Identification, Quantification, and Characterization of Nursing Home Resident Pain Trajectories

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DEDICATION

This dissertation is dedicated to my son, Tyler, who died on November 29, 2017. You are gone, but your pride in my accomplishments propels me ever onward.

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Connie Sue Cole

IDENTIFICATION, QUANTIFICATION, AND CHARACTERIZATION OF NURSING HOME RESIDENT PAIN TRAJECTORIES

Pain prevalence in nursing home (NH) residents is high. Studies report up to 85.0% of NH residents experience pain and up to 58.0% experience persistent pain. Pain in NH residents can lead to decreased happiness, quality of life, and life satisfaction. Traditionally, pain has been studied in relation to specific comorbid conditions or pain subtypes (nociceptive, neuropathic) with little consideration for the dynamic (temporal) nature of pain. Current pain subtypes are clinically linked to recommended pain treatments and provide insight into underlying mechanisms. However, current pain subtypes are limited by their focus on pain origin, do not include severity or duration of the pain experience, and do not illustrate how the course or trajectory of pain changes over time. Understanding the trajectory of pain experience can provide opportunities to alter the course of pain experience, improve residents' quality of life and prevent adverse outcomes.

This dissertation provides the first evidence of four distinct pain trajectories among NH residents including persistent pain which was associated with several resident characteristics and clinically relevant diagnosis. Using residents' characteristics associated with persistent pain, such as a history of fracture or contracture, may improve care planning based on early identification or risk stratification and can improve mitigation of persistent pain. To identify and characterize pain trajectories in NH residents, the following activities were completed (1) systematic review of the literature related to prevalence of pain and associated factors in NH residents, (2) cross-sectional

analysis of secondary data to examine prevalence of pain, persistent pain, and factors associated with pain in NH residents, and (3) a longitudinal retrospective analysis of secondary data using group-based trajectory modeling to identify, quantify, and characterize NH pain trajectories. The findings from this study highlight the prevalence and complexity of pain in NH residents.

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LIST OF ABBREVIATIONS

Abbreviation	Term
ADL	Activities of Daily Living
AOR	Adjusted Odds Ratio
APS-J	Abbey Pain Scale – Japanese
BIC	Bayesian Information Criterion
BMI	Body Mass Index
CFS	Cognitive Function Scale
CI	Confidence Interval
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CHF	Congestive Heart Failure
CMS	Centers for Medicare and Medicaid Services
COPD	Chronic Obstructive Pulmonary Disease
FPS-R	Faces Pain Scale – Revised
GBTT	Group Based Trajectory Modeling
GPA	Geriatric Pain Assessment
IRAI-LTC	International Resident Assessment Instrument – Long Term Care
MDS	Minimum Data Set
MMSE	Mini Mental Status Exam
NH	Nursing Home
NRS	Numeric Rating Scale
OPTIMISTIC	Optimizing Patient Transfers, Impacting Medical quality, and Improving Symptoms: Transforming Institutional Care

OR	Odds Ratio
PAINAD	Pain Assessment in Advanced Dementia Scale
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PAD	Peripheral Arterial Disease
PHQ-9	Patient Health Questionnaire-9
PVD	Peripheral Vascular Disease
REPOS	Rotterdam Elderly Pain Observation Scale
SD	Standard Deviation
US	United States
VAS	Visual Analog Scale
VDS	Verbal Descriptor Scale
VRS	Verbal Rating Scale

CHAPTER ONE: INTRODUCTION

Background

Pain in NH residents is common and negatively impacts outcomes.[1-6] Pain is defined as a subjective unpleasant sensory and emotional experience.[7] Studies have reported NH resident pain prevalence rates between 22.0%[1] to 85.0%,[2] including up to 32.0%[3] with substantial pain, and up to 59.0%[1] with persistent pain. Pain in NH residents is associated with poor quality of life,[5, 6] higher likelihood of depression,[8, 9] decreased happiness,[5, 10, 11] decreased life satisfaction,[11] greater ADL dependency,[8, 9, 12-14] and sleep problems.[4, 6, 15] Given the negative impacts of pain on NH residents, it is important to effectively manage pain in this population.

Pain is temporal, changing over time, particularly for older adults with chronic conditions such as osteoarthritis which tend to wax and wane over time. Despite the temporality of time, most studies conducted to describe NH resident pain use a cross-sectional or snapshot in time approach. While there are several studies conducted using a longitudinal approach, they are limited to a small number of time points, small window of time (14 days) or the last 90 days of life.[16, 17] Because the median length of stay for NH residents is 2.2 years,[18] identifying the trajectory of pain beyond these small windows of time is important. A trajectory approach that identifies changes in pain over time could allow opportunities to alter the course of illness, plan care and set priorities, prevent adverse outcomes, and provide supportive therapies to improve quality of life.

Purpose

The purpose of this dissertation is to identify, quantify and characterize NH resident pain trajectories. This dissertation addresses this purpose in the following ways:

- Chapter Two: A systematic review of the literature related to prevalence of pain and associated factors in NH residents was conducted to examine the pain prevalence in NH residents and the factors associated with the experience of pain.
- Chapter Three: A cross-sectional analysis of secondary data to examine factors associated with pain in NH residents was conducted to evaluate the association between pain and resident demographic and clinical characteristics including pain management strategies.
- Chapter Four: A longitudinal retrospective analysis of secondary data was conducted using group-based trajectory modeling to identify, quantify, and characterize NH resident pain trajectories.

Chapters 2, 3, and 4 include three different research studies that build upon one another to address the dissertation purpose comprehensively. Chapter 5 provides an integration of the results from each study, resulting in one complete document, the dissertation.

