perception and that vascular dementia may in fact heighten pain perception (Buffum et al., 2007).

For people with dementia and pain, there is a significant association between pain and neuropsychiatric symptoms (Flo et al., 2014). LTC residents with cognitive impairment experience higher rates of pain associated neuropsychiatric symptoms than residents without cognitive impairment (Agit et al., 2018; Bjork et al., 2016; Cipher et al., 2006; Nakashima et al., 2019; Rostad, 2020). Responsive behaviours occur in up to 90% of people with dementia and are often secondary to untreated pain (Gallagher & Long, 2011). Burfield et al. (2012) found that

neuropsychiatric pain symptoms included agitation, crying, fidgeting, resistance, guarding, and rigidity. Other symptoms also found to be associated with pain were anxiety and depression, insomnia, weight loss, and gait disturbances (Burfield et al., 2012; Cipher et al., 2006).

Pain has a significant effect on the quality of life and long-term health outcomes in nursing home residents (Agit et al., 2018; Burfield et al., 2012; Cipher et al., 2006; Nakashima et al., 2019). Symptoms like agitation and aggression may lead to institutionalization or inappropriate prescriptions for antipsychotic medications (Agit et al., 2018). LTC residents with late-stage dementia and pain experience more symptoms and a lower quality of life than residents with no pain, which may inadvertently increase care needs (Rostad, 2020). The increased needs increase the strain on and costs for the healthcare system (Gutmanis et al., 2015). Untreated pain can potentially increase the severity of cognitive impairment (Monroe et al., 2014). Since those with dementia and pain are more likely to experience delirium, improved pain management may reduce their overall risk for delirium (Feast et al., 2018). They are also six times more likely to be admitted to hospital with delirium than those without dementia, and the delirium is associated with an increased risk of death (Feast et al., 2018).

### ***Treatment of Pain***

Pain is often unrecognized and undertreated in residents with dementia (Griffioen et al., 2019). Cognitively impaired residents have been found to receive less pharmacological pain treatment than cognitively intact residents (Buffum et al., 2007; Kaasalainen et al., 2007; Nakashima et al., 2019). For older adults, treating pain can be difficult given the need to balance physiological and psychological factors (Chau et al., 2008). Improving how pain is managed can improve the psychological well-being of LTC residents with cognitive impairment (Lee et al., 2013).

Analgesics should be the first-line treatment to manage pain in LTC residents (Knopp-Sihota et al., 2016). Individualized pain regimens that include a multifaceted approach are required for effective pain management (Knopp-Sihota et al., 2016). Residents with dementia and pain require more effective and well-tolerated analgesics (Chow et al., 2016). Implementing scheduled pharmacological treatment in a timely fashion is preferred over PRN administration as it ensures that residents receive more of the amount of medication ordered and is more logical for people with impaired ability to report pain (Buffum et al., 2007). It is also essential to titrate medication according to pain level based on verbal, behavioural, and functional responses to medication to ensure adequate control while limiting the side effects from pharmaceuticals (Buffum et al., 2007). Husebo et al. (2014) recommended a systematic approach to pain management that included the proper use of analgesics for the elderly population, which would reduce agitation for residents with dementia. They believed this approach could also reduce the use of psychotropic drugs (Husebo et al., 2014). Barry et al. (2015) found that high use of antipsychotic medication for people with dementia was correlated with the presence of pain.

Though the appropriate use of opiates can significantly improve the quality of life for people with chronic pain, opiates are often underused because of side effects and other drug related interactions (Caracci, 2003). Older adults are at a greater risk for side effects given their comorbidities and the high incidence of polypharmacy (Chau et al., 2008). Despite the ongoing occurrence of pain and secondary symptoms, symptom management may be suboptimal and seems to only increase during palliation (Hendriks et al., 2015). A qualitative study done by Fry et al. (2016) found that nurses often reported a balancing act in treating pain and managing the side effects of analgesics.

Erdal et al. (2017) found an association between pain and depressive symptoms in people with dementia and that reducing pain reduced depressive symptoms; they also noted that the efficacy of antidepressants for depression in people with dementia is unclear. A systematic review done by Dudas et al. (2018) concluded that the efficacy of antidepressants in treating depression in dementia is insufficient and that antidepressants may cause adverse events. Non-pharmacological treatments have been shown to have benefits. A systematic review by Coronado (2020) found that touch therapy, including massage, acupressure, and reflexology, had positive effects on people with dementia, including reducing agitation and stress that could be related to pain. Strengthening and balance exercises can also significantly decrease agitation for people with cognitive impairment (Aman & Thomas, 2009).

### ***Specialized Assessment of Pain***

Since pain is expressed in a variety of ways, tools that incorporate a wide range of pain indicators can best determine levels of pain for people with dementia (Nakashima et al., 2019). The RAI-MDS 2.0 is the assessment tool provided to LTC homes in Canada (Ministry of Health and Long-Term Care, 2013). For the assessment of pain, the RAI-MDS 2.0 includes a two-item scale that measures pain frequency (0=no pain; 1= pain less than daily; 2= daily pain) and intensity (1= mild pain; 2= moderate pain; 3= times when pain is horrible or excruciating; 8=no pain indicated in element) (Centers for Medicare & Medicaid Services, 2002). This scale is efficient for those who are cognitively intact however it has been identified as less valid for use in residents with more advanced cognitive impairment who are less able to self-report pain (Knopp-Sihota, 2019). Fries et al. (2001) found that residents with advanced levels of cognitive impairment had less pain reported and suggests that clinicians be vigilant when considering pain indicators for those with cognitive impairment.

Several observational bed-side tools have been developed to screen for pain for those with cognitive impairment and includes the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC). This tool provides a checklist of 60 behaviours grouped into four categories: facial expression, social/personality/mood, activity/body movement, and others (Fuchs-Lacelle & Hadjistavropoulos, 2004). Behaviours include grimacing, physical and verbal aggression, anxiousness, agitation, wandering, and calling out, and each behaviour shown by a senior is checked. The score for the assessment is the number of behaviours with a checkmark, thus to generate a total, the user must sum all sub-scale totals. The total can be used as a comparison throughout time, an increasing score indicates increased pain, and a decreased score indicates a decrease in pain. The checklist should be implemented on admission to LTC to provide a baseline, on quarterly review, any time the resident reports a change in pain, every 8 hours for residents with behavioural symptoms related to pain, and one hour following treatment of pain to evaluate effectiveness. This tool allows the user to review various potential indicators to identify pain for people who may not be able to effectively participate in a self-reporting or analog pain scale. It is imperative to implement pain assessment and management strategies that adapt to the limited ability of residents with dementia to report and express pain.

A revised version of this tool, PACSLAC-II, has also been published. This tool also provides a checklist and includes 31 behaviours grouped into six categories: facial expression, crying, body movements, changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes (Chan et al., 2014). The creators of this tool recommend that this checklist be conducted during observations of activity or movement which can include transferring or walking. This tool should be implemented on admission, on quarterly review, weekly for those with ongoing pain issues, any time a change in behavior is reported that may be

related to pain, and to assist in determining if treatment was effective. The user observes for the presence or absence of each behavior on the checklist and sums each checked behavior for a total score. The scores can be used after each collection for comparison; an increased score suggests that an increase in pain is likely whereas a reduction in score suggests that pain has diminished.

The Pain Assessment in Advanced Dementia (PAINAD) scale is to be used at rest and during movement (Warden et al., 2003). This tool includes five categories: breathing, negative vocalization, facial expression, body language, and consolability. The observer is to score each of the items from 0-2 based on the detailed characteristics within the tool. The total score is then tabulated; higher scores suggest greater pain severity; totals can be used as a reference to note potential changes over time and to evaluate pain treatment.

The Abbey pain scale was developed to measure the severity of pain in people with late-stage dementia (Abbey et al., 2004). The Abbey pain scale includes six categorized to score: vocalization, facial expression, change in body language, behavioral change, physiological change, and physical change. Each item is scored from 0-3 for severity of behavior (absent: 0; mild: 1; moderate: 2; severe: 3). The sum of scores is tabulated and used as an interpretation of pain severity: no pain: 0-2; mild: 3-7; moderate: 8-13; severe: 14+. The observer is also asked to indicate if the pain is acute, chronic, or acute on chronic.

Many valid and reliable tools that have been developed to assess pain for those with cognitive impairment. An individualized approach should be considered when selecting the appropriate tool and while collecting baseline and ongoing scores; the observations should always be made under relatively consistent circumstances (Herr et al., 2011). In addition to implementing these tools, it is also important to include consideration of health history and physical exam findings. Analgesics should also be implemented to help determine if pain is the

root of behaviors; if the addition of analgesic reduces behavior it may be pain-related, and behaviors should be considered pain-related.

### **Limitations**

The reviewed studies had limitations. Standardized pain scales adapted to assess people with cognitive impairment were not used consistently (Burfield et al., 2012). The scales that were used varied from study to study, limiting comparability (Bjork et al., 2016). Studies also assessed various types of pain, for example, osteoarthritic pain, which may also limit comparability to other types of pain. Pain data may be limited because, within the dynamic of expressing and assessing pain, some residents with cognitive impairment may not be able to report pain at all (Nakashima et al., 2019). Many of the studies were cross-sectional and did not provide a long-term perspective of the dynamic antecedents and pain consequences (Bjork et al., 2016; Burfield et al., 2012; Cipher et al., 2006; Nakashima et al., 2019). Only one study incorporated a conceptual model. Further use of a conceptual model may have better guided the questions and themes related to pain and provided a more in-depth understanding.

### **Summary of Literature Review**

In summary, pain is a very dynamic and subjective experience that unfortunately becomes increasingly challenging to assess and manage in residents with dementia. Pain can have devastating impacts on LTC residents with dementia and can result in secondary neuropsychiatric symptoms and responsive behaviours. An increase in responsive behaviours leads to an increase in institutionalization, increased care needs of residents in LTC, and greater demands on their care providers. Implementing more inclusive pain assessment tools could significantly improve the quality of life of residents with pain and dementia.

## Thesis Format

This thesis is presented through this introduction, two articles, and a final discussion. The aim of the research was to explore assessment and treatment of pain in LTC residents with dementia. The questions driving this research were:

- How does the clinical judgment of nurses affect the assessment and treatment of pain for people with dementia?
- What characteristics of pain are associated with people who have dementia and no reported pain in LTC?

This research highlights the complexity of assessing and managing pain for residents with dementia in LTC homes.

The first article includes a concept analysis conducted to provide a better understanding of nursing clinical judgment in assessing and treating individuals with dementia and pain. It provides insight into the challenges nurses face and provides proof that further investigation is needed into the assessments being conducted. The concept of nurses' clinical judgement in pain assessment provides a foundation for the interpretation of the findings of the analysis of the RAI MDS 2.0 data, the direction of future research, and the potential for policy and practice changes within LTC, which are outlined in the discussion chapter. The second article is a secondary analysis of the RAI-MDS 2.0 obtained from the Canadian Institute for Health Information (CIHI). Nursing assessment of resident behaviors, seen with advancing cognitive impairment, are captured in the RAI-MDS. Responsive behaviors may also be expressions of pain. This analysis was conducted to determine the association of each responsive behavior with reported pain. The secondary analysis explores assessments conducted and whether potential indicators of pain are being considered or not.

When evaluating the rigour of the data used for this study, the validity and reliability of the RAI-MDS 2.0 tool needs to be considered. The RAI-MDS 2.0 is used in all LTC facilities in Ontario to structure resident assessments and indicate areas for further investigation and care (Ministry of Health and Long-Term Care [MOHLTC], 2013). It is also used to develop individualized care plans based on information regarding a resident's preferences, strengths, and weaknesses. Further, built-in quality indicators are used to monitor standards and quality of care within LTC facilities. The validity of this tool can be measured by how effectively it provides data and indicators that reflect the quality of practice and related resident outcomes. Validity was found to vary between assessment categories and overall was inconclusive (Hutchinson et al., 2010). Reliability refers to the consistency of measurement obtained when using an instrument repeatedly on a population of individuals or groups (Hutchinson et al., 2010). An international study by Hirdes et al. (2008) explored the overall performance of RAI-MDS 2.0 and concluded that the tool has substantial reliability according to kappa statistics. Internal validity, or empirical relationship, in a study can be achieved by having a homogeneous sample with respect to confounding variables (Pilot & Beck, 2017). Within this study this was achieved by using a sample that was sorted into residents with dementia and those without. External validity, or generalizability, can be achieved using a representative sample (Pilot & Beck, 2017). This study used a sample of residents in LTC with and without dementia to ensure representation.

In terms of study controls, a clear research purpose and detailed research design ensure rigour (Burns & Grove, 2010). This was established by outlining a clear research question of what characteristics of pain are associated with people who have dementia and no reported pain in LTC and designing a descriptive retrospective population-based study to explore.

Objectivity was achieved by limiting all controllable bias in selecting RAI-MDS 2.0 questions by using the PACSLAC list of behaviours and finding related assessed behaviours. Chi-squared tests were done to determine if differences found in behaviors reflected true significance and were not based on chance alone. Cramers' V index of relationship was also calculated to measure the association between variables. An expert in statistics was consulted to ensure that all tools were appropriate for the research questions and design.

Data were stored on a T storage drive of thesis supervisor Roberta Heale at Laurentian University's School of Nursing. Only the research members had access to these data. All data received from CIHI were received without identifying information to ensure anonymity and confidentiality. Information technologists of Laurentian University managed the privacy of the T drive. Virtual private network (VPN) access was required, with password protection. Data will be stored for seven years and destroyed by information technologists at Laurentian University, who will provide CIHI a data destruction certificate.

### **Data Dissemination**

Findings from this study will be disseminated through thesis format and will be provided to research journals for consideration for publication. Further, they will be provided to the MOHLTC for consideration in LTC policy development to support the creation, implementation, and use of adequate pain assessment and treatment policies. Creators of pain scales for people who are cognitively impaired may employ the study as supportive data to encourage the use of such tools. Findings could be used for educational purposes to allow for insight and understanding of the prevalence and special considerations required when treating pain in people with dementia. Vehicles of dissemination could include journals, educational in-services, conference presentations, and clinical guidelines.

## Summary

The chapters of this thesis are significant to nursing in many ways. The articles explore and articulate the challenges nurses working in LTC homes face in managing pain for residents with dementia. By uncovering the factors that contribute to clinical judgment, nurses can understand the decision-making process and depth of consideration required when managing pain for residents with dementia in LTC. In understanding that there are several factors for nurses to consider, the secondary analysis of RAI MDS 2.0 assessments provides concrete data of current assessment practices and where potential gaps may be. The RAI MDS 2.0 assessments completed by nursing staff represents information collected over a 3-month period, significant change in condition, discharge/re-admission, or annually. Clinical judgement of nurses is significantly pertinent as it demonstrates that health care providers may observe responsive behaviors and document throughout assessments however may not also recognizing them as indicators of pain. The examination of indicators of pain documented for residents with dementia and no reported pain highlight the importance of assessment and how including adapted observer rated pain scales may improve pain management.