CHAPTER TWO: PREVALENCE AND FACTORS ASSOCIATED WITH PAIN IN NURSING HOME RESIDENTS: A SYSTEMATIC REVIEW OF THE LITERATURE

Introduction

Among nursing home (NH) residents, pain decreases quality of life[5, 6] and is associated with depression,[8, 9] dependency,[8, 9] and sleep problems.[4, 6, 15] In the United States, NH residents' multiple comorbidities and associated cognitive, medical, behavioral, and/or functional impairments increase the likelihood of experiencing pain.[19] Furthermore, the high prevalence of dementia (48.0%)[20] and cognitive impairment (37.0%)[21] among NH residents creates challenges in accurately assessing and measuring pain, particularly because these residents may be limited in their ability to verbalize pain complaints.

Interest in pain and pain management therapies has been increasing, as evidenced by increased recognition of pain as a public health problem,[7, 22] development of improved and validated pain assessment instruments,[15, 23-26] publicly reported NH quality measures for pain,[27] and changes in prescribing practices associated with the opioid epidemic.[3, 7, 22, 23] In response, several major policies have been launched, including implementation of the Minimum Data Set (MDS) 3.0 in October 2010 with a change to pain survey items required of NHs[28] and strengthened NH survey guidance for pain assessment and management, federal tag (F-tag) 309 in 2009[29-31] and F-tag 697 in 2017.[32] The last comprehensive synthesis of the literature on pain in NH residents was published over a decade ago.[33] These changing priorities and new policies suggest that systematic literature reviews from a decade ago may no longer be relevant to the current pain milieu in NHs.

The purpose of this systematic review was to examine the pain prevalence in NH residents and the factors associated with the experience of pain. Generating an up-to-date systematic review of pain prevalence and factors that underlie the experience of pain will be directly useful for clinicians who are evaluating pain and tailoring pain management therapies and to researchers for addressing gaps in knowledge uncovered by the review.

Methods

Authors followed the Preferred Reporting Items for Systematic Reviews and Meta- Analysis (PRISMA),[34] did not register the review protocol, and did not conduct a meta-analysis.

Search and Study Selection

One author performed searches in PubMed, CINAHL, and PsycInfo using keywords of pain (limited to title) AND (nursing home OR long-term care). One author searched reference lists of relevant review articles for any additional potentially eligible studies. Authors used a structured program available at Covidence.org to organize the review process. The program de-duplicates articles from searches and shows progress on screening and full text review. Initial study selection was based on titles and abstracts before proceeding to full-text screening. At both stages, two independent reviewers voted on studies and resolved disagreements through discussion.

Eligibility Criteria

Inclusion criteria were 1) descriptive studies that examined pain in NH residents; 2) reported pain prevalence and/or associated factors; 3) were written in English; and 4) were published in peer-reviewed journals from January 2010 to September 2020. The

year 2010 was chose as the start date to begin where the prior review focused on pain and associated factors in NH residents ended.[35]

Exclusion criteria were: 1) review articles; 2) case reports; 3) qualitative designs; 4) intervention designs; 5) studies focused exclusively on a specific disease or type of care such as cancer, end-of-life, hospice, or palliative care; and 6) studies focused on NH residents that were younger than 65 years of age.

Quality Assessment and Data Extraction

Two authors independently appraised the methodological quality of studies included in the review. Using the Joanna Briggs Institute Checklist for Prevalence Studies, a critical appraisal tool for use in observational epidemiological studies reporting prevalence and incidence data.[35] This tool allows for assessing risk of bias in sample frame, sampling approach, sample size, description of sample and setting, coverage of identified sample, methods for identification of condition, statistical analysis and response rate. Risk of bias for each domain was judged by two independent reviewers as "high", "low", or "unclear". Disagreements were resolved through discussion.

One author (C.S.C.) independently extracted the following elements for each study: author, year published, country, purpose, sample and setting, pain prevalence, type of pain, source of pain information, time frame of pain occurrence, definition of pain, assessment tool, comorbidities, and cognition. A second author (S.H., J.C., C.X.C., J.B.) reviewed and validated the extracted information. Disagreements were resolved through discussion.

Results

Description of Studies

The flow of records is shown in the PRISMA Figure 2-1. Of 400 unique articles screened, 45 proceeded to full-text review, of which 26 were included in this review. The methodological quality of studies included varies, as displayed in the risk of bias summary in Figure 2-2.

As shown in Table 2-1, all studies were published from 2010-2020 across 19 countries. Sample sizes ranged from 106 to 1,387,405. Seven studies excluded NH residents that were short stay,[2, 5, 8, 12-14, 36] 2 excluded NH residents that were end of life,[37, 38] and 7 excluded NH residents with cognitive impairment.[4, 5, 8, 10, 39-41]

All 26 studies reported data on pain prevalence and 20 studies reported factors associated with pain. Twenty-two studies reported prevalence of current pain, 2 studies reported prevalence of chronic pain,[8, 42] and 3 studies reported prevalence of persistent pain.[1, 6, 12] Chronic pain was defined as pain with a duration of six months or more[42] or a duration of three months or more[8] by the studies that reported this outcome. Persistent pain was defined as pain that was present at initial and subsequent assessment, typically ninety days apart.[1, 6, 12]