## Chapter 2: Concept Analysis

### Abstract

The purpose of this article is to provide a conceptual analysis of nurses' clinical judgment in relation to providing pain management for residents in long-term care who live with dementia. The clinical judgment of nurses has been widely studied and has an enormous impact on the care they provide. Assessing and treating pain is a complex task, and for nurses caring for people with dementia, there are added challenges. Nurses' clinical judgment is vital to the proper assessment and treatment of pain for residents with dementia. A comprehensive review of the literature was completed. The steps from Walker & Avant (2019) were used to structure this concept analysis. The key components of clinical judgment in managing pain for people with dementia are quality assessment, critical thinking, intuition, and reflection. This analysis found that nurses can improve pain management by applying clinical judgment that incorporates evidence-based knowledge to individualize care planning and improve resident outcomes. Clinical judgment is an ambiguous concept that requires exploration within many different contexts for a true understanding. Nurses can use the analysis of clinical judgment and its components to better understand their judgment and the consequences of their actions when managing the pain of people with dementia. This analysis provides conceptual clarity of clinical judgment and articulates its impact on pain management for residents with dementia.

*Keywords:* clinical judgment, pain, dementia, long-term care

### Clinical Judgment of Nurses Caring for Residents with Dementia and Pain

The concept of clinical judgment has been defined and explored through several different lenses, including qualitative experiences and perspectives, and quantitative data and trends. Although some information is transferable, it is vital to explore the concept within the context of pain and dementia to comprehend its components and its impact on providing care. Using Walker and Avant's (2019) process for concept analysis, this paper explores nurses' clinical judgment related to pain management for people with dementia. Definitions and characteristics are provided. Antecedents, consequences, empirical referents, exploratory cases, and implications for practice were reviewed. This concept analysis was conducted to offer insight

into what is necessary for nurses to adequately identify and address pain in long-term care (LTC).

### **Background: Pain and Dementia**

Assessing and treating pain is a complex task, and for nurses caring for people with dementia there are added challenges due to communication barriers. Dementia disrupts the cognitive-linguistic system, which in turn reduces communicative abilities and effectiveness. This impairment strains basic communication and thus a patient's ability to articulate needs, feelings, or preferences in ways that others can comprehend (Dooley & Walshe, 2019). Understanding nurses' clinical judgment is vital to properly assessing and treating pain for LTC residents with dementia.

It is estimated that up to 80% of residents living in LTC have dementia and that one in four people living with dementia have difficulty communicating as a result of their cognitive impairment (Nakashima et al. 2019). Cognitive impairment can reduce their ability to express their care needs, including the presence of pain (Nakashima et al., 2019). As a result, it is an added challenge for nurses to assess and manage pain for people with dementia. Approximately 50% of people with dementia suffer from pain; however, they are often subject to minimal pain assessments, lack of documentation, and overall longer wait times to receive analgesia (Lichtner et al., 2016). Lee et al. (2013) found that there were also large gaps in knowledge in providing adequate end-of-life care and pain management for residents with dementia.

Neuropsychiatric symptoms in dementia result from brain changes related to dementia and unmet physical needs, including pain (Pieper et al., 2016). In advanced dementia, 90% of residents develop neuropsychiatric symptoms, including agitation, psychosis, and sleep disturbances many of which are associated with pain (Aasmul et al., 2016). Proper management

of pain can reduce these symptoms (Aasmul et al., 2016). LTC residents who live with dementia are less likely to receive as-needed (pro re nata, or PRN) pain medication (Nakashima et al., 2019). Significant consequences of poorly managed pain in dementia include depression, anxiety, loss of appetite, and insomnia (Nakashima et al., 2019). Inadequate pain management can lead to functional decline, impaired movement, and increased risk of falls (Lichtner et al., 2016).

### **Background: Clinical Judgment**

Clinical judgment has been researched and discussed for decades. Several authors offer interesting perspectives and information, and a significant amount of information is available. However, it is essential to explore clinical judgment within specific contexts. Tanner (2006) developed the concept of clinical judgment and, according to their model, the process of clinical judgment has four phases: noticing, interpreting, responding, and reflecting. She explained that clinical judgment is necessary in ambiguous clinical situations, requiring nurses to be flexible in identifying complex situations and interpreting and responding appropriately.

Knopp-Sihota et al. (2015) found that in LTC, resident care is often rushed or missed because of time constraints and that nurses are removed from a large portion of direct care hours. Despite being removed, nurses remain responsible for the formal assessment and management of pain. When faced with time constraints and the already existing complexity of assessing pain for residents with dementia, the clinical judgement of nurses is integral to understand how balance can be achieved for staff and residents in the management of pain.

## Aim

This analysis aims to expose the different components of clinical judgment related to pain management for LTC residents with dementia. The goal is to develop a deeper understanding and provide insight into special considerations.

## Methods

A concept analysis examines the basic elements of a concept to outline its internal structure and explore similarities and differences with related terms (Walker & Avant, 2019). In this paper, the concept of the clinical judgment of nurses caring for residents with dementia and pain in LTC was analyzed using the eight steps outlined by Walker and Avant (2019): selecting a concept, determining the aim/purpose of analysis, identifying all uses of the concept, determining attributes, exploring cases, identifying antecedents and consequences, and defining empirical referents.

The following databases were searched using the terms residents, pain, dementia, cognitive impairment, and clinical judgment: PubMed, Scholars Portal, ProQuest, and Cumulative Index of Nursing and Allied Health Literature. Inclusion criteria were: articles in English, qualitative and quantitative studies, all classes of nurses, cognitive impairment (all types of dementia), LTC settings, and pain, and all countries were included. Excluded were physicians, residents/patients without cognitive impairment, and grey literature. Literature was reviewed for relevance, aim and scope, design, findings, and transferability.

## Definitions and Uses of the Concept

By separating and defining words within a concept, its meaning and how it pertains to nursing practice can be better understood (Walker & Avant, 2019). “Clinical” is defined as subjects related to the diagnosis and treatment of medical, psychological, or other disorders

(American Psychological Association [APA], n.d.). “Judgment” is the ability to identify relationships, draw conclusions, and make evaluations of people and events (APA, n.d.). “Clinical judgment” is an interpretation or conclusion regarding the needs or concerns of a patient and whether any action is required (Tanner, 2006). “Dementia” is defined as a generalized deterioration of memory and at least one other cognitive function, including language, secondary to a variety of causes where the loss of intellectual abilities interfere with daily function (APA, n.d.). It is important to note that the term dementia has been replaced in some research and writing by neurocognitive disorder. Neurocognitive disorders involve structural or functional changes in brain function that result in secondary memory impairment (Black & Andreasen, 2020). “Pain” is the unpleasant sensation that results from stimulation or damage to nerve tissue or excessive stimulation (APA, n.d.). Physical pain is caused by the stimulation of pain receptors; other pain can also be experienced as emotional or sensory unpleasantness (APA, n.d.). “Behaviour” is a function or action that can be observed or measured as a response to stimuli (APA, n.d.).

### **Defining Attributes**

The defining attributes of a concept allow insight into its defining characteristics (Walker & Avant, 2019). The literature was searched for defining attributes of clinical judgment that can be applied to nursing care for people with pain and dementia. Quality assessment, critical thinking, intuition, and reflection were found individually or as a group as defining characteristics (Alfaro-Lefevre, 2016; Benner & Tanner, 1987; Tanner, 2006).

A quality nursing assessment occurs when the nurse considers the context and background of the patient’s experience by noticing physical, social, and emotional cues to

understand and interpret the care required (Tanner, 2006). By implementing an individualized assessment of pain, nurses can uncover residents' needs and plan care accordingly.

Critical thinking is achieved through a contextual analysis of the problem at hand, considering confounding variables and problem-solving to reach a final judgment (Alfaro-Lefevre, 2016). A nurse treating residents with dementia and pain must consider their residents' individual needs and problem-solve to meet those needs.

Intuition is a nurse's understanding of a problem based on experience and background combined with knowledge and pattern recognition (Benner & Tanner, 1987). It allows the nurse to understand that the resident's behaviour may be related to pain and thus provide the required assessment to manage pain holistically.

Reflection is required to evaluate the effectiveness of care and change course as needed to improve the outcome of patient care (Tanner, 2006). It is imperative to reflect on and reassess the patient's pain to ensure that needs are adequately met on an ongoing basis.

## **Exploratory Cases**

### ***Model Case***

A model case is an example that contains all the defining attributes of the concept (Walker & Avant, 2019). The following example includes all of the defining attributes of a nurse's clinical judgment in managing pain for a dementia patient: a quality assessment, critical thinking, intuition, and reflection.

A nurse prepared for her shift by reviewing Mr. Diamond's care plan, where she found his history of dementia. She noted that he was once involved in a workplace accident while working as a contractor, where he fell and fractured several bones and had resulting chronic arthritis in the affected areas. She attended a morning report where the night shift staff explained that Mr. Diamond was awake all night wandering the halls. She entered his room to complete her

initial assessment and observed the patient rocking back and forth in his bed. When she walked toward his bedside, he began to clench his fists. Her intuition told her that there was an underlying cause of his behaviour. She calmly explained that she was there to provide help if needed. She opened the curtains to show Mr. Diamond men working on the roof of a nearby building and asked him questions about the work he did. She recalled that he once had an injury from work and asked if he still had any residual pain. He hung his head and held his knees. She collected his vital signs, which showed an elevated pulse and used a pain scale diagram for the patient to report his level of pain. She stepped out of the room and completed an additional pain scale for residents with dementia that rates behaviours associated with pain. She began a chart review and discovered that his home medication included a low dose fentanyl patch that was not ordered on admission to LTC. She placed a call to the physician and obtained an order for the fentanyl patch, which was applied immediately. She continued to re-evaluate Mr. Diamond's pain and behaviours throughout the day and during shifts in the following days. Mr. Diamond was no longer restless and was reported to be sleeping on all rounds at night. She reflected on the importance of pain management and added an entry into his care plan highlighting the history of pain and potential for resulting behaviours when not managed in hopes the patient would not endure this experience again.

All defining attributes of a nurse's clinical judgment in managing pain for dementia residents were shown in this case. A quality nursing assessment included a thorough evaluation of current and background information. Intuition was demonstrated when the nurse recognized the behaviours were potential initial indicators of a problem that required further investigation. Critical thinking was demonstrated when the nurse contacted the physician with her assessment, the patient's background information, and a request for treatment. And, reflection was carried out to assess treatment effectiveness.

### ***Borderline Case***

A borderline case contains most, but not all, defining attributes of the concept (Walker & Avant, 2019).

A nurse entered the dining room where she saw that her patient Mrs. Cook had not eaten any of her meal. She checked Mrs. Cook's chart and discovered her patient had a good appetite and typically ate well. The nurse assessed Mrs. Cook to uncover why she was not eating and her intuition told her something was limiting her patient's ability or willingness to eat. The nurse asked Mrs. Cook to open her mouth so she could check it. Mrs. Cook reluctantly agreed and opened her mouth. The nurse discovered what appeared to be thrush. The nurse contacted the physician who confirmed the thrush diagnosis and ordered nystatin, which the nurse promptly provided to Mrs. Cook. The nurse did not return to re-evaluate the effectiveness of treatment. Unfortunately, the patient developed diarrhea and stomach cramps, which are side effects of nystatin.

This case demonstrated the nurse's intuition that an investigation was required. A quality assessment of the patient's condition was implemented with critical thinking regarding the patient's symptoms and the problem that required solving. However, the nurse did not reflect on the resolution, which negatively affected the patient's well-being.

### ***Contrary Case***

A contrary case is one in which the concept is not demonstrated or successfully achieved (Walker & Avant, 2019).

A nurse began his shift in LTC by organizing his patient assignments. He noticed that Mrs. Cooper was scheduled for a shower and that previous nurses had provided naproxen before bathing because Mrs. Cooper was recovering from shingles and the water irritated her healing sores. He entered the room and saw that Mrs. Cooper was sleeping soundly, so he elected to omit the dose of analgesic. Following breakfast, a personal support worker attempted to shower Mrs. Cooper, who became aggressive and uncooperative. The personal support

worker reported the behaviours to the nurse. He left a note on the patient's chart requesting a prescription of haloperidol from the physician.

The nurse conducted a quality assessment of the patient's needs by leaving Mrs. Cooper sleeping. He did not demonstrate critical thinking to explore potential causes of behaviour within the context of the situation. He did not demonstrate intuition that there may be an underlying cause of Mrs. Cooper's behaviours. There was no reflection on the effect of not providing analgesia or appropriate re-evaluation of the patient's needs.

### **Antecedents**

Antecedents are events or attributes that must be present prior to the occurrence of the concept (Walker & Avant, 2019). To provide a high standard of clinical judgment in managing pain for dementia residents, clinical competence is required. Clinical competence is the ability to integrate knowledge and skills within the context of the situation (Lejonqvist et al., 2016). It allows a nurse to apply scientific knowledge about pain management to the individual needs of their residents. To achieve clinical competence regarding pain management, adequate education and training are required. With dementia residents, pain management is dynamic and nurses require adequate and specific training to meet their residents' needs. Valuable training regarding pain assessment, benefits of pharmacological and non-pharmacological methods of pain management, and parameters for monitoring and treating pain positively impact patient outcomes (Bonkowski et al., 2018).