Pain experience was measured using the following assessment tools: the Pain Assessment in Advanced Dementia (PAINAD),[14, 36-38, 43] the Numeric Rating Scale (NRS),[3, 5, 10, 44, 45] the Minimum Data Set 2.0 (MDS 2.0),[1, 6, 9, 46, 47] the Geriatric Pain Assessment (GPA),[11, 39] the InterRAI Instrument for Long Term Care Facilities (IRAI-LTC), [13, 48-50] the Verbal Rating Scale[4] (VRS),[4, 36, 40, 44] the Minimum Data Set 3.0 (MDS 3.0),[12, 28, 46, 51, 52] the Visual Analog Scale (VAS), [8, 38, 45] the Verbal Descriptor Scale

(VDS),[2, 53, 54] the Japanese Abbey Pain Scale (APS-J), [2, 53, 55] the Verbal Pain Scale (VPS),[3, 44] the Rotterdam Elderly Pain Scale (REPOS),[3, 50] the Faces Pain Scale-Revised (FACES-R),[37, 56] and researcher-generated pain items.[42, 57, 58] Additionally, three studies collected data during or following a movement protocol.[2, 36, 53]

Pain Prevalence

Overall, the prevalence of current pain ranged from 22.2%[**1**] to 85.0%,[2] the prevalence of persistent pain ranged from 19.5%[**12**] to 58.5%,[1] and the prevalence of chronic pain ranged from 55.9%[8] to 58.1%.[42] Pain prevalence varied depending upon the type of pain measured (current, chronic, persistent), the source of information (interview, proxy, chart), the time frame of pain occurrence (pain occurring over a certain time period such as over the past week), definition of pain (intensity, frequency), and prevalence of cognitive impairment within the sample.

Pain experience was collected via self-report (n=9), proxy only report (n=2), chart review (n=2), unspecified (n=2) or combinations of self-report, proxy report and chart review (n=11). Pain prevalence for those using self-report measures (31.8%[2] to 78.8%[40]), or proxy measures (29.5%[37] to 85.0%[2]) were substantially higher than those using chart review (22.2%[1] to 29.3%[1]) as the source of pain information.

In addition, pain prevalence varied depending upon the definition of pain used within each study. For example, those including only residents meeting a threshold of pain such as moderate to severe (22.2%)[1] or substantial pain (32.0%),[3] identified less pain than those including any intensity or frequency of pain (32.2%[9] to 78.7%[40]). Intensity did vary based upon method of assessment. Tan et al[37] found little difference in those with mild pain based on self-report (21.9%) compared to proxy measure (23.5%). This gap

widened significantly when looking at moderate to severe pain (38.1% self-report vs 6.0% proxy).[37] Thus, those that were able to self-report and rate the intensity of their pain were apt to rate their pain higher than a proxy observer.

Commonly used time frames of pain occurrence included pain in the last six months,[40, 42] last three months,[5, 11, 39] week,[1, 6, 9, 57, 58] five days,[12, 13, 48, 51] three days,[49] one day,[37] five minutes,[14, 37] two minutes,[3] and pain at the time of assessment.[2-4, 36, 49, 53, 57] As would be expected, lengthier time frames of pain occurrence were related to higher pain prevalence due to the increased opportunity to experience pain. Prevalence ranged from 32.0%[3] to 55.0%[4] of individuals with current pain and up to 78.7%[40] of individuals with pain during the previous six months.

The prevalence of cognitive impairment within the sample also affected the pain prevalence reported. Studies excluding residents with cognitive impairment reported a minimum pain prevalence of 47.1%[41] whereas studies that included residents with cognitive impairment reported pain prevalence of 22.2%.[1] See below for further examination of the association between pain and dementia/cognitive impairment.

Pain Management

Across studies, up to 76.3% of residents with pain were using an oral analgesic.[3, 5, 11, 37, 39, 40, 42, 49, 58] Oral analgesics were prescribed on a routine basis,[12, 36, 49, 51] (35.9%[36] to 63.2%[12]), as needed basis,[36, 49, 51] (9.8%[49] to 80.9%[51]) or a combination of routine and as needed[49] (13.9%[49]). Of those with pain, 45.0%[3] to 62.5%[49] received non-opioid analgesics,[3, 49] 7.8%[49] to 12.0%[3] received weak opioid analgesics, 9.7%[49] received strong opioid analgesics, 5.0%[3] received neuroactive agents[3] and 20.1%[49] received combination therapy.[49] In addition, residents with pain indicated using non-pharmacological pain

treatments (44.0%[51] to 76.1%[11]), most commonly consisting of topical analgesic ointments,[5, 11, 39, 40, 51] massage,[5, 11, 39, 40] heat[11, 39] and/or physical therapy.[42]

Equally important, 14.5%[39] to 29.0%[4] of those experiencing pain and 38.0%[3] of those experiencing substantial pain were not using any treatments.[3, 4, 12, 39, 42, 49, 51, 58] Falls, severe pressure ulcers and depression were associated with insufficient pain management.[49] Inability to self-report pain and cognitive impairment were associated with lack of analgesic use[12, 36, 37] Additionally, residents with cognitive impairment received fewer prescribed routine and as needed pain medications overall.[12]

Resident Factors Related to Pain

Demographic Factors

As shown in Figure 2-3, a total of 7 demographic factors were studied in association with the experience of pain. For most factors, findings were equivocal. For gender, although 8 studies showed women were more likely to report any pain,[5, 8, 13, 39, 40, 49, 51] or persistent pain compared to men,[12] 6 studies showed no significant associations between pain and gender.[2, 4, 9, 14, 42, 53] For race, although 4 studies (all US samples) reported pain by race, only 2 statistically evaluated the association and found that Whites were more likely to report pain[51] or persistent pain[12] compared to non-Whites. For age, 8 studies showed no association between age and pain,[2, 4, 5, 8, 9, 39, 40, 49] 3 showed older residents were more likely to report pain,[13, 42, 53] and 3 showed younger residents were more likely to report pain[51] or experience persistent pain.[1, 12]

For receipt of Medical Aid, only 1 study evaluated an association with pain, finding that Medical Aid beneficiaries were more likely to experience pain compared to those not receiving Medical Aid.[13] Other demographics with equivocal associations to

pain included marital status[4, 5, 9, 13, 39], level of education,[4, 5, 8, 39, 40] and length of stay.[5, 8, 14, 39, 40, 53]

Only 1 study tested environment as a factor associated with pain. Living in an urban area and residing in a large (≥ 100 bed) nursing home were associated with greater pain.[13] Meeting the standard for staffing was associated with greater reporting of pain but also associated with lessened intensity of pain.[13] Authors hypothesized that ascertainment bias from higher staffing led to more pain experience documentation and thus improved pain management.[13]

Clinical Conditions and Comorbid Factors

The reviewed studies provide support that certain diseases and clinical conditions are associated with pain. Cognition, dementia, and depression are the most widely studied factors and show the strongest association.

Dementia and Impaired Cognition. A diagnosis of dementia was associated with a decreased risk of reported pain[4, 9, 39, 49]and persistent pain.[12] However, findings between impaired cognitive functioning and pain were mixed.[4, 9, 12, 14, 36, 37, 51] Overall, pain prevalence varied depending upon the prevalence of residents with dementia within the sample. For example, in a study in which 60.0% of residents had a diagnosis of dementia, pain prevalence was 36.9%,[13] whereas in another study in which only 29.0% of residents had a diagnosis of dementia, pain prevalence was higher at 65.2%.[51] While no studies specifically excluded residents with a diagnosis of dementia, as mentioned earlier, seven excluded residents with cognitive impairment which likely includes many with diagnosed or undiagnosed dementia.[4, 5, 8, 10, 39-41]

Clinical. Residents with a higher number of chronic diseases[8] and unstable health conditions[49] were at greater risk for experiencing pain. Specific comorbidities associated with greater pain in NH residents were (see Figure 2-3): depression,[5, 8, 9, 11, 12, 40, 49, 51] arthritis,[5, 6, 9, 12, 39] ADL impairment,[8, 9, 12-14, 53] sleep problems,[5, 6, 49, 51] falls,[41, 49] and pressure ulcers.[12, 49] As shown in Figure 2-3, findings for other comorbidities and pain were equivocal including diabetes,[1, 5, 9, 10, 13, 40, 49] COPD,[9, 49] CHF,[9, 13] stroke,[4, 5, 9, 13, 39, 49] Parkinson's disease,[5, 9, 39] fracture,[1, 4, 5, 9, 12, 39, 40, 49] cancer,[2, 9, 12, 49] and osteoporosis.[2, 9, 12]

Other Factors

Psychosocial. Psychosocial aspects associated with pain include having a negative affect,[4] lower happiness,[5, 11, 40] lower life satisfaction,[11] higher loneliness,[11] lower quality of life,[5, 40] and substance use disorder.[51]

Attitudes and Beliefs. Takai et al. queried residents on their attitudes toward pain. More than half, 51.9%, reported believing that pain is a natural part of aging and 68.5% felt it should be tolerated, with only 27.4% consistently reporting their pain to a staff member.[2]

Discussion

Pain Prevalence

This systematic review examined pain prevalence and associated factors in NH residents. Our review shows that 22.0% to 85.0% of NH residents experience pain, 20.0% to 56.0% experience persistent pain, and approximately 56.0% experience chronic pain. Consistent with prior reviews,[33] pain prevalence of pain was highly variable and influenced by length of pain detection time (minutes, days, months), source of pain data (self-report, proxy, chart review), intensity of pain assessed (mild, moderate, severe), and

sample characteristics (cognition, pain related conditions). The 26 studies in this review used 14 different assessment tools for measuring and assessing pain. Inconsistent definitions and measurement of pain complicate comparisons across studies and ability to detect changes in pain prevalence over time.

The pain prevalence was highest among NH residents able to self-report pain, followed by those evaluated via observational proxy. The selection of data source (self-report vs proxy report vs chart review) often influences the time period for pain assessment. For example, typically, self-reports are obtained from a three month or one-week pain detection time period, whereas observational measures typically cover only a few minutes. Given that a longer period to detect pain will increase the opportunity to identify pain, prevalence rates should be interpreted with caution and may not be comparable across measures.

Studies employing chart review as the source of pain information reported the lowest pain prevalence. This likely underrepresents true pain prevalence and should be interpreted cautiously as prevalence of "documented" pain. Documentation of pain can be influenced by factors such as staff workload and resident beliefs and preferences for reporting their pain to a staff member. Studies indicated only 27.4% of residents consistently reported their pain to a staff member,[2] highlighting the importance of an active approach to asking residents about pain. The concept of "documented" pain may be related to the finding that meeting the standard for staffing was associated with higher reporting of pain (i.e. more staff leads to more documentation), and also with lower severity of pain (i.e. more staff and assessment data leads to lower levels of pain severity).[13, 59]

Resident Factors Associated with Pain

It is important to identify factors that increase the likelihood of NH residents experiencing pain to enhance the ability to anticipate, identify, and treat pain. In this review we identified depression, cognitive impairment and dementia as associated with pain across the subset of studies that analyzed these factors. These findings are important for risk stratification and can also provide potential targets for intervention.