Nurses must consider their personal beliefs and the beliefs of their residents concerning pain. These beliefs may affect the pain management nurses provide (Yildizeli-Topcu, 2018). Factors that affect pain beliefs include age, gender, ethnicity, and past experiences (Registered Nurses' Association of Ontario [RNAO], 2013). It is also valuable to consider a nurse's interpersonal skills. Skills that contribute to a nurse's clinical judgment include flexibility and

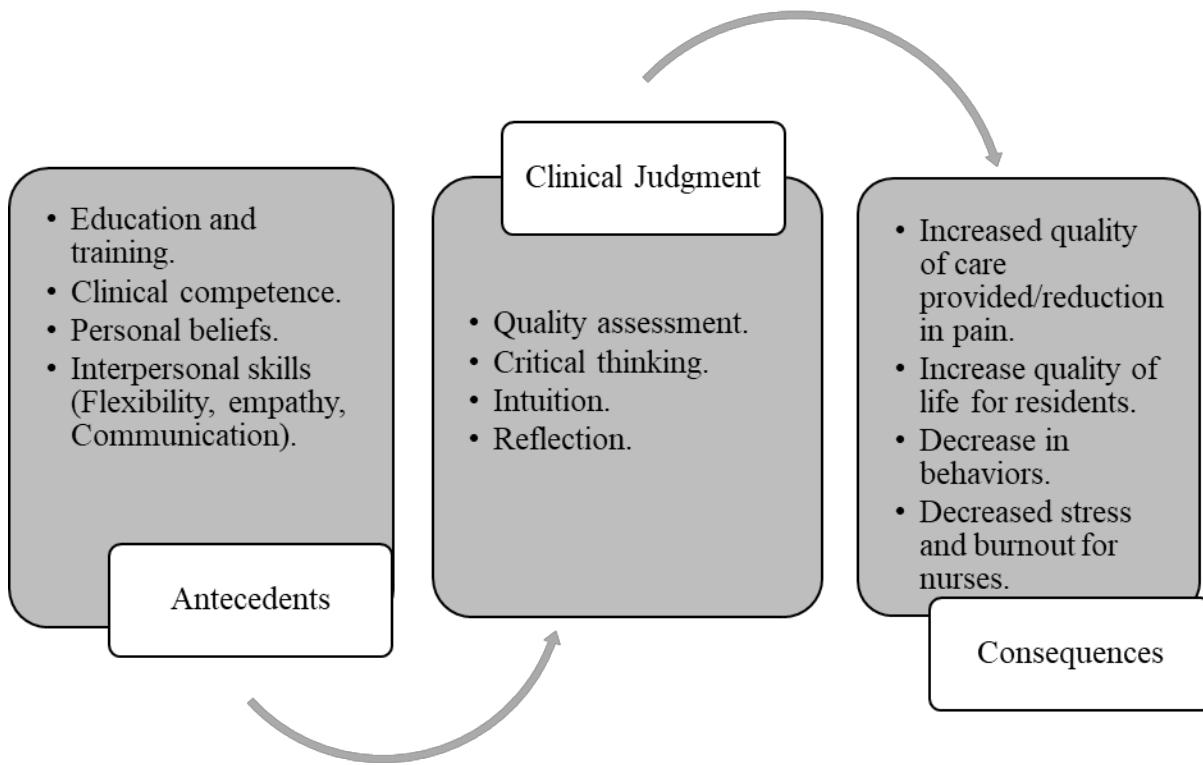
empathy (Alfaro-LeFevre, 2016). Encompassing these skills enables a nurse to evolve with the patient's needs and appreciate the significance of pain. Communication skills are also imperative as they enable nurses to engage well with residents and collaborate with colleagues and family members as needed (Alfaro-LeFevre, 2016). With the complexity of pain management with dementia residents, communication and collaboration enable nurses to collect valuable information and provide adequate treatment.

### **Consequences**

Consequences are defined by Walker and Avant (2019) as the outcome of the concept. In this case, if the antecedents are present, a nurse will implement appropriate clinical judgment by assessing and managing the pain of residents with dementia in LTC and produce consequences for residents and staff (Figure 1). The clinical judgment of a nurse is vital for proper assessment and treatment of pain for people with cognitive impairment (Davies et al., 2004). It allows a nurse to incorporate evidence-based knowledge into each patient's pain needs (Binnekade et al., 2018). In practice, clinical judgment increases a nurse's ability to improve and maintain their residents' health and well-being (Standing, 2017). Residents with dementia cannot always clearly express pain and depend on their healthcare providers to assess and manage pain accurately in various ways. Nurses can help manage pain using their clinical judgment to incorporate knowledge while fluently altering care (Samuels & Leveille, 2010). Clinical judgment applied to care improves the patient's overall quality of life (Standing, 2017). Effectively managed pain improves a patient's emotional and psychological well-being (Yildizeli-Topcu, 2018). When pain is well managed and thus negative behaviours associated with pain are reduced, there is a subsequent reduction in stress and burnout for nurses (Aasmul et al., 2016). By comprehensively monitoring and assessing residents for pain, nurses apply

expert clinical judgment to pain management and improve their ability to provide care and meet residents' needs.

**Figure 1. Clinical Judgment Concept Map**



### Empirical Referents

Empirical referents are categories of phenomena that demonstrate the concept's occurrence and make the concept measurable (Walker & Avant, 2019). To adequately assess and manage pain for residents with dementia, special considerations are required. Nurses should include both self-reported pain and observed pain behaviour since self-reported pain becomes less valid with increasing cognitive impairment (Lautenbacher & Kunz, 2019). When possible,

nurses should assess facial expression, body movements, and vocalization during rest and movement (Lautenbacher & Kunz, 2019).

Several tools have been created to assess pain for those with cognitive impairment including the Abbey pain scale, The Pain Assessment in Advanced Dementia (PAINAD) scale, and the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC). For the purposes of this analysis, we will explore the PACSLAC and PACSLAC-II. The PACSLAC was developed to assess the pain of seniors with cognitive impairment, including dementia, who may have a reduced ability to communicate (Fuchs-Lacelle & Hadjistavropoulos, 2004). The checklist of 60 behaviours is broken down into four categories: facial expression, social/personality/mood, activity/body movement, and others. Behaviours include but are not limited to grimacing, teeth clenching, physical and verbal aggression, anxiousness, agitation, thrashing, wandering, limping, crying, and calling out. During an assessment, the nurse marks each displayed behaviour within each category and determines the total score, which can later be referred to and compared. Increasing scores suggest increasing pain, and declining scores suggest lessening pain. The checklist should be implemented on admission to LTC to provide baseline data, on quarterly review, any time a change in pain is reported, every 8 hours for residents with behavioural symptoms related to pain, and one hour following treatment of pain to evaluate its effectiveness. The scores should be documented in a location easily accessible by other providers involved in the patient's care. Following the implementation and further review of the PACSLAC, a revised version known as the PACSLAC-II was created. This tool is similar in nature however includes 31 behaviours and is recommended to be conducted during movement or activity (Chan et al., 2014). Behaviours are grouped into six categories: facial expression, crying, body movements, changes in interpersonal

interactions, changes in activity patterns or routines, and mental status changes. The user observes for the presence of the included behaviors; the summation of behaviors provides the total score. An increased score indicates an increase in pain is likely. By implementing a pain assessment tool that considers the behaviours related to pain for cognitively impaired residents, nurses can include a holistic assessment and improve pain management.

### **Implications for Nursing Practice and Research**

The results of a concept analysis can serve several different functions (Walker & Avant, 2019). This analysis of the clinical judgment of nurses providing care to LTC residents with dementia and pain shows the complexities and challenges that nurses face and provides insight into how to adapt practice and improve outcomes for both nurses and residents. By understanding the components of clinical judgment, nurses can break down each step required and shape care to best suit each patient's needs. The significance of a quality assessment has been outlined, as has how to accommodate the needs of residents with dementia. Nurses can understand and articulate how their critical thinking and intuition impact the care provided, heightening self-awareness. By better understanding the role of reflection when treating pain, nurses can enforce meaningful follow through and follow up to improve patient outcomes. Overall, this concept analysis can highlight common issues and increase awareness during practice. Further research to support educating staff and implementing tools that assess pain for residents with cognitive impairment could contribute to improved patient outcomes.

### **Conclusion**

Cognitive impairment increases the complexity of pain management. Clinical judgment is essential to adequately managing pain for residents with dementia. Nurses must strive to improve assessment and treatment of pain for LTC residents with dementia and potentially reduced

communication ability. By using their clinical judgment, nurses can improve quality of life for many residents. The concept analysis of clinical judgment and its components can be used by nurses to better understand their judgment and the consequences of their actions when managing pain. Pain is subjective and for dementia residents to be treated adequately, nurses must use clinical judgment to assess the patient's individual needs, interpret findings, and formulate treatment accordingly, while continuing to reassess the patient's condition and the outcome of their treatment.

## **Chapter 3: Secondary Analysis**

### **Abstract**

For nurses caring for residents with dementia, assessing and managing pain is a complex task. Residents in long-term care who live with dementia may express pain differently than those without cognitive or communication impairments. Responsive behaviours that may occur in advancing dementia may also be indicators of pain. The aim of this article is to explore the behaviours related to pain indication for residents with dementia. This secondary analysis is a retrospective population-based descriptive study of Resident Assessment Instrument-Minimum Data Set version 2.0 assessments conducted in long-term care homes across Ontario. Results show that, in many circumstances when a resident with dementia exhibits responsive behaviors that may be related to both dementia and pain, no pain is reported. These items include wandering, resisting care, and repetitive verbalizations. The findings suggest that pain may not be identified or treated in people with dementia. Residents with dementia require an individualized approach to assessing and treating their pain. By acknowledging deficits and improving practice guidelines, the hope is to improve pain management and quality of life for residents with dementia and pain.

*Keywords:* resident, long-term care, pain, treatment, management, assessment, dementia, responsive behaviours

### **Exploring Behaviours Related to Pain Indication for Residents in Long-Term Care with Dementia**

As many as 85% of residents in long-term care (LTC) suffer from pain, and nearly 80% have cognitive impairment (Nakashima et al., 2019). Unfortunately, cognitive impairment can increase the difficulty of communicating pain (Nakashima et al., 2019). Cognitive impairment and difficulty communicating increase the complexity of assessing and managing pain (Burfield et al., 2012). Therefore, pain is found to be underreported in cognitively impaired LTC residents (Burfield et al., 2012).

Untreated pain increases the risk of secondary neuropsychiatric symptoms, including agitation, resisting care, anxiety and depression, and insomnia (Burfield et al., 2012). Untreated pain can heighten the severity of cognitive impairment (Monroe et al., 2014). Residents with

late-stage dementia and pain experience more symptoms, lower quality of life, and overall increased care needs (Rostad, 2020). It is crucial to improve the identification and treatment of pain for people with dementia to improve their quality of life (Rajkumar et al., 2017). Nurses should incorporate tools that include verbal and behavioural manifestations of pain for residents with cognitive impairment (Cipher et al., 2006).

With the high incidence of cognitive impairment and pain in LTC, nurses are faced with the complex task of accurately assessing and treating pain to maintain quality of life for these residents. Gaining a better understanding of the extent to which the expression of pain for residents with dementia is recognized will give insight to how pain is best assessed and managed. The purpose of this research was to determine if LTC residents with advanced dementia, and no documentation of pain, are demonstrating pain related behaviors. The research question was: What characteristics of pain are associated with residents who have dementia and no reported pain in LTC?

Responsive behaviours and potential indicators of pain from the Resident Assessment Instrument Minimum Data Set version 2.0 (RAI-MDS 2.0) assessment questions that correspond with indicators listed in the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) tool were selected. These responses were then examined to determine the prevalence of potential secondary neuropsychiatric symptoms of untreated pain. Based on these findings, the hope is to improve pain assessment and ultimately pain management and quality of life for residents in LTC with dementia and pain.

## **Methods**

This population-based, retrospective study analyzed all RAI-MDS 2.0 assessments conducted in all of Ontario's LTC facilities, from April 1, 2019, through March 31, 2020. The

RAI-MDS 2.0 is used in several countries as a comprehensive tool to assess the strengths, weaknesses, risks, and needs of LTC residents. The assessment results are used to plan care and as indicators of care quality (Hutchinson et al., 2010). RAI-MDS 2.0 assessment information is gathered by nursing staff as a part of their standard assessment; RAI-MDS 2.0 assessments are completed on admission, annually, with a significant change in status, significant correction of comprehensive assessment, quarterly reviews, discharge from the facility, and re-entry to the facility (Centers for Medicare & Medicaid Services, 2002).

The RAI-MDS 2.0 includes two items in the assessment of pain coded for the highest level of pain present in the previous seven days (Centers for Medicare & Medicaid Services, 2002). The first explores the frequency of pain (0 = no pain; 1 = pain less than daily; 2 = pain daily). The second question collects information regarding intensity (1 = mild pain; 2 = moderate pain; 3 = times when pain is horrible or excruciating; 8 = no pain indicated in element). . Dementia is scored within two questions including dementia not Alzheimer's (0 = no; 1 = yes), and Alzheimer's (0 = no; 1 = yes) We created a dichotomous variable to determine the case of residents with dementia and no reported pain versus all others (dementia and pain + no dementia no pain + no dementia and pain). The intensity of pain was not included in our variable measurement as we were exploring whether pain was identified, not its quantification, for those with dementia

The RAI-MDS 2.0 pain assessment items require that either the resident is able to verbalize pain, or that the care provider and nurse recognize that the resident has pain. Since different types, and stages of dementia correspond with different trajectories of decline and can impact a variety of indicators in different ways, including language, memory, attention and executive functioning (Smits et al., 2014), there may be circumstances where a resident is able to

verbalize certain things, but unable to indicate they had pain. For this reason, the level of cognitive dysfunction was not considered important to this study and we chose not to integrate the Cognitive Performance Scale, a tool within the MDS which is used to detect early changes to levels of cognitive decline (interRAI, n.d.). In this study we sought to see the relationship between individual responsive behaviors and the documentation of pain, to determine if nurses were potentially missing pain in their resident assessments.

The PACSLAC is an observational assessment tool that was developed to assess pain for seniors with limited ability to communicate (Fuchs-Lacelle & Hadjistavropoulos, 2004). It is a checklist of 60 behaviours grouped into four categories: facial expression, social/personality/mood, activity/body movement, and others. Each behaviour that a resident demonstrates is noted. The total scores can then be compared after each use to the previous score. An increase in score indicates a probable increase in pain. The PACSLAC was selected as it encompassed the largest number and widest range of behaviors that could indicate pain. Although there is a multitude of tools available that include behavioral indicators of pain, many are adapted for efficiency in practice (including the revised version PAACLAC-II). For the purposes of this study, use efficiency was not the primary goal. Therefore, the utilization of the PACSLAC allowed for the greatest number of variables inclusion and yielded the largest number of variables to study.

In this study, pain assessment using the PACSLAC was not conducted. Rather individual items from the PACSLAC pain assessment tool were matched to a responsive behavior in the RAI-MDS 2.0 and analyzed (Appendix B). Final decisions about matched items were conducted by consensus between the researchers. Findings were grouped according to the four PACSLAC assessment categories. Other variables were included in the analysis based on the literature

review, including analgesic administration and geographical considerations, such as urban vs. rural and north vs. south of the province.

The analysis consisted of frequencies and descriptive statistics which were completed using the Statistical Package for the Social Sciences (SPSS) software. Descriptive analysis was chosen as it would demonstrate individual variables that were significantly associated with reported pain, as well as the strength of that association. A chi-squared test of independence was conducted to determine if there were significant statistical associations between residents with dementia who did not have recorded pain, and the targeted behavioural variables that could indicate pain. The strength and direction of the association was reflected in the expected frequencies versus the observed frequencies. For statistically significant chi square analysis, when the frequency of dementia/no reported pain was greater than expected when a responsive behavior was present, there was potential that pain may have been missed. The findings provide insight into patterns of responsive behavior variables that are potentially unrecognized or missed as pain indicators by the nurse assessors and serve as a foundation for further research.

An ethics application (Appendix C) was approved by Laurentian University's Ethics Review Board (Appendix D).

## **Results**

From April 1, 2019, through March 31, 2020, 372,180 assessments were completed for 101,315 unique LTC residents as a part of the following criteria: for admission, quarterly review, for significant change in resident status, for correction of assessment, discharge from the facility, and re-entry to the facility. All assessments were used to ensure full data saturation.