Eight studies in this review reported a positive association between depression and pain. Depression in older adults is common with prevalence rates ranging from 42.6% of short-stay NH residents to 53.0% of long-stay NH residents.[20] Pain is known to exacerbate depression but the mechanistic link between pain and depression remains elusive. Possible mechanisms include that depression may reduce the pain threshold and sensitize pain perception, or that chronic pain can lead to an altered emotional state, including depression.[60] Regardless of the mechanism, tricyclic and selective serotonin-norepinephrine reuptake inhibitor (SNRI) antidepressants are effective in treating widespread musculoskeletal and neuropathic pain, and are commonly prescribed.[61, 62] Use of antidepressant (psychoactive) medications in the NH can be limited by potential interactions with other medications NH residents may be taking and NH regulations which include the need to receive gradual dose reductions.[29] Finally, the therapeutic benefit of antidepressant medications for pain management should be weighed carefully against potential adverse effects.

Findings also highlight the complicated association between dementia and pain. Dementia and impaired cognition negatively affect the residents' ability to communicate and report pain. For residents who are unable to provide self-report, pain is usually

inferred from behaviors such as facial grimacing, guarding of a body part, crying, or calling out. NH residents without the ability to communicate their pain, may still have pain that may go undetected and unreported. Numerous studies show lower documented pain in NH residents with cognitive impairment.[63-65] While it is possible that neuropathology related to dementia may influence the pain threshold and pain experience accounting for the lower pain prevalence, it is more likely related to a decreased report or detection of pain.

The inability to self-report pain makes assessment of pain in NH residents with dementia and cognitive impairment difficult despite the availability of validated observational pain instruments. Evidence is emerging that assessing pain during movement can better capture pain than assessing pain only at rest. This is especially true when proxy report is necessary.[26] This emerging evidence may account for greater reports of pain by proxy, when using a body movement protocol.

Other findings for associations between resident factors and pain were mostly equivocal. The effect of resident factors on pain is complex. For example, fractures are notably a painful condition, but were associated with pain in only four of nine studies. Lack of an association between pain and painful conditions such as fracture may be related to the expectation that some conditions are painful and appropriate pain management is initiated. Moreover, residents may be more willing to report acute pain that occurs with falls or fracture if it is expected to improve over time than chronic pain with which they may feel they have to live.

Conclusion

This review highlights the complexities of pain in NH residents and has implications for both clinical practice and future research. Understanding the factors that underlie the experience of pain, such as depression, is useful for clinicians evaluating pain and tailoring pain management therapies. In addition, the gaps in knowledge uncovered in this review are important areas for future research. Further work is particularly needed to examine the sociodemographic and clinical variables with mixed or limited study.