Of the sample, 91.5% of residents were in Southern Ontario (n=92,655) and 8.5% were in Northern Ontario (n=8,660), with 87.3% considered urban (n=88,457) and 12.7% rural

(n=12,858). Of the residents assessed, 32.6% were male and 67.3% were female. The mean age was 83.63 and the median age was 86.00 (see Table 1).

**Table 1. Demographics/Characteristics**

Male	33054	32.6%
Female	68158	67.3%
North	8660	8.5%
South	92655	91.5%
Urban	88457	87.3%
Rural	12858	12.7%
Residents with Dementia	57218	56.5%
Residents without Dementia	44097	43.5%
Ages	Mean	83.63
	Median	86.00
	Range	113

Findings of the chi-squared analysis of independence were grouped according to the four PACSLAC assessment categories (see Table 2). Please refer to Appendix E for further data detail.

**Table 2. Data Analysis**

<b>PACSLAC Categories that corresponded to RAI-MDS 2.0 Behaviour</b>	<b>RAI-MDS 2.0 Behaviours Matched to Pain Indicators</b>	<b>Chi Square analysis of independence</b>
<b>Facial Expression</b> Grimacing Sad look Tighter face Change in eyes (squinting, dull, bright, increased eye movements) Frowning Pain expression Grim face Wincing Open mouth Creasing forehead Screwing up nose	Sad, apathetic, anxious appearance: sad pained, worried facial expression	Observed Count: 57379 Expected Count: 60253.6 $\chi^2(1) = 385.313, p = .001$
	Sad, apathetic, anxious appearance: crying, tearfulness	Observed Count: 15762 Expected Count: 17691.3 $\chi^2(1) = 412.209, p = .001$
<b>Activity/Body Movement</b> Fidgeting Pulling away Restless Pacing Wandering Trying to leave Refusing to move Thrashing Refusing medications Impulsive behaviours (repeat movements) Uncooperative/resistance to care Guarding sore area Touching/holding sore area	Sad, apathetic, anxious appearance: repetitive physical movements	Observed Count: 45228 Expected Count: 39087.3 $\chi^2(1) = 2229.299, p = .001$
	Wandering (moved with no rational purpose, seemingly oblivious to needs or safety)	Observed Count: 31734 Expected Count: 23317.5 $\chi^2(1) = 6200.120, p = .001$
	Wandering (moved with no rational purpose, seemingly oblivious to needs or safety), behaviour was not easily altered	Observed Count: 13032 Expected Count: 9751.7 $\chi^2(1) = 2046.342, p = .001$

<b>PACSLAC Categories that corresponded to RAI-MDS 2.0 Behaviour</b>	<b>RAI-MDS 2.0 Behaviours Matched to Pain Indicators</b>	<b>Chi Square analysis of independence</b>
	Resist's care (resisted taking meds or injections, assistance with activities of daily living, or eating)	Observed Count: 65379 Expected Count: 55116.1  $\chi^2(1) = 5101.81, p = .001$
	Resist's care (resisted taking meds or injections, assistance with activities of daily living, or eating) behaviour was not easily altered	Observed Count: 33489 Expected Count: 29131.0  $\chi^2(1) = 1390.485, p = .001$
<b><u>Social/Personality/Mood</u></b> Physical aggression (e.g., pushing people and/or objects, scratching others, hitting others, striking, kicking) Verbal aggression Not wanting to be touched Not allowing people near Angry/mad Throwing things Increased confusion Anxious Upset Agitated Cranky/irritable Frustrated	Verbal expression of distress: repetitive questions  Verbal expression of distress: repetitive verbalizations  Verbal expression of distress: persistent anger with self or others  Verbal expression of distress: Self depreciation.	Observed Count: 42758 Expected Count: 40314.1  $\chi^2(1) = 345.906, p = .001$  Observed Count: 40308 Expected Count: 39840.7  $\chi^2(1) = 12.748, p = .001$  Observed Count: 52349 Expected Count: 49888.9  $\chi^2(1) = 308.257, p = .001$  Observed Count: 9218 Expected Count: 10882.0  $\chi^2(1) = 475.500, p = .001$

<b>PACSLAC Categories that corresponded to RAI-MDS 2.0 Behaviour</b>	<b>RAI-MDS 2.0 Behaviours Matched to Pain Indicators</b>	<b>Chi Square analysis of independence</b>
	Verbal expression of distress: expression of what seem to be unrealistic fears	Observed Count: 20919 Expected Count: 21589.6  $\chi^2(1) = 41.971, p = .001$
	Verbal expression of distress recurrent statements that something terrible is about to happen	Observed Count: 9707 Expected Count: 11039.0  $\chi^2(1) = 300.659, p = .001$
	Verbal expression of distress: repetitive health complaints	Observed Count: 17466 Expected Count: 27218.4  $\chi^2(1) = 7343.701, p = .001$
	Verbal expression of distress: repetitive anxious complaints or concerns – non-health related	Observed Count: 37197 Expected Count: 42081.2  $\chi^2(1) = 1343.731, p = .001$
	Verbally abusive behavioural symptoms: others were threatened, screamed at, cursed at	Observed Count: 29769 Expected Count: 26890.4  $\chi^2(1) = 646.002, p = .001$
	Verbally abusive: others were threatened, screamed at, cursed at – behaviour was not easily altered	Observed Count: 11716 Expected Count 10916.0  $\chi^2(1) = 109.583, p = .001$

<b>PACSLAC Categories that corresponded to RAI-MDS 2.0 Behaviour</b>	<b>RAI-MDS 2.0 Behaviours Matched to Pain Indicators</b>	<b>Chi Square analysis of independence</b>
	Verbal expression of distress: resident made negative statements	Observed Count: 22159 Expected Count: 24441.8 $\chi^2(1) = 438.805, p = .001$
	Mood persistence: one or more indicators of depressed, sad, or anxious mood were not easily altered by attempts to “cheer up,” console, or reassure the resident	Observed Count: 88337 Expected Count: 87098.9 $\chi^2(1) = 68.082, p = .001$
	Change in mood: resident’s mood status has changed as compared to 90 days ago (or since last assessment if less than 90 days ago)	Observed Count: 23401 Expected Count: 25181.2 $\chi^2(1) = 260.441, p = .001$
	Loss of interest: withdrawal from activities of interest	Observed Count: 9666 Expected Count: 10151.2 $\chi^2(1) = 43.120, p = .001$
	Loss of interest: reduced social interaction	Observed Count: 12574 Expected Count: 13325.0 $\chi^2(1) = 80.437, p = .001$
	Physically abusive behavioural symptoms: others were hit, shoved, scratched, sexually abused	Observed Count: 23704 Expected Count: 18141.3 $\chi^2(1) = 3352.576, p = .001$

<b>PACSLAC Categories that corresponded to RAI-MDS 2.0 Behaviour</b>	<b>RAI-MDS 2.0 Behaviours Matched to Pain Indicators</b>	<b>Chi Square analysis of independence</b>
	Physically abusive: others were hit, shoved, scratched, sexually abused – behaviour was not easily altered	Observed Count 9620 Expected Count 7470.8  $\chi^2(1) = 1129.342, p = .001$
	Socially inappropriate or disruptive behavioural symptoms: made disruptive sounds, noisiness, screaming, self-abusive acts, sexual behaviours or disrobing in public, smeared or threw food or feces, hoarding, rummaging through other's belongings	Observed Count: 35300 Expected Count: 30848.7  $\chi^2(1) = 1388.318, p = .001$
	Socially inappropriate or disruptive behavioural symptoms: made disruptive sounds, noisiness, screaming, self-abusive acts, sexual behaviours or disrobing in public, smeared or threw food/feces, hoarding, rummaging through other's belongings – behaviour was not easily altered	Observed Count: 16230 Expected Count: 14658.6  $\chi^2(1) = 323.060, p = .001$
	Indicators of delirium – periodic disordered thinking/awareness: periods of restlessness	Observed Count: 40898 Expected Count: 35306.0  $\chi^2(1) = 1983.806, p = .001$
<b>Other</b> (physiological changes/eating sleeping changes/vocal behaviours)  Changes in Sleep Routine	Change in communication/hearing: resident's ability to express, understand, or hear information has changed as compared to 90 days ago (or since last assessment if less than 90 days)	Observed Count: 7763 Expected Count: 7545.2  $\chi^2(1) = 11.488, p = .001$

<b>PACSLAC Categories that corresponded to RAI-MDS 2.0 Behaviour</b>	<b>RAI-MDS 2.0 Behaviours Matched to Pain Indicators</b>	<b>Chi Square analysis of independence</b>
	Change in behavioural symptoms: resident's behavioural status has changed as compared to status of 90 days ago (or since last assessment if less than 90 days)	Observed Count: 24120 Expected Count: 22661.1 $\chi^2(1) = 190.748, p = .001$
	Sleep cycle issues: unpleasant mood in morning	Observed Count: 35410 Expected Count: 33421.5 $\chi^2(1) = 261.001, p = .001$
	Sleep cycle issues: insomnia or change in usual sleep pattern	Observed Count: 24898 Expected Count: 25270.5 $\chi^2(1) = 11.371, p = .001$
	Indicators of delirium – periodic disordered thinking/awareness: periods of lethargy	Observed Count: 22363 Expected Count: 21454.3 $\chi^2(1) = 77.481, p = .001$

**Table 3**

<b>Analgesia Administered to Residents with Dementia</b>	<b>Analgesia Not Administered to Residents with Dementia</b>	<b>Association of Variables</b>
Count: 66757 Percentage: 42.13%	Count: 91681 Percentage: 57.8%	Observed Count: 91681 Expected Count 106284.4 $\chi^2(1) = 10607.804, p = .001$

The study looked at 32 RAI-MDS 2.0 potential indicators of pain related to individual corresponding items from the PACSLAC pain assessment checklist. Of the 32 behaviours studied, 20 were found to have higher observed frequencies than expected due to chance alone for residents with dementia but no reported pain. In the activity/body movement category, all behaviours showed significantly higher observed frequencies than expected for residents with dementia and no recorded pain. In the social/personality/mood category, 11 of the 20 assessed indicators exhibited higher observed frequencies in occurrence for residents with dementia and no recorded pain. The final category, other, included three RAI-MDS 2.0 assessed behaviours of which one showed higher than expected observed frequencies. For residents with dementia but no pain, changes in the residents' ability to express, understand, or hear information, changes in behavioural symptoms, unpleasant mood in the morning, and periods of lethargy were observed more frequently than expected. In addition, when analyzing the treatment of pain, significantly fewer than expected residents with dementia received analgesia (see Table 3).

A total of 12 behaviours showed lower than expected frequencies for residents with dementia and no recorded pain. In the facial expression category, two behaviours showed significantly lower than expected frequencies: sad pained, worried facial expression, and crying and tearfulness. Within the social/personality/mood category, frequencies for verbal expressions

of self-deprecation, expression of what seems to be unrealistic fears, and recurrent statements that something terrible is about to happen were significantly lower than expected. Also, significantly lower than expected were repetitive health complaints, repetitive anxious complaints that were non-health related, and negative statements. There were also lower than expected observed frequencies for mood status changes, withdrawal from activities of interest, and reduced social interaction.

## **Discussion**

In this study, significantly fewer residents with dementia received analgesia. This finding correlates with the research done by Nakashima et al. (2019) who found residents with dementia received less analgesic and non-medical pain interventions than other residents who did not have cognitive impairment. Overall, residents with dementia were reported as exhibiting high rates of pain-related behaviours and neuropsychiatric symptoms but were not recorded as having pain. A conclusion arising from these findings is that residents are not appropriately assessed or treated for pain or provided with tools that enable a holistic evaluation of pain that includes potential indicators.

Of all the variables, frequencies of physical pain indicators were increased while the frequency of verbal pain indicators were decreased. A total of five behaviours that were decreased were all verbal in nature. This finding may suggest that people with dementia and no reported pain have a decreased ability to communicate verbally to express pain. For some residents, their cognitive impairment may have a decreased their ability to verbally articulate or express pain but they may exhibit more physical signs of pain. Since some people with dementia may have difficulty reporting sensory and emotional responses to pain verbally, assessing external motor displays of pain are important (Monroe et al., 2012). Verbal self-reports of pain

are inadequate in assessing pain for people with dementia, and observational tools that incorporate physical signs of pain are necessary for adequate assessment (Malara et al., 2016).

One study found that there are strong associations between pain and behavioral indicators leaving to the recommendation that physical traits including facial expression, body movements, vocalizations, and behavioral indicators be observed as indicators of pain (Strand et al., 2019). In this study, not all behaviors were exhibited by residents with dementia and no recorded pain, however, these behaviors should be recognized as potential indicators of pain. These results suggest significant value in assessing a wide range of behavioural pain indicators when evaluating pain in people with dementia.

A study done by Lukas et al. (2013) showed that the utilization of observer-rated pain scales improved recognition of both the presence and absence of pain by up to 25.4 percent for residents with dementia as well as improved the classification of their level of pain by up to 42.5 percent. Assessment tools, including the PACSLAC, encourage nurses to consider several different indicators of pain. Nurses must not merely rely on verbal reporting when assessing pain in residents with dementia. By using a more holistic assessment that incorporates physical and behavioural indicators, nurses may find pain that would otherwise go undiagnosed and thus untreated. By improving the assessment and management of pain, nurses can improve the quality of life of residents with pain and dementia (Rajkumar et al., 2017).

Although many studies confirm the relationship between behaviors and pain for those with dementia, the findings of this analysis demonstrate that residents with dementia many endure unrecognized pain that can have detrimental impacts on their well-being and quality of life. It is important to consider this data to guide new research and encourage policy change that improves pain management. Through enhanced pain management, the lives of residents with

dementia and pain and their caregivers can be improved while reducing strain on the health care system.

### **Limitations**

Although using previously collected information has many advantages, some limitations require mentioning. These data lack flexibility because information is limited to the questions used for RAI-MDS 2.0 assessments. For example, the RAI-MDS 2.0 does not include information about non-pharmacological interventions, such as applying hot or cold compresses. Information is also limited by the primary user's views and knowledge of and familiarity with the resident being assessed. Further, there is potential for researcher bias in the selection of variables studied and the formation of research questions. Data were collected from April 1, 2019, through March 31, 2020, which may limit relevance to other periods in time. Also, the information is cross-sectional and omits information regarding transitions in cognitive impairment or pain. The nature of secondary data also limits information regarding whether pain interventions were implemented throughout time and if there were any concurrent changes in data. Secondary data also lack context and the researchers were unable to seek clarity if required. Finally, the PACSLAC variables were not developed to correspond with the RAI-MDS 2.0 variables and some potential indicators may have therefore been excluded.