Figure 2-1: Flow diagram of study selection

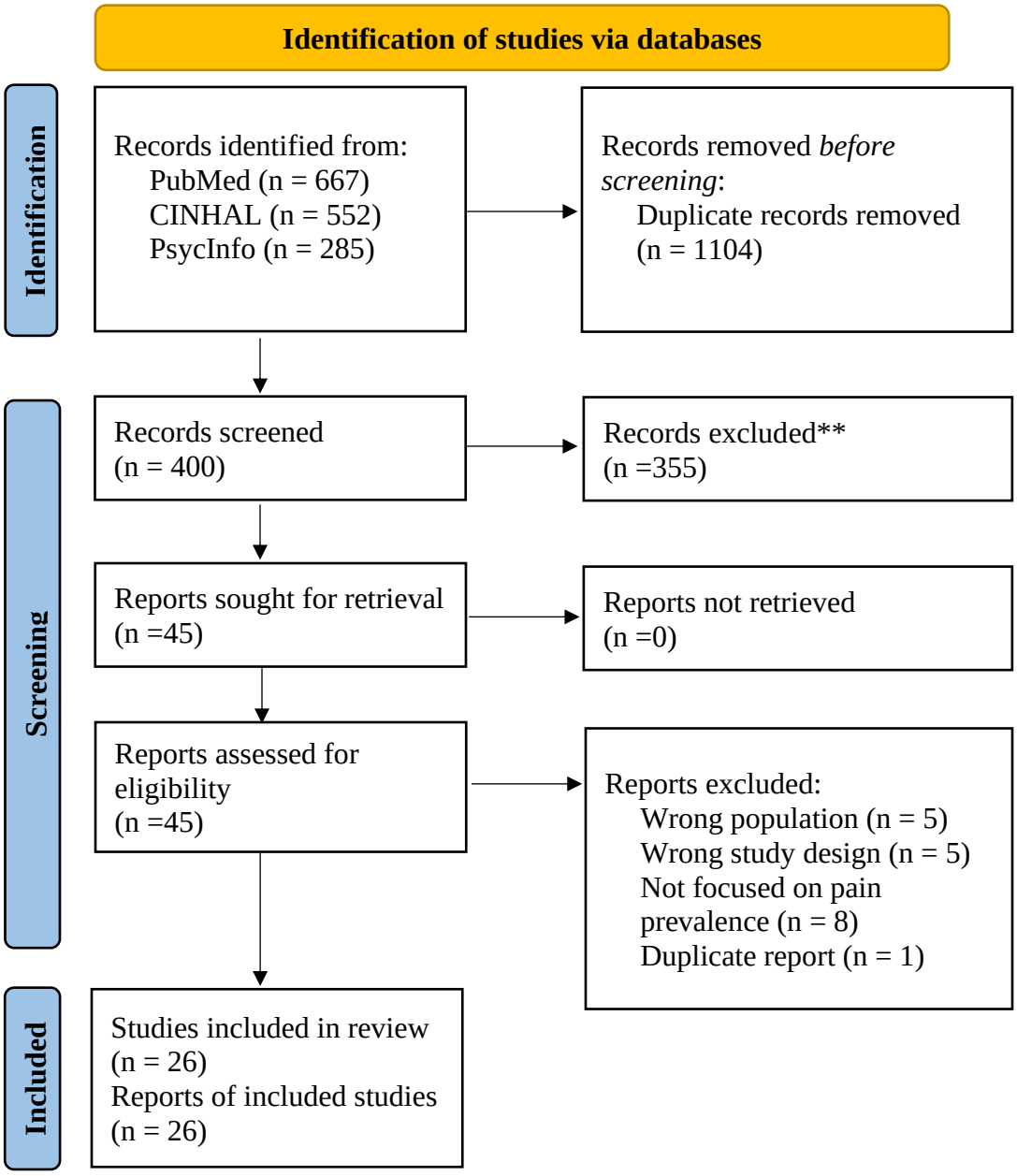


Figure 2-2: Risk of bias for prevalence studies

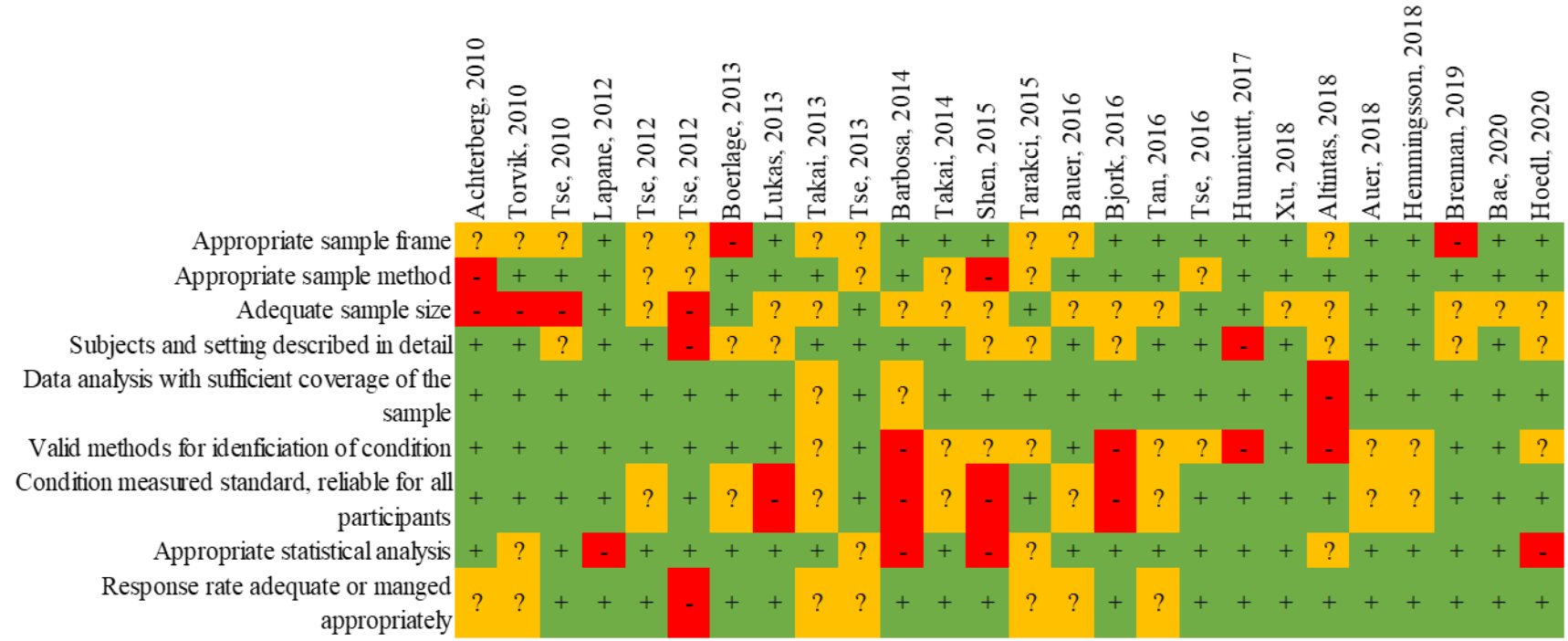


Table 2-1: Included studies

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Achterberg, 2010[7]	Finland (5761) Netherlands (2295) Italy (1959)		MDS 2.0	Did not specify	7 days	57.1 % Finland 43.0% Netherlands 32.2% Italy	Dementia diagnosis: 60.0% Finland 47.0% Netherlands 44.0% Italy
Torvik, 2010[4]	Central Norway (106)	Excluded those with MMSE <12	VRS (no pain, mild pain, moderate pain, severe pain)	Patient interview	Now	55.0% Of those in pain: 55.0% mild 29.0% moderate 16.0% severe	87.0% of sample had mild or moderate cognitive impairment 19 mean MMSE
Tse, 2010[41]	Hong Kong (365)	Excluded those with history of mental disorders or cognitive impairment	Geriatric Pain Assessment	Patient interview	3 months	68.2% 4.45 ± 2.44 mean pain score in the pain group (0-to-10-point scale)	Not specified

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Lapane, 2012[14]	United States (9952)	Excluded those with cancer diagnosis, comatose, or severe communication difficulties, minimum of 2 assessments	MDS 2.0	Chart review	7 days	25.2% persistent pain across 2 assessments	30.0% mild cognitive impairment 56.0% moderate cognitive impairment 14.0% severe cognitive impairment
Tse, 2012[11]	Hong Kong (302)	Excluded those with history of mental disorder. Included those with orientation to time and place	Geriatric Pain Assessment	Patient interview	3 months	67.9% 4.51 (SD 2.51) mean pain score in the pain group (0-to-10-point scale)	12.6% of sample had dementia diagnosis
Tse, 2012[42]	Hong Kong (239)	Excluded those with history of mental disorder or cognitive impairment	Verbal Rating Scale (11 words commonly used to describe pain)	Patient interview	6 months	78.7% 3.18 ± 1.71 mean pain score (0 to 11 scale)	Not specified