### **Conclusion**

In LTC, a large proportion of residents suffer from pain and dementia. Residents with dementia may have difficulty expressing pain, which often results in their pain being poorly managed. Unmanaged pain can have a detrimental impact on a resident's quality of life and may induce secondary neuropsychiatric symptoms. By gaining a better understanding of the pain

experienced and expressed by residents with dementia, we gain insight into pain's prevalence and how it should be assessed and managed.

The purpose of this research was to examine the assessment and management of pain in residents in LTC with dementia and potential indicators of unmanaged pain and explore whether variables related to dementia and pain were found when the resident was not identified as having pain. The study demonstrated that LTC residents with dementia and no pain had high rates of responsive behaviours that could indicate pain, including wandering and resisting care. The findings suggest that pain is not recognized, and that responsive behaviours and neuropsychiatric symptoms are not included in pain assessments for residents with dementia in LTC. Nurses caring for residents in LTC who are living with dementia are encouraged to use specialized assessment tools that adapt to cognitive impairment and include a variety of pain indicators. Residents with dementia require an individualized approach to assess and treat their pain. These findings could be considered in LTC policy development to support the creation, implementation, and utilization of adequate pain assessment and treatment policies. This study's findings may improve nursing practice in LTC by highlighting the importance of including a wide range of pain indicators for those with dementia. By including these indicators nurses may recognize and treat pain that could have otherwise been untreated and improve pain management and quality of life for residents with dementia and pain. It also has the potential to inform further research related to pain assessment in LTC to encourage the uptake of observer rated pain scales.

## Chapter 4: Summary

### Summary, Applications, and Future Research

This thesis focused on assessing and managing pain for long-term care (LTC) residents with dementia and the role of nurses in meeting this challenge. The prevalence of dementia increases with age, as does the prevalence of pain (Pergolizzi et al., 2019). Because of the increased risk and probability of overlapping conditions, nurses must understand how to effectively assess and manage pain in residents with dementia. Underassessment and undertreatment of pain are common among people with cognitive impairment (Gilmore & Bowers, 2013). Therefore, the approach to pain management must include a comprehensive understanding of the challenges in assessing pain and must be multifaceted to improve patient outcomes. Nurses must consider communication difficulties and responsive behaviours while weighing the risks and benefits of treating pain (Pergolizzi et al., 2019). For people living with dementia, secondary symptoms of pain can range from agitation and sleep disturbances to psychosis (Aasmul et al., 2016). By implementing tools such as the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) that include behaviours such as agitation, aggression, and anxiousness, nurses can improve their assessments of pain and then intervene appropriately to address the problem (Fuchs-Lacelle & Hadjistavropoulos, 2004).

The concept analysis of the clinical judgment of nurses caring for LTC residents with dementia serves as a foundation for this thesis. The analysis provides conceptual clarity for clinical judgment and highlights the impact of clinical judgment on managing pain for residents with dementia. The study outlines the significance of a quality assessment that considers physical, social, and emotional pain cues and accommodates the needs of residents with dementia in order to develop the best care plan. The analysis of clinical judgment can help nurses

understand their critical thinking and intuition while encouraging reflection on their actions and related consequences. It offers insight into what is necessary for nurses in the identification and management of pain in LTC for residents with dementia; it also exposes the need for the secondary analysis conducted of RAI-MDS 2.0 assessments conducted by nurses in LTC to explore the tool currently offered and if all indicators of pain are being captured.

The secondary analysis highlights the strong association between dementia and responsive behaviours that are potential indicators of pain for this population. Its results show that nurses cannot rely on only one sign, symptom, or behaviour when assessing pain in a person with dementia. It is highly beneficial for nurses to rely on assessment tools that incorporate a wide range of pain predictors when caring for residents with dementia. This article can help nurses understand their role in assessing and treating pain and improving the quality of life for affected residents.

### **Implications for Nursing Practice**

The importance of the role of nurses in pain assessment and management in LTC residents living with dementia cannot be underestimated. In 2017, in Ontario, over 10,000 registered nurses worked in LTC (College of Nurses of Ontario, 2017). As life expectancy and the age of the population continue to grow in Canada, the prevalence of age-related conditions is also rising (Meisner et al., 2017). With the evolution of the population, nurses must understand how to meet the needs of older adults. Residents with dementia may have a reduced ability to communicate, however they continue to experience pain and distress (Pergolizzi et al., 2019).

Karlsson et al. (2012) found that nurses often felt that their role in LTC consisted of duties that often removed them from the immediate care of residents, which had a negative impact on their ability to care for residents. The removal supports the need to improve

assessment and treatment of pain in LTC residents with dementia. Nurses should be supported in their role and provided with adequate pain assessment tools and treatment guidelines for residents with dementia to enhance this population's pain management. By understanding and improving pain management, nurses can reduce responsive behaviours and improve sleep patterns, nutritional status, functional capacities, and overall quality of life. By reducing responsive behaviours through proper pain management, nurses also reduce their own stress and burnout (Aasmul et al., 2016). The results of these studies imply that pain must be adequately treated to reduce behavioural disturbances and maintain the quality of life of LTC residents with dementia and pain.

### **Implications for Nursing Education**

One challenge is the level of confidence nurses have in addressing pain in people with dementia. Despite an average of 10 years of work experience in LTC, staff have been found to have significant educational needs in pain assessment and management (Tousignant-Laflamme et al., 2012). There is a deficit of knowledge regarding the interpretation of behaviors that can indicate pain. Rababa and Al-Rawashdeh (2019) found that many nurses lacked confidence and experienced uncertainty in managing pain in LTC residents with dementia. They found that the more severe the dementia and the worse the verbal communication impairment, the more uncertain nurses became. The findings of the studies in this thesis highlight the complexity of assessing and treating pain in LTC residents with pain and dementia and show that it is essential to recognize the knowledge gap and encourage improved education in current and future nurse training.

Nursing education should include the significance of assessing various indicators of pain in residents with dementia, including responsive behaviours. The Registered Nurses' Association

of Ontario (RNAO, 2013) has established best practice guidelines for treating pain. The association recommends that nurses participate in ongoing education and training that enhances specific knowledge and skills and increases competency. Nurses should implement a systematic and consistent assessment of pain. If a person's ability to self-report is negatively affected by cognitive or communication impairments, nurses should incorporate behavioural indicators or behavioural pain scales validated for the specific population.

Healthcare providers who care for residents with dementia can benefit from learning how to assess and treat pain for this population specifically (Pergolizzi et al., 2019). The articles included in this thesis articulate the importance of considering behaviours and potential pain indicators when assessing the pain of residents in LTC with dementia and provide nurses with strategies to process and respond accordingly. They also offer educational institutions and LTC homes insight into the dynamics of treating the pain of residents with dementia and can encourage better education and support for nursing staff.

### **Implications for Health Policy**

Other considerations for assessing and managing the pain of LTC residents living with dementia are the policies and processes related to LTC institutions. Gallant et al. (2020) found that clinical guidelines for assessing pain in residents with cognitive impairment are not widely implemented in LTC facilities across Canada. They found general underuse of specialized pain assessment tools for impaired cognition or communication. In Ontario, pain management directives are included in regulations set out by the *Long-Term Care Homes Act, 2007*, and General Regulation, O.R. 79/10 (Gallant et al., 2020). The Resident Assessment Instrument-Minimum Data Set version 2.0 (RAI-MDS 2.0) is the only tool provided to staff to assess pain;

there are no other best practice guidelines or additional tools used or encouraged (Gallant et al., 2020).

Proctor and Hirdes (2001) found that RAI-MDS 2.0 assessments showed a low prevalence of pain in people with cognitive impairment despite having pain-related conditions. The RAI-MDS 2.0 does not require the use of additional scales and could be enhanced using specialized pain assessment tools like the PACSLAC (Gallant et al., 2020). The articles in this thesis indicate that pain is a very individualized experience that benefits from a thorough assessment. They also conclude that people with dementia express pain in several different ways and, if communication abilities are reduced, self-reported pain is not always reliable. Existing policies therefore fail to consider or address the underassessment and undermanagement of pain in residents in LTC facilities despite the recommendations found throughout the literature (Gallant et al., 2020).

The *Long-Term Care Homes Act* requires that a plan of care is created to deliver and evaluate care (MOHLTC, 2011). A plan of care can include one or more documents depending on the resident's needs, including medication administration records, treatment administration records, physician orders, medical directives, activity plans, and dietary logs. The plan of care must be based on an interdisciplinary assessment, including but not limited to disease diagnosis, health conditions, routines, skin condition, continence, cognition, communication abilities, vision, mood and potential behavioural triggers, risk of falls, and pain. Though the requirements for a plan of care recognize the need for individualized and holistic care planning, there is no consideration for cognitive impairment. Although mandated by LTC regulations, the RAI-MDS 2.0 fails to meet the recommended practice guidelines for pain assessment and management (Gallant et al., 2020). These data produced allow for health system monitoring however it

inadequately captures resident pain for those with dementia. Facilities, staff, and residents would benefit from updated policies that include the use of adapted assessment tools. Results of the secondary analysis of the RAI-MDS 2.0 suggest that nurses can capture a wider variety of pain indicators by including adapted pain assessment tools for residents with dementia. By including a wider range of potential pain indicators, nurses can conduct assessments with a higher sensitivity to pain and can engage in more holistic pain treatment.

In Ontario's LTC facilities, 58% of employees are personal support workers and 25% are nursing staff. Of the nurses working in LTC facilities, 62.0% are registered nurses, 36.5% are registered practical nurses, and 0.6% are nurse practitioners (MOHLTC, 2020). Each resident receives an average of 3.73 direct care hours a day, two hours and 18 minutes of this care from personal support (PSW) workers, one hour and two minutes from a registered nurse or registered practical nurse, and the other 24 minutes from allied health and programming support (MOHLTC, 2020). The majority of the direct care hours are provided by staff other than registered nurses, however, nurses are conducting the formal resident assessments. Therefore, nurses require tools to efficiently and adequately assess pain during the limited time they are able to spend with residents. Unregulated care providers, including PSWs, would also benefit from the inclusion of various pain indicators for reporting to regulated staff to help support them in managing all required care tasks.

### **Implications for Future Research**

More research is needed to further explore barriers to pain management for people with dementia and how nursing practice can be improved. Many studies explore the reliability and validity of the RAI-MDS 2.0 pain assessment, but they exclude residents with limited ability to communicate (Gallant et al., 2020). Future research should include the evaluation of this tool

with LTC residents with cognitive and communication impairments. Further research into how the current RAI-MDS 2.0 could be adapted to include an observations pain scale should be considered. To date, the majority of research has relied on verbal expression of pain (Hadjistavropoulos et al., 2018). Future research should explore pain using different indicators, including responsive behaviours for people with dementia. Future research should examine why adapted pain scales have not been included as standard practice and how they can best be integrated into regulations and everyday practice. The accreditation requirements in LTC could also be researched to examine how thresholds and parameters for pain are developed. Further studies are needed to explore the most effective nursing interventions to manage the pain experienced by residents with dementia. By contributing research to this challenging area of care, nurses are offered supportive data that can be used to improve their practice and related quality of life for the people they care for. Future research could also include key stakeholders in LTC including front-line staff, residents, and their families to best understand how to improve care.

### **Limitations**

Limitations of this thesis include its focus on Ontario. Although the aim was to fill a gap in information, the results may lack transferability to areas where LTC facilities are funded and staffed differently and may implement different legislation and assessment tools. The focus on dementia may also have limited generalizability to LTC residents without cognitive impairment who experience pain. The focus on nursing staff may also limit the usefulness of this study since most direct care hours are provided by unregulated care providers.

## Conclusion

Cognitive impairment increases the complexity of pain management. With the high prevalence of both pain and cognitive impairment in LTC facilities, nurses must be aware of the challenges of assessing and managing pain for residents with dementia. Unmanaged pain can have detrimental effects on the quality of life and outcomes for residents. The studies in this thesis illustrate the vital role nurses play in assessing and treating pain in residents with dementia. One study offers nurses information on pain and dementia, and how clinical judgment affects the care nurses provide. The other study explicitly represents pain dynamics and how residents living with dementia may portray pain uniquely. By gaining a better understanding of pain indicators for people with dementia, we can gain insight into how we can improve care. Findings from this research may be considered in LTC policy development to support using adequate pain assessment and treatment tools and guidelines. The findings in this thesis may improve nursing practice in LTC and quality of life for residents with dementia and pain.

## Summary

This thesis has explored pain through the lens of nurses caring for residents with dementia in LTC. It clarifies the vital role that nurses' clinical judgment plays in assessing and treating pain. It shows that residents with dementia demonstrate a wide range of pain indicators verbally and physically with responsive cues and behaviours. It is imperative that assessment tools that adapt to a variety of pain indicators be implemented to improve pain management and quality of life for LTC residents with dementia and pain.