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Boerlage, 2013[3]	Netherlands (201)		NRS (n=144) VPS (n=6) REPOS (n=51)	Did not specify Data collected by MD and nurse pain specialist trained in REPOS	Current pain 2-minute observation during a potentially painful moment (transfer)	32.0% substantial pain	Not specified
Lukas, 2013[15]	Czech Republic, England, Finland, France, Germany, Netherlands, Italy, Israel (3926)	Excluded those with missing data about pain	InterRAI Instrument for Long Term Care Facilities	Patient interview Proxy Chart review	Current pain 3 days	48.4% pain in past 3 days	53.6% of sample had dementia diagnosis

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Takai, 2013[53]	Japan (171)		VDS (7-point scale) Japanese Abbey Pain Scale (APS-J) Pain measured during a movement protocol	Patient Interview (self-report n=96) Proxy (unable to self-report n=75)	Current pain	46.2% of sample 41.7% self-report group 52.0% proxy group	9.1 MMSE Sample mean 14.3 (SD 8.1) Self-report group mean MMSE 2.4 (SD 5.1) Unable to self-report group mean MMSE
Tse, 2013[5]	Hong Kong (535)	NH=10; N=535; Excluded those not oriented to time, place and person; in nursing home for <1 year, history of mental disorder or cognitive impairment	NRS (11-point scale)	Patient Interview	3 months	74.0% 45.7% constant pain	9.7% of sample had dementia diagnosis

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Barbosa, 2014[44]	Brazil (124)	Excluded those younger than 60 or unable to express self	Researcher generated survey tool	Patient interview	6 months	58.1% chronic pain – 6 months or longer	Not specified
Takai, 2014[2]	Japan (246)	Excluded temporary residents and residents with short term memory problems	VDS (7-point scale) Japanese Abbey Pain Scale (APS-J) Pain measured during a movement protocol	Patient Interview (self-report n=179) Proxy (unable to self-report n=67)	Current pain	47.2% of sample 31.8% self-report group 85.0% proxy group	10.6 ± 9.7 MMSE sample mean 59.8% of sample had dementia diagnosis

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Shen, 2015[1]	United States Pain prevalence (3828) Persistent pain prevalence, only those with pain on initial assessment (607)	Persistent pain sample included only those with pain on initial assessment	MDS 2.0	Chart review	7 days Moderate to Severe Pain at 2 assessments during the year (persistent pain)	29.3% (2006) 28.5% (2007) 24.9% (2008) 22.2% (2009) *Moderate to severe pain 67.0% persist (2006) 62.0% persist (2007) 58.5% persist (2008) 65.2% persist (2009)	Not specified

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Tarakci, 2015[6]	Turkey (186)	Required cognitive abilities sufficiently good for answering questions, in NH for at least 6 months, excluded those with pain lasting < 3 months; excluded those with MMSE of 23 or less	Pain yes/no VAS to measure degree of pain	Patient interview	3 months or longer	55.9% chronic pain 5.07 ± 1.98 pain score for those with chronic pain	Not specified

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Bauer, 2016[38]	Austria (425)	Excluded short term care, day care, mental disabilities, aphasia, acute illness & life-threatening situations	VRS PAINAD-Gm Pain measured during a movement protocol	Patient interview Proxy for all with cognitive impairment Highest score for those with both measures (CI and able to self-report)	Current pain	72.6% of sample	Not specified
Bjork, 2016[13]	Sweden (4831)	Excluded short term or temporary residents	PAINAD Swedish version	Proxy	5 minutes	47.9% of sample	66.6% of sample cognitively impaired

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Tan, 2016[39]	Australia (383)	Excluded those unable to participate in structured assessments, medically unstable or estimated to have less than 3 months to live	FACES-R PAINAD	Patient interview Proxy	1 day 5-minute observation	60.5% of FACES-R sample 29.5% of PAINAD sample	44.1% of sample with dementia diagnosis
Tse, 2016[10]	Hong Kong (178)	Excluded those that were not cognitively intact with abbreviated mental test score of 7 or less, history of mental disorder, or unable to communicate	NRS (11-point scale)	Patient interview	Not specified	54.7% 4.2 ± 2.2 mean pain score	Not provided

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Hunnicutt, 2017[8]	United States (1,387,405)	Excluded those less than 100 cumulative days in same NH, gaps in residency >30 days, without 2 assessments, without a comprehensive MDS in study period	MDS 3.0	Patient interview Proxy	5 days Pain at 2 contiguous assessments (persistent pain)	19.5% persistent pain	Not provided
Xu, 2018[50]	China (400)	Excluded those younger than 65 *only the NH sample included here	InterRAI Instrument for Long Term Care Facilities	Patient interview Proxy	5 days	51.0% of sample 49.0% no pain 28.9% mild to moderate pain 22.1% daily horrible or excruciating pain	12.2% of NH sample with dementia diagnosis

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Altintas, 2018[43]	Turkey (291)	Excluded those younger than 60, communication disability, cognitive impairment, and not dependent upon others for ADLs	Geriatric Pain Measure	Patient interview	With activities, no specific time frame	47.1% moderate to severe pain in sample Of those in pain: 52.9% mild pain; 34.0% moderate pain; 13.1% severe pain	Not provided