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## Appendix A

### Literature Review

Inclusion Criteria	Exclusion Criteria
Quantitative studies Qualitative studies Cognitively impaired (all types of dementia) Long Term Care Home settings Acute care settings Community settings Older Adults (65+) Pain All Countries Full text articles 2000-2020	No cognitive impairment Articles published 1999 and prior Grey Literature

Database	Returned	Search terms
ProQuest	8139	((Residents OR seniors) AND (Long term care) AND (Cognitive impairment) AND (Pain) *Full text only *2000-2020
PubMed	777	((Residents OR Patients OR Older adults OR seniors) AND (Long term care) AND (Cognitive impairment) AND (Pain) AND (qualitative) or (quantitative)) *Full text only *2000-2020
CINAHL	206	((Residents OR Patients OR Older adults OR seniors) AND (Long term care) AND (Cognitive impairment) AND (Pain) AND (qualitative) or (quantitative)) *Full text only *2000-2020
Scholars Portal	331	((Residents OR Patients OR Older adults OR seniors) AND (Long term care) AND (Cognitive impairment) AND (Pain) AND (qualitative) or (quantitative)) *Full text only *2000-2020

## Appendix B

### PACSLAC and RAI-MSD 2.0 Variable Mapping

<b>PACSLAC</b>	<b>RAI-MDS 2.0 Variable Code</b>
<b><u>Facial Expression</u></b>	
Grimacing: <i>E1l</i>	<i>E1l</i> Sad, Apathetic, Anxious appearance: Sad pained, worried facial expression.
Sad look: <i>E1l, E1m</i>	
Tighter Face: <i>E1l</i>	<i>E1m</i> Sad, Apathetic, Anxious appearance: Crying, tearfulness.
<b><u>Dirty Look</u></b>	
Change in Eyes (Squinting, dull, bright, increased eye movements): <i>E1l</i>	
Frowning : <i>E1l</i>	
Pain Expression: <i>E1l</i>	
Grim Face: <i>E1l</i>	
<b><u>Clenching Teeth</u></b>	
Wincing: <i>E1l</i>	
Open Mouth Creasing Forehead: <i>E1l</i>	
Creasing forehead: <i>E1l</i>	
Screwing Up Nose: <i>E1l</i>	
<b><u>Activity/Body Movement</u></b>	
Fidgeting: <i>E1n</i>	<i>E1n</i> Sad, Apathetic, Anxious Appearance: Repetitive physical movements.
Pulling Away: <i>E1n</i>	<i>E4aA</i> Wandering (moved with no rational purpose, seemingly oblivious to needs or safety).
<b><u>Flinching:</u></b>	
Restless: <i>E1n</i>	<i>E4aB</i> Wandering (moved with no rational purpose, seemingly oblivious to needs or safety), behavior was not easily altered.
Pacing: <i>E1n; E4aA</i>	
Wandering: <i>E4aA</i>	<i>E4eA</i> Resists care (resisted taking meds or injections, ADL assistance, or eating).
Trying to Leave: <i>E4aB</i>	
Refusing to Move: <i>E4eA, E4eB</i>	<i>E4eB</i> Resists care (resisted taking meds or injections, ADL assistance, or eating) behavior was not easily altered.
Thrashing: <i>E1n</i>	
<b><u>Decreased Activity</u></b>	

<p>Refusing Medications: <i>E4aA; E4aB</i></p> <p><b>Moving Slow</b></p> <p>Impulsive Behaviours (Repeat Movements):  <i>E1n Uncooperative/Resistance to care: E4eA; E4eB</i></p> <p><b>Guarding Sore Area Touching/Holding</b></p> <p><b>Sore Area Limping</b></p> <p><b>Clenching Fist</b></p> <p><b>Going into Fetal Position</b></p> <p><b>Stiff/Rigid</b></p>	
<p><b><u>Social/Personality/Mood</u></b></p> <p>Physical Aggression (e.g. pushing people and/or objects, scratching others, hitting others, striking, kicking): <i>E4cA; E4cB</i></p> <p>Verbal Aggression: <i>E1c, E1d; E1e; E4bA; E4bB; E1a; E4dA; E4dB</i></p> <p>Angry/Mad: <i>E1c, E1d; E1e; E4bA; E4bB; E4cB; E4dA; E4dB</i></p> <p>Not Wanting to be Touched: <i>E1o; E1p</i></p> <p>Not Allowing People Near: <i>E1o; E1p</i></p> <p>Throwing Things: <i>E4dA; E4dB</i></p> <p>Increased Confusion: <i>B5d</i></p> <p>Anxious: <i>E1b; E1c; E1f; E1g; E1h; E1i; E1a; E2; E3' E4dA; E4dB</i></p> <p>Upset: <i>E1c; E1d; E1f; E1g; E4bA; E1a; E2; E3; E4cB' E4dA; E4dB</i></p> <p>Agitated: <i>E1c; E1d; E4bA; E4bB; E3; E4cB' E4dA; E4dB</i></p> <p>Cranky/Irritable: <i>E1c; E1d; E4bA; E4bB; E3; E4cB' E4dA; E4dB</i></p> <p>Frustrated: <i>E1b;l E1d; E1e; E3' E4dA; E4dB</i></p>	<p><i>E1b Verbal Expression of Distress: Repetitive Questions</i></p> <p><i>E1c Verbal Expression of Distress: Repetitive Verbalizations.</i></p> <p><i>E1d Verbal Expression of Distress: Persistent anger with self or others.</i></p> <p><i>E1e Verbal Expression of Distress: Self depreciation.</i></p> <p><i>E1f Verbal Expression of Distress: Expression of what seem to be unrealistic fears.</i></p> <p><i>E1g Verbal Expression of Distress Recurrent statements that something terrible is about to happen.</i></p> <p><i>E1h Verbal Expression of distress: Repetitive health complaints.</i></p> <p><i>E1i Verbal expression of distress: Repetitive anxious complaints or concerns - non health related.</i></p> <p><i>E4bA Verbally abusive behavioral symptoms: Others were threatened, screamed at, cursed at.</i></p> <p><i>E4bB Verbally Abusive: Others were threatened, screamed at, cursed at- behavior</i></p>

	<p>was not easily altered</p> <p><i>E1a</i> Verbal Expression of Distress: Resident made negative statements</p> <p><i>E2</i> Mood persistence: One or more indicators of depressed, sad, or anxious mood were not easily altered by attempts to “cheer up”, console, or reassure the resident.</p> <p><i>E3</i> Change in mood: Resident’s mood status has changed as compared to 90 days ago (or since last assessment if less than 90 days ago).</p> <p><i>E1o</i> Loss of interest: Withdrawal from activities of interest.</p> <p><i>E1p</i> Loss of interest: Reduced social interaction.</p> <p><i>E4cA</i> Physically Abusive Behavioral Symptoms: Others were hit, shoved, scratched, sexually abused.</p> <p><i>E4cB</i> Physically Abusive: Others were hit, shoved, scratched, sexually abused - behavior was not easily altered.</p> <p><i>E4dA</i> Socially Inappropriate or Disruptive Behavioral Symptoms: Made disruptive sounds, noisiness, screaming, self abusive acts, sexual behaviors or disrobing in public, smeared or threw food or feces, hoarding, rummaging through other’s belongings.</p> <p><i>E4dB</i> Socially Inappropriate or Disruptive Behavioral Symptoms: Made disruptive sounds, noisiness, screaming, self abusive acts, sexual behaviors or disrobing in public, smeared or threw food/feces, hoarding, rummaging through other’s belongings - behavior was not easily altered.</p> <p><i>B5d</i> Indicators of delirium-Periodic Disordered Thinking/Awareness: Periods of Restlessness</p>
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<b><u>Other</u></b>	<i>C7 Change in Communication/Hearing:</i> Resident's ability to express, understand, or hear information has changed as compared to 90 days ago (or since last assessment if less than 90 days).
(Physiological changes/Eating Sleeping Changes/Vocal Behaviors): <i>C7 E5; E1j; B5E</i>	
<b>Present Pale</b>	<i>E5 Change in Behavioral Symptoms:</i> Resident's behavioral status has changed as compared to status of 90 days ago (or since last assessment if less than 90 days).
<b><del>Face Flushed, Red Face</del></b>	
<b><del>Teary Eyed</del></b>	
<b><del>Sweating</del></b>	<i>E1j Sleep Cycle Issues:</i> Unpleasant mood in Morning.
<b><del>Shaking/Trembling</del></b>	<i>E1k Sleep Cycle Issues:</i> Insomnia or change in usual sleep pattern.
<b><del>Cold Clammy</del></b>	<i>B5E Indicators of Delirium-Periodic Disordered Thinking/Awareness:</i> Periods of Lethargy
Changes in Sleep Routine: <i>E1k</i>	

## Appendix C

### \*Laurentian University Ethical Review Form for Research Involving Human Subjects

#### Project Info.

**File No:** Ref No: 18124

**Project Title:** What are the differences in assessment and treatment of pain for residents in long-term care with and without dementia?

**Principal Investigator:** Mrs. Danielle Hamilton (Faculty of Health\School of Nursing)

**Start Date:** 2020/06/01

**End Date:** 2021/06/01

**Keywords:** dementia, pain, treatment, clinical judgment

#### Project Team Info.

##### *Principal Investigator*

**Prefix:** Mrs.

**Last Name:** Hamilton

**First Name:** Danielle

**Affiliation:** Faculty of Health\School of Nursing

**Rank:** Undergraduate Student

**Email:** dhamilton@laurentian.ca

**Phone1:** 705 929 8234

**Phone2:**

**Fax:**

**Primary Address:** 4 Eve St., Lively ON P3Y 1E3

**Institution:** Laurentian University / Université Laurentienne

**Country:** Canada

**Comments:**

## Common Questions

### ***1.1: Guidelines***

#	Question	Answer
1.1	See Attachments tab for General Guidelines for submission.	

### ***2.2: Type of Ethics Review Requested***

#	Question	Answer
2.1	Is this research a multi-centre study?	Yes
2.2	If 'Yes' for 2.1, please list the centre(s):	All long-term care (LTC) homes in Ontario
2.3	Has this proposal been (or will it be) submitted to any other Research Ethics Board?	No
2.4	If 'Yes' for 2.3, provide the name of the Research Ethics Board, the date of ethics review (if available), and the decision detailing any conditions/limitations.	This proposal has not been submitted to any other research board. Following approval from Laurentian University's Ethics Board, this proposal will be submitted to The Canadian Institute of Health Information (CIHI) for permission to review the data.
2.5	Do you believe your project should receive a delegated review?	Yes
2.6	If 'Yes' for 2.5, briefly explain why/how your research is minimal risk and cite specific articles from the Tri-Council Policy Statement (TCPS) 2.	Please expedite this research as it is an analysis of secondary, anonymized data, from a population database. This research does not include harm or influence on human subjects.
2.7	If your research is currently or will be funded, please provide the title of the project related to this application as submitted on the Research Proposal Approval Form.	No.
2.8	If this project is funded, please provide the "Awards" ROMEO file number (i.e., 601XXXX).	

### ***3.3: Project Dates***

#	Question	Answer
3.1	Indicate pending deadline by which ethics approval is required, with a brief explanation.	This project will begin following ethical approval from Laurentian University's Ethic's Board. Pending deadline is June 2020, as CIHI requires approval prior to permission to review data.

### ***4.4: Abstract of Proposed Research***

#	Question	Answer
4.1	Using lay language, briefly and concretely describe the purpose of the research. Please describe the context for your research but do not provide a literature review. If the research is part of a larger project, describe its relationship with the larger project. Do not describe research methods in this section 300-500 words maximum (a few paragraphs).	The purpose of this research is to highlight the complexity of assessing and managing pain in LTC homes for residents with dementia. In order to support the developments and implementation of policies that consider dementia in the management of pain, supportive data is required. Assessing and treating pain for residents in LTC homes with dementia is a highly complex task. As a result, this population is vulnerable to poorly managed pain. A secondary analysis of a data set received from the Canadian Institute of Health Information of the RAI-MDS 2.0 assessment completed in LTC homes of Ontario, Canada will be conducted. Thesis data will be studied for differences in assessment and treatment of pain for residents with dementia and those without. The assessment and documentation of pain and the resulting treatment will be studied. Variables demonstrating behaviours associated with pain, including agitation and aggression, will also be reviewed for people with dementia who cannot always verbalize their pain. By conducting a secondary analysis of LTC homes in Ontario, we can gain insight into the prevalence of pain, and the effects of unmanaged pain. Thesis findings have

		the potential to support the implementation of policies, procedures, and tools that acknowledge and adapt to the needs of this vulnerable population. By acknowledging deficits and improving practice guidelines, there are hopes in improving pain management and quality of life for residents with dementia and pain.
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### 5.5: Research Methods

#	Question	Answer
5.1	Describe procedure(s) for selecting participants (type of sampling, # of participants etc.).	Data were collected by CIHI from all LTC homes in Ontario in 2015–2016 with a total of 65,541 cases.
5.2	Describe characteristics of the participants (e.g., age, gender, institutional affiliations). Also describe if any groups are excluded, and why. Consult TCPS: 4, if required.	LTC home residents (other characteristics unknown until data released from CIHI).
5.3	Describe the recruitment methods that will be used. Describe compensation or incentives (financial or other) for participation, if any, why and what influence they might exert on participants (e.g., physical, psychological, financial, deprivation).	N/A
5.4	If existing records will be used to identify potential participants, describe how permission to access, collection, and use of this information will be obtained. Describe precautions to be taken to ensure that participants' rights, including privacy. Consult TCPS: 3.1, if required.	N/A
5.5	Describe method(s) of collecting data (interviews, questionnaire, web-based surveys, etc.). Include all questionnaires etc. when submitting this proposal.	Secondary analysis.
5.6	If deception is involved, describe. Also describe what information / debriefing	N/A

	will be provided to participants after their participation in the project. Consult TCPS: 3.7, if required.	
5.7	Is the population captive? If in a position of influence over the participants (e.g., professor-student, manager-employee, co-worker), describe how you will deal with potential coercion issues for recruitment. Consult TCPS: 3.1, if required.	No
5.8	Does your research involve vulnerable populations (institutionalized persons, elders, children, sick persons etc.)? Consult TCPS: 1.1, 3.9, 4.6, 3.8, 4A, 4.6, if required.	Yes
5.9	Does your research involve Indigenous populations or communities? If required, consult TCPS Chapter 9.	No
5.10	If 'Yes' for 5.7 or 5.8 please describe the procedures and special considerations that may be needed to protect their interests.	This study is a secondary analysis of data already collected by CIHI from LTC facilities in Ontario. While most of this data was collected about a vulnerable population, this study will not have any direct contact with these participants.
5.11	Does your research involve human tissues, remains, cadavers, biological fluids or fetus? Consult TCPS: 2.1, 6.11, 6.12, if required.	No
5.12	If 'Yes' for 5.9, please identify if biological specimen be linked to personally identifiable information. Please include justification for its inclusion/retention. Explain how participants' identities will be protected during each stage of the research: recruitment, data collection, data storage and during the dissemination. Remember that human tissue itself deserves some degree of respect for reasons of the dignity of the person from whom tissue is obtained.	N/A

5.13	Does your research involve human genetics? Consult TCPS: 13, if required.	No
5.14	If 'Yes' for 5.11, provide details of process for individuals to access or withdraw data. Provide details of custody, security, and stewardship of biological specimens. Provide details of disposal of biological specimens and explain how participants' identities will be protected during each stage of research. Remember that issues of privacy and confidentiality may affect the individual, the family and the group to which the individual belongs.	N/A
5.15	Does your research involve drugs or biological substances, or clinical trials? Consult TCPS: 11, if required.	No
5.16	If 'Yes' for 5.13, please explain.	N/A
5.17	Does your research involve mechanical or medical devices involving direct or indirect contact (e.g., electrodes, sensory devices, remote sensory devices etc.)? Consult TCPS: 2.7, if required.	No
5.18	If 'Yes' for 5.15, is there scientific evidence of its compliance with Canadian norms? Provide Research Ethics Board (REB) with the peer-reviewed literature (e.g., description of the apparatus, its function and how it will be used and administered).	N/A
5.19	Does your research involve radioisotopes or other forms of ionizing radiation (or magnetic induction)? Consult TCPS: 2.6, if required.	No
5.20	If 'Yes' for 5.17, please state the 'exemption levels' for ionizing radiation.	N/A
5.21	Does your research involve biohazardous risks (e.g., chemicals, smoke inhalation, used needles)? Consult TCPS: 2.7, if required.	No

5.22	If 'Yes' for 5.19, please explain further.	N/A
5.23	Will the study be conducted over the internet using survey instruments (e.g., Fluidsurveys.com, SurveyMonkey.com etc.) or chatrooms? Consult TCPS: 2.2, 5, if required.	No

### ***6.6: Research Methods: Secondary Data***

#	Question	Answer
6.1	Is secondary data being used for the purposes of this study? If 'No', please skip to the next tab.	Yes
6.2	Who is the owner of the original data? Have you obtained administrative approval/consent from the holder to access the data (e.g., from a hospital, Registrar's office)? Attach evidence of their administrative consent. Also, explain how participants' identities will be protected during each stage of research: recruitment, data collection, data storage, and during dissemination.	Data will be provided by CIHI pending ethics approval. Data will be securely stored on Laurentian University's U drive. It will only be accessed by research team members.
6.3	Are the data denominalized? Did the participants consent to use of their data for secondary purposes? If so, how was their permission to access the records and to collect and use their records obtained? If they did not consent, is there even a remote possibility they can be identified indirectly?	CIHI has a consent process for the collection and release of data for secondary analysis. CIHI releases cleaned data so that there is no possibility of participants being identified indirectly since data will be presented in a denoninalized format, without identifying characteristics. "The Canadian Institute for Health Information is committed to protecting the privacy of individuals and ensuring the security of their personal health information. CIHI is a prescribed entity under Section 45 of the Ontario Personal Health Information Protection Act (PHIPA) and is authorized to collect personal health information for the purpose of analysis or compiling statistical information with respect to

		<p>the management, evaluation or monitoring of the allocation of resources to or planning for all or part of Canada's health systems. As a prescribed entity, CIHI is subject to independent oversight by the Ontario Information and Privacy Commissioner and must have its information practices reviewed and approved by the Commissioner every 3 years. This review process provides the Canadian public with the assurance that CIHI's information management practices comply with PHIPA and with privacy and security standards of practice expected from the Commissioner. As a result, CIHI adheres to this and any other applicable privacy legislation" CIHI De-identification processes:</p> <ul style="list-style-type: none"> <li>• Removal of name and address, if present •</li> <li>Removal/encryption of identifying numbers, such as personal health number and chart number;</li> <li>• Truncating postal code to the first 3 digits •</li> <li>Converting date of birth to month and year of birth, age or age group •</li> <li>Converting date of admission and date of discharge to month and year only •</li> <li>Reviewing the remaining data elements to ensure that they do not permit identification of the individual by a reasonably foreseeable method.</li> </ul> <p>"Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010. (n.d.). 19.</p>
6.4	Briefly describe the type of data that you intend to collect (e.g., disease, diagnosis, outcome, demographic, aggregate, personal-level).	The following data will be analyzed from the RAI-MDS 2.0 assessments collected from CIHI: 1. Disease Diagnosis (dementia) 2. Behaviours 3. Medication/treatment received
6.5	Specify the minimum number of charts/records required to conduct the	Data was collected from all LTC homes in Ontario from 2015-2016 with a total of

	study.	65541 cases.
6.6	Are you collecting personally identifying information? If Yes, indicate the type of personally identifying information you will be collecting. Please include a justification of why it is required.	No
6.7	Is the identifiable information essential to the research? If Yes, please provide further justification/explanation.	No
6.8	What appropriate measures will the researchers take to protect the privacy of individuals and to safeguard the identifiable information?	The dataset is obtained from CIHI and will be stored by Laurentian University's information technology department (IT) and accessible to Roberta Heale (my thesis supervisor) through the Citrix VPN stored on her T drive. I will be able to view the data through Dr. Heale's portal. The file will only be accessible through Laurentian's Citrix VPN account, stored on Roberta Heale's password-protected T file. All identifying information will be removed prior to release from CIHI.
6.9	Is it impossible or impractical to seek consent from individuals to whom the information relates? If Yes, please provide an explanation.	Yes. It is impractical to seek consent from individuals to whom the information relates because of the large demographic area covered and the amount of subjects involved. This study involves minimal risks and as per CIHI can be considered for waiving of consent. "Under specified circumstances, given a satisfactory rationale by the researcher, an REB may approve the waiver of a consent requirement, or a partial waiver of some elements of a consent requirement. According to TCPS Article 2.1(c), the REB must find and document that: (i) The research involves no more than minimal risk to the subjects; (ii) The waiver or alteration is unlikely to adversely affect the rights and welfare of the subjects; (iii) The research could not practicably be carried out without the waiver or

		alteration; (iv) Whenever possible and appropriate, the subjects will be provided with additional pertinent information after participation; and (v) The waived or altered consent does not involve a therapeutic intervention.” Government of Canada, C. I. of H. R. (2005, September 15). CIHR Best Practices for Protecting Privacy in Health Research (September 2005)—CIHR. <a href="https://cihr-irsc.gc.ca/e/29072.html">https://cihr-irsc.gc.ca/e/29072.html</a>
6.10	Have the researchers obtained any other necessary permissions for secondary use of the information for research purposes? Provide further explanation or justification if required.	An application must be submitted to CIHI for release of data – approval is required prior to the release of any data.
6.11	Describe the risks associated with the possible disclosure of the data. Include any foreseeable circumstances where disclosure of identifying data may be required by law.	N/A
6.12	Will the research involve linking multiple data sets? Which fields will be linked for the purposes of this research project?	No
6.13	Describe how the identity of the participants will be protected both during and after the research study. Include how the participants will be identified on data collection forms.	CIHI has a consent process for the collection and release of data for secondary analysis. CIHI cleans data before release so that: 1. There is no possibility of participants being identified indirectly since data will be presented in a denormalized format, without identifying characteristics. 2. Data will be securely stored on Laurentian University's U drive. It will only be accessed by research team members.
6.14	Explain who will have access to the data at each stage of collection, processing and analysis. Indicate whether a current list of the names of study personnel (including co-investigators) and their delegated tasks will be maintained in the	The dataset is obtained from CIHI and will be stored by Laurentian University IT and accessible to Roberta Heale (my thesis supervisor) through the Citrix VPN stored on her T drive. I will be able to view the data through Dr. Heale's portal.

	study file. If a list will not be maintained, please explain.	The file will only be accessible through Laurentian's Citrix VPN account, stored on Roberta Heale's password-protected T file. All identifying information will be removed prior to release from CIHI.
6.15	Describe how the data will be stored (e.g., computerized files, hard copy, video-recording, audio-recording, personal digital device, other). Describe the safeguards in place to protect the confidentiality and security of the data.	The dataset is obtained from CIHI and will be stored by Laurentian University IT and accessible to Roberta Heale (my thesis supervisor) through the Citrix VPN stored on her T drive. I will be able to view the data through Dr. Heale's portal. The file will only be accessible through Laurentian's Citrix VPN account, stored on Roberta Heale's password-protected T file. All identifying information will be removed prior to release from CIHI.
6.16	Describe what will happen to the data at the end of the study, including how long the data will be retained as well as where, when, and how the data will be destroyed. What plans are there for future use of the data? also, describe who will have access to the data in the future and for what purpose.	Data will be stored for 7 years. Laurentian IT will permanently destroy the data as per the contract with CIHI and will provide CIHI with a certificate of destruction.
6.17	Provide any other information not already described above.	

### 7.7: Potential Risks

#	Question	Answer
7.1	Check all possible risks that apply to your research:	N/A
7.2	Are any of the possible risks to participants greater than those the participants might encounter in their everyday life?	No
7.3	If any possible risks apply for 7.1, including 'Other', elaborate. Do not describe 'fatigue' as a risk unless it is significant for the population you are studying. Indicate if a list of resources will	N/A

	be given to participants so they know where to go if needed (e.g., counselling).	
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### ***8.8: Potential Benefits***

#	Question	Answer
8.1	Describe in detail any potential benefits to the participants from their involvement in the project.	Participants in this study do not directly benefit from participation in this research study. Participant data provides valuable information about the prevalence of pain for people with dementia and the complexity of managing pain and providing treatment.
8.2	Comment on the potential benefits to the scientific/scholarship community or society that would justify involvement of participants in this study.	The study results will be shared with all stakeholders, including participants, and LTC home administrations to provide an understanding of pain management for dementia residents. The aims of this study are to improve pain management in LTC homes for residents with dementia by way of promoting the implementation of policies, procedures, education, and adapted tools that allow for improved treatment of pain and reduction in potential secondary effects of untreated/managed pain. Knowledge from this research will form the basis of a thesis for Danielle Hamilton as a requirement of the MSc Nursing program at Laurentian University. In addition, the results will be submitted for academic publication. Efforts will be made to present findings at professional conference proceedings.
8.3	Provide full details of any reimbursement for expenses or payments, incentives or gifts-in-kind to be offered, with amounts, payments, and value.	N/A

### ***9.9: Informed Consent***

#	Question	Answer
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9.1	<p><b>CONSENT FOR PARTICIPANTS NOT LEGALLY COMPETENT or WHO ARE MENTALLY INCOMPETENT:</b> Please note that this includes children (minors).</p> <p>Describe the process that you will use to obtain free and informed consent of the research participants or of their authorized representatives to give consent, including a description of who will be obtaining consent and a script of what they will say. Ensure that they are given an opportunity to express their wish to participate or not, either verbally or non-verbally or via an assent. See TCPS 3.9, 4.6.</p>	N/A
9.2	<p><b>IF YOU FEEL THAT USING A WRITTEN CONSENT IS IMPOSSIBLE</b>, explain why. Examples: cultural appropriateness, low level of educational achievement, sensitivity etc. When written consent forms are not used, a letter should describe the research and identify and provide contact information on the researcher(s). If the study uses an online survey, consent may be requested on the first screen after the research is explained. A copy of the consent letter (or information on the study and contact information for the investigators) should be given to participants. See TCPS: When Written Consent Not Possible (3B).</p>	Secondary analysis
9.3	<p><b>IF DEALING WITH SPECIFIC, CULTURAL, SOCIAL, OR ETHNIC GROUPS:</b> Describe the measures you have taken to adapt the research protocol (e.g., recruitment, consents, tests, questionnaires, etc.) to the divergent values, traditions, privacy issues, and modes of communication of the target group. In cases, where there will be verbal consent rather than written, explain why this is so, and describe the alternative means that will be used to document the consent. See</p>	N/A

	TCPS 3.2, 3.3.	
9.4	ORGANIZATIONAL OR COMMUNITY CONSENT: If research is taking place within a recognized organization or community which may require formal consent to be sought prior to involvement of individual participants (e.g., band council, school board), describe the consent process and provide a copy of the approval document to the LU REB once received. If consent will NOT be sought, provide justification and describe any alternative forms of consultation that may take place. See TCPS 3.2, 3.3.	N/A
9.5	If consent will not be sought, provide justification and describe any alternative forms of consultation that may take place.	Consent will not be sought as the research will involve no more than minimal risk to the subjects and does not involve a therapeutic intervention. The waiver or alteration is unlikely to adversely affect the rights and welfare of the subjects.

#### ***10.10: Consent Forms***

#	Question	Answer
10.1	In cases where there is any risk to the subjects or need for confidentiality, written consent forms are required. Check here to confirm that you have included the following, using lay language:	
10.2	CONSENT FOR STUDIES CARRIED OUT OVER THE INTERNET (e.g., SurveyMonkey, FluidSurveys, internet chatrooms, etc.) Participants who are asked to answer questions or fill out a questionnaire should have to read the equivalent of a consent form. Thereafter, there could be a paragraph to the effect that the person has read the information and that they accept to	

	participate in the project, namely to complete the questionnaire. Although participants did not sign a consent form, information relevant to their participation is transmitted, and answering questions/completing the questionnaire can be interpreted as consent.	
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### ***11.11: Confidentiality and Storage of Data***

#	Question	Answer
11.1	Online tools to assist with deleting or safeguarding confidential information. Check which applies:	FOR PC USERS: Delete and Digital Shredder are available online. <a href="https://technet.microsoft.com/en-us/sysinternals/bb897443.aspx">https://technet.microsoft.com/en-us/sysinternals/bb897443.aspx</a>
11.2	Where will the data be stored during the research? Will you be using any portable computers, disks, or USB keys? What method of data encryption will you use (in addition to passwords)?	The dataset is obtained from CIHI and will be stored by Laurentian University IT and accessible to Roberta Heale (my thesis supervisor) through the Citrix VPN stored on her T drive. I will be able to view the data through Dr. Heale's portal. All portable computers will be password protected.
11.3	If you will be gathering data over the internet (FluidSurveys, SurveyMonkey, etc.) how will anonymity and security be ensured? Additionally, if data are to be kept on the web, what precautions have been taken to prevent it from being copied?	N/A
11.4	For how long will the data be stored? Also, if data will be shared with other researchers, please describe how.	7 years
11.5	How will the data be stored and protected while in storage?	The file will only be accessible through Laurentian's Citrix VPN account, stored on Roberta Heale's password-protected T file. All identifying information will be removed prior to release from CIHI.
11.6	How will the data be destroyed?	Laurentian IT will permanently destroy the data as per the contract with CIHI

		and will provide CIHI with a certificate of destruction.
11.7	If using US-based servers for your research, how will you make your participants aware that data entrusted to US-based service providers may be subject to production orders under the USA Patriot Act?	N/A

### ***12.12: Informing Research Participants***

#	Question	Answer
12.1	Describe how research participants will be made aware of the findings and how the findings will be disseminated in the academic community. Please note that public dissemination (e.g., academic lectures or publications) is not a good way to inform the participants, particularly vulnerable groups.	Findings from this study will be disseminated through thesis format. They will also be provided to research journals for consideration to publish. These findings will likely be used by front line staff providing care to this population to improve practice in LTC. They may also be considered in LTC policy development to support the creation, implementation, and utilization of adequate pain assessment and treatment policies. Creators of pain scales for cognitively impaired individuals may also use the study as supportive data to encourage the use of such tools. Findings may be used for educational purposes to allow for insight and understanding of the prevalence and special considerations required when treating pain in patients with dementia. Vehicles of dissemination may include journals, educational in-services, and clinical guidelines.

### ***13.13: Potential Conflicts of Interest/Influence***

#	Question	Answer
13.1	Will the investigator(s), members of the research team, and/or their partners or immediate family members receive any	No

	personal benefits? If Yes, please describe the benefits and if they were as a result or, or in connection with this study (e.g., financial benefit such as remuneration, intellectual property rights, rights of employment, consultancies, board membership, share ownership, stock options, etc.)? Do not include conference and travel expense coverage, or other benefits that are standard.	
13.2	Do any of the researchers conducting this study have multiple roles with potential participants (e.g., acting as researcher and healthcare provider, teacher, adviser, student/peer, employer/employee) that may create real, potential, or perceived conflicts, ensue influence, power imbalance, or coercion? Please describe how any conflicts of interest will be avoided, minimized, or managed.	No

#### ***14.14: Signature and Acknowledgements***

#	Question	Answer
14.1	I have read the General Guidelines for submission.	Yes
14.2	I am familiar with the Laurentian University Ethics Procedures and Guidelines for Research Involving Humans and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and I agree to comply with these guidelines in carrying out this proposed research.	Yes
14.3	My signature on this application form confirms that I am aware of, understand, and will comply with all relevant laws governing the collection and use of personally identifiable information in research. I understand that for research involving extraction or collection of	Yes

	personally identifiable information, provincial, national, and/or international laws may apply and that any apparent mishandling of personally identifiable information must be reported to the Office of Research Services.	
14.4	My signature confirms that I will ensure that all procedures performed will be conducted in accordance with all relevant University, provincial, national, and international policies and regulations that govern research involving humans. I understand that if there is any significant deviation from the project as originally approved (including research design, procedures, or participants) I must submit an amendment to the Research Ethics Board for approval prior to implementing any change.	Yes
14.5	If any unforeseen incident occurs during the course of research that may indicate risk to participants, I will immediately cease research and inform the REB. I also will inform the REB when the research is complete.	Yes

**15.15: Supervisor's Approval (Students Only)**

#	Question	Answer
15.1	All REB application by a student must be approved by their faculty supervisor as part of the submission process. Students, please have your supervisor send you an email, in which they reference your project, by title or file number. In the email, they should indicate that they have reviewed and approved the scholarly methods of your project and that all the necessary program reviews have taken place. Upload a copy of this email via the Attachments tab. By	

<p>selecting 'Yes' below, you are confirming that you have attached your supervisor's approval for the REB application and that you have attained all of the necessary departmental or faculty approvals for this research.</p>	
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## Appendix D



### **APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS**

#### **Research Ethics Board – Laurentian University**

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

<b>TYPE OF APPROVAL / New X / Modifications to project / Time extension</b>	
<b>Name of principal investigator and school/department</b>	Daniele Hamilton, Roberta Heale, Nursing
<b>Title of project</b>	What are the differences in assessment and treatment of pain for residents in long-term care with and without dementia?
<b>REB file number</b>	6020659
<b>Date of original approval of project</b>	May 20, 2020
<b>Date of approval of project modifications or extension (if applicable)</b>	
<b>Final/interim report due on: (You may request an extension)</b>	May 20, 2021
<b>Conditions placed on project</b>	

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form in ROMEO.

All projects must submit a report to REB at least once per year on the anniversary date of the original approval. If involvement with human participants continues for longer than one year (e.g., you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement. Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair,  
Laurentian University Research Ethics Board

## Appendix E

<b>Sad, apathetic, anxious appearance: sad pained, worried facial expression</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	100944	57379	Observed Count: 57379 Expected Count: 60253.6 $\chi^2(1) = 385.313$ , $p = .001$
	<b>Expected Count</b>	98069.4	60253.6	
<b>All Others</b>	<b>Count</b>	129594	84263	$\chi^2(1) = 385.313$ , $p = .001$
	<b>Expected Count</b>	132468.6	81388.4	
<b>Sad, apathetic, anxious appearance: crying, tearfulness</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	142561	15762	Observed Count: 15762 Expected Count: 17691.3 $\chi^2(1) = 412.209$ , $p = .001$
	<b>Expected Count</b>	140631.7	17691.3	
<b>All Others</b>	<b>Count</b>	188031	25826	$\chi^2(1) = 412.209$ , $p = .001$
	<b>Expected Count</b>	189960.3	23896.7	
<b>Sad, apathetic, anxious appearance: repetitive physical movements</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	113095	45228	Observed Count: 45228 Expected Count: 39087.3 $\chi^2(1) = 2229.299$ , $p = .001$
	<b>Expected Count</b>	119235.7	39087.3	
<b>All Others</b>	<b>Count</b>	167200	46657	$\chi^2(1) = 2229.299$ , $p = .001$
	<b>Expected Count</b>	161059.3	52797.7	
<b>Wandering (moved with no rational purpose, seemingly oblivious to needs or safety)</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	126589	31734	Observed Count: 31734 Expected Count: 23317.5 $\chi^2(1) = 6200.120$ , $p = .001$
	<b>Expected Count</b>	135005.5	23317.5	
<b>All Others</b>	<b>Count</b>	190777	23080	$\chi^2(1) = 6200.120$ , $p = .001$
	<b>Expected Count</b>	182360.5	31496.5	
<b>Wandering (moved with no rational purpose, seemingly oblivious to needs or safety), behaviour was not easily altered</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	145291	13032	Observed Count: 13032 Expected Count: 9751.7 $\chi^2(1) = 2046.342$ , $p = .001$
	<b>Expected Count</b>	148571.3	9751.7	
<b>All Others</b>	<b>Count</b>	203965	9892	$\chi^2(1) = 2046.342$ , $p = .001$
	<b>Expected Count</b>	200684.7	13172.3	

<b>Resist's care (resisted taking meds or injections, assistance with activities of daily living, or eating)</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	92944	65379	Observed Count: 65379 Expected Count: 55116.1
	Expected Count	103206.9	55116.1	
All Others	Count	149671	64186	$\chi^2(1) = 5101.81$ , $p = .001$
	Expected Count	139408.1	74448.9	
<b>Resist's care (resisted taking meds or injections, assistance with activities of daily living, or eating) behaviour was not easily altered</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	124834	33489	Observed Count: 33489 Expected Count: 29131.0
	Expected Count	129192.0	29131.0	
All Others	Count	178866	34991	$\chi^2(1) = 1390.485$ , $p = .001$
	Expected Count	174508.0	39349.0	
<b>Verbal expression of distress: repetitive questions</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	115565	42758	Observed Count: 42758 Expected Count: 40314.1
	Expected Count	118008.9	40314.1	
All Others	Count	161846	52011	$\chi^2(1) = 345.906$ , $p = .001$
	Expected Count	159402.1	54454.9	
<b>Verbal expression of distress: repetitive verbalizations</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	118015	40308	Observed Count: 40308 Expected Count: 39840.7
	Expected Count	118482.3	39840.7	
All Others	Count	160509	53348	$\chi^2(1) = 12.748$ , $p = .001$
	Expected Count	160041.7	53815.3	
<b>Verbal expression of distress: persistent anger with self or others</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	105974	52349	Observed Count: 52349 Expected Count: 49888.9
	Expected Count	108434.1	49888.9	
All Others	Count	148929	64928	$\chi^2(1) = 308.257$ , $p = .001$
	Expected Count	146468.9	67388.1	
<b>Verbal expression of distress: Self depreciation.</b>				

		Not Present	Present	Significance
Dementia No Pain	Count	149105	9218	Observed Count: 9218 Expected Count: 10882.0
	Expected Count	147441.0	10882.0	
All Others	Count	197494	16363	$\chi^2(1) = 475.500$ , $p = .001$
	Expected Count	199158.0	14699.0	
<b>Verbal expression of distress: expression of what seem to be unrealistic fears</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	137404	20919	Observed Count: 20919 Expected Count: 21589.6
	Expected Count	136733.4	21589.6	
All Others	Count	184024	29833	$\chi^2(1) = 41.971$ , $p = .001$
	Expected Count	184694.6	29162.4	
<b>Verbal expression of distress recurrent statements that something terrible is about to happen</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	148616	9707	Observed Count: 9707 Expected Count: 11039.0
	Expected Count	147284.0	11039.0	
All Others	Count	197614	16243	$\chi^2(1) = 300.659$ , $p = .001$
	Expected Count	198946.0	14911.0	
<b>Verbal expression of distress: repetitive health complaints</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	140857	17466	Observed Count: 17466 Expected Count: 27218.4
	Expected Count	131104.6	27218.4	
All Others	Count	167339	46518	$\chi^2(1) = 7343.701$ , $p = .001$
	Expected Count	177091.4	36765.6	
<b>Verbal expression of distress: repetitive anxious complaints or concerns – non-health related</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	121126	37197	Observed Count: 37197 Expected Count: 42081.2
	Expected Count	116241.8	42081.2	
All Others	Count	152131	61726	$\chi^2(1) = 1343.731$ , $p = .001$
	Expected Count	157015.2	56841.8	
<b>Verbally abusive behavioural symptoms: others were threatened, screamed at, cursed at</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	128554	29769	Observed Count: 29769

	<b>Expected Count</b>	131432.6	26890.4	Expected Count: 26890.4 $\chi^2(1) = 646.002$ , $p = .001$
All Others	<b>Count</b>	180413	33444	
	<b>Expected Count</b>	177534.4	36322.6	
<b>Verbally abusive: others were threatened, screamed at, cursed at – behaviour was not easily altered</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
Dementia No Pain	<b>Count</b>	146607	11716	Observed Count: 11716 Expected Count 10916.0 $\chi^2(1) = 109.583$ , $p = .001$
	<b>Expected Count</b>	147407.0	10916.0	
All Others	<b>Count</b>	199912	13945	
	<b>Expected Count</b>	199112.0	14745.0	
<b>Verbal expression of distress: resident made negative statements</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
Dementia No Pain	<b>Count</b>	136164	22159	Observed Count: 22159 Expected Count: 24441.8 $\chi^2(1) = 438.805$ , $p = .001$
	<b>Expected Count</b>	133881.2	24441.8	
All Others	<b>Count</b>	178559	35298	
	<b>Expected Count</b>	180841.8	33015.2	
<b>Mood persistence: one or more indicators of depressed, sad, or anxious mood were not easily altered by attempts to “cheer up,” console, or reassure the resident</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
Dementia No Pain	<b>Count</b>	69986	88337	Observed Count: 88337 Expected Count: 87098.9 $\chi^2(1) = 68.082$ , $p = .001$
	<b>Expected Count</b>	71224.1	87098.9	
All Others	<b>Count</b>	97445	116412	
	<b>Expected Count</b>	96206.9	117650.1	
<b>Change in mood: resident’s mood status has changed as compared to 90 days ago (or since last assessment if less than 90 days ago)</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
Dementia No Pain	<b>Count</b>	134922	23401	Observed Count: 23401 Expected Count: 25181.2 $\chi^2(1) = 260.441$ , $p = .001$
	<b>Expected Count</b>	133141.8	25181.2	
All Others	<b>Count</b>	178063	35794	
	<b>Expected Count</b>	179843.2	34013.8	
<b>Loss of interest: withdrawal from activities of interest</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
Dementia No	<b>Count</b>	148657	9666	Observed Count:

<b>Pain</b>				9666 Expected Count: 10151.2 $\chi^2(1) = 43.120$ , p = .001
	<b>Expected Count</b>	148171.8	10151.2	
<b>All Others</b>	<b>Count</b>	199660	14197	
	<b>Expected Count</b>	200145.2	13711.8	
<b>Loss of interest: reduced social interaction</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	145749	12574	Observed Count: 12574
	<b>Expected Count</b>	144998.0	13325.0	Expected Count: 13325.0
<b>All Others</b>	<b>Count</b>	195107	18750	$\chi^2(1) = 80.437$ , p = .001
	<b>Expected Count</b>	195858.0	17999.0	
<b>Physically abusive behavioural symptoms: others were hit, shoved, scratched, sexually abused</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	134619	23704	Observed Count: 23704
	<b>Expected Count</b>	140181.7	18141.3	Expected Count: 18141.3
<b>All Others</b>	<b>Count</b>	194915	18942	$\chi^2(1) = 3352.576$ , p = .001
	<b>Expected Count</b>	189352.3	24504.7	
<b>Physically abusive: others were hit, shoved, scratched, sexually abused – behaviour was not easily altered</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	148703	9620	Observed Count 9620
	<b>Expected Count</b>	150852.2	7470.8	Expected Count 7470.8
<b>All Others</b>	<b>Count</b>	205915	7942	$\chi^2(1) = 1129.342$ , p = .001
	<b>Expected Count</b>	203765.8	10091.2	
<b>Socially inappropriate or disruptive behavioural symptoms: made disruptive sounds, noisiness, screaming, self-abusive acts, sexual behaviours or disrobing in public, smeared or threw food or feces, hoarding, rummaging through other's belongings</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
<b>Dementia No Pain</b>	<b>Count</b>	123023	35300	Observed Count: 35300
	<b>Expected Count</b>	127474.3	30848.7	Expected Count: 30848.7
<b>All Others</b>	<b>Count</b>	176639	37218	$\chi^2(1) = 1388.318$ , p = .001
	<b>Expected Count</b>	172187.7	41669.3	
<b>Socially inappropriate or disruptive behavioural symptoms: made disruptive sounds, noisiness, screaming, self-abusive acts, sexual behaviours or disrobing in public, smeared or</b>				

<b>threw food/feces, hoarding, rummaging through other's belongings – behaviour was not easily altered</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	142093	16230	Observed Count: 16230 Expected Count: 14658.6
	Expected Count	143664.4	14658.6	
All Others	Count	195628	18229	$\chi^2(1) = 323.060,$ $p = .001$
	Expected Count	194056.6	19800.4	
<b>Indicators of delirium – periodic disordered thinking/awareness: periods of restlessness</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	117425	40898	Observed Count: 40898 Expected Count: 35306.0
	Expected Count	123017.0	35306.0	
All Others	Count	171759	42098	$\chi^2(1) = 1983.806,$ $p = .001$
	Expected Count	166167.0	47690.0	
<b>Change in communication/hearing: resident's ability to express, understand, or hear information has changed as compared to 90 days ago (or since last assessment if less than 90 days)</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	150560	7763	Observed Count: 7763 Expected Count: 7545.2
	Expected Count	150777.8	7545.2	
All Others	Count	203883	9974	$\chi^2(1) = 11.488,$ $p = .001$
	Expected Count	203665.2	10191.8	
<b>Change in behavioural symptoms: resident's behavioural status has changed as compared to status of 90 days ago (or since last assessment if less than 90 days)</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	134203	24120	Observed Count: 24120 Expected Count: 22661.1
	Expected Count	135661.9	22661.1	
All Others	Count	184706	29151	$\chi^2(1) = 190.748,$ $p = .001$
	Expected Count	183247.1	30609.9	
<b>Sleep cycle issues: unpleasant mood in morning</b>				
		Not Present	Present	Significance
Dementia No Pain	Count	122913	35410	Observed Count: 35410 Expected Count: 33421.5
	Expected Count	124901.5	33421.5	
All Others	Count	170701	43156	

	<b>Expected Count</b>	168712.5	45144.5	$\chi^2(1) = 261,001$ , $p = .001$
<b>Sleep cycle issues: insomnia or change in usual sleep pattern</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
Dementia No Pain	<b>Count</b>	133425	24898	Observed Count: 24898
	<b>Expected Count</b>	133052.5	25270.5	Expected Count: 25270.5
All Others	<b>Count</b>	179350	34507	$\chi^2(1) = 11.371$ , $p = .001$
	<b>Expected Count</b>	179722.5	34134.5	
<b>Indicators of delirium –periodic disordered thinking/awareness: periods of lethargy</b>				
		<b>Not Present</b>	<b>Present</b>	<b>Significance</b>
Dementia No Pain	<b>Count</b>	135960	22363	Observed Count: 22363
	<b>Expected Count</b>	136868.7	21454.3	Expected Count: 21454.3
All Others	<b>Count</b>	185786	28071	$\chi^2(1) = 77.481$ , $p = .001$
	<b>Expected Count</b>	184877.3	28979.7	