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Auer, 2018[40]	Austria (571) Czech Republic (514)	Excluded those with an acute serious health crisis or persons in the process of dying	VAS Pain scale (0 to 10) PAINAD (for those unable to communicate)	Patient interview Proxy	Not specified	Austria 44.8% 2.6 ± 3.1 mean VAS pain score (Austria only) Czech Republic 51.5%	58.8% Austria sample with dementia diagnosis; 85.2% with cognitive impairment; mean MMSE 14.3 ± 9.4 55.0% Czech Republic sample with dementia diagnosis; 53.0% with cognitive impairment; mean MMSE 17.7 ± 9.5

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Hemmingsson, 2018[58]	Sweden 2007: N=1814 2013: N=2119	Excluded those in hospital wards, younger than 65	Researcher generated survey tool	Proxy Staff member that knew resident best	7 days	2007: 63.4% 2013: 62.3%	2007: 71.1% of sample cognitively impaired 2013: 72.4% of sample cognitively impaired
Brennan, 2019[9]	United States (8300)	VA nursing homes	MDS 3.0	Patient interview Proxy	5 days	65.2% Of those in pain: 61.2% frequent or constant pain 35.9% severe or horrible pain	29.0% of sample with dementia diagnosis 47.3% cognitively impaired
Bae, 2020[12]	Korea (144)	Excluded those younger than 65, less than 30 days in NH	InterRAI Instrument for Long Term Care Facilities	Patient interview Proxy	5 days	36.9% 63.9% no pain 20.6% mild 12.9% moderate 2.8% horrible	60.2% of sample with dementia diagnosis

Author and Year	Location & (Sample Size)	Participants	Methodology Pain Assessment Tool	Methodology Pain Assessment Source	Methodology Pain Assessment Time Frame	Pain Prevalence	Cognitive Level of Samples
Hoedl, 2020[57]	Austria (1239)		Researcher generated survey tool	Patient interview Proxy	7 days Current pain	40.4% Of those in pain: 15.3% mild 10.9% moderate 1.8% severe 0.2% very severe	Not provided

Figure 2-3: Factors associated with pain in nursing home residents by study

	Achterberg, 2010	Torvik, 2010	Tse, 2010	Lapane, 2012	Tse, 2012	Tse, 2012	Boerlage, 2013	Lukas, 2013	Takai, 2013	Tse, 2013	Barbosa, 2014	Takai, 2014	Shen, 2015	Tarakci, 2015	Bauer, 2016	Bjork, 2016	Tan, 2016	Tse, 2016	Hunnicutt, 2017	Xu, 2018	Altintas, 2018	Auer, 2018	Hemmingsson, 2018	Brennan, 2019	Bae, 2020	Hoedl, 2020
Gender (Female)	NS	NS	+			+		+	NS	+	NS	NS		+		NS			+					+	+	
Age (Older)	NS	NS	NS			NS		NS	*	NS	+	NS	-	NS					-					-	+	
Education (Lower)		NS	+			NS				+				NS												
Race (White)																			+					+		
ADL Imapirment	+	NS						NS	+	NS	NS			+		+			+					-	+	NS
Cognition (Impaired)	-	NS							NS						+	+	+		-					-	-	
Depression	+			+	+	+		+		+		NS		+										+		
Arthritis	+	NS	+	+		NS			NS	+		NS							+							
Fracture	+	NS	NS			NS		+		NS		+	NS						+							
Diabetes	NS		NS			NS		NS		NS			+												NS	
Dementia	-		-					-		NS									-						-	
Stroke	NS	NS	NS					NS		NS															NS	
Cancer	NS							+				NS							+							
Sleep Problems				+				+		+														+		
Osteoporosis	+											NS							NS							
Parkinson's Disease	NS		NS							NS																
Falls								+													+					
Pressure Ulcer								+											+							
COPD	NS							NS																		
CHF	NS																								NS	
Anxiety	+			+																						
Contracture									+			NS														
PVD	+																									

Note: + Indicates increased pain, - indicates decreased pain, NS indicates nonsignificant association

CHAPTER THREE: PAIN AND ASSOCIATED FACTORS IN NURSING HOME RESIDENTS

Introduction

Pain prevalence in nursing home (NH) residents is high and inadequate pain management is common.[1-3] Studies have reported pain prevalence rates in NH residents between 22.0%[1] – 85.0%,[2] including up to 32.0%[3] with substantial pain, and up to 38.0%[3] with untreated pain. Pain in NH residents can lead to decreased happiness,[5, 6, 11] quality of life[5, 6] and life satisfaction.[11] Given the negative impact of pain on NH residents, it is important to effectively manage pain in this population.

Appropriate pain management begins with the identification and assessment of pain. However, NH residents frequently experience dementia (48.0%[20]) or cognitive impairment (37.0%[21]) which create challenges in accurately assessing and measuring pain. NH residents without the ability to communicate pain may have undetected, unreported, and untreated pain. For residents unable to self-report, pain is usually inferred from behaviors such as facial grimacing, guarding of a body part, or crying out, but inferring pain is challenging. Notably, there is less documentation of pain in NH residents with cognitive impairment.[63-65]

Approaches to improving identification and treatment of pain in NH residents have focused on improving staff knowledge regarding pain assessment[66-68] and pain management,[69-72] using pain medication decision support aids[69, 71, 73, 74] or clinical algorithms,[69, 70, 75, 76] and utilizing pain champions.[76, 77] Another important area for improving pain management in NH residents is proactively identifying which residents are at the highest risk of pain (risk stratification). NHs regularly use risk stratification

tools to identify residents' level of risk for conditions such as falls[78] and pressure ulcers.[79] However, no tools have been developed to identify NH residents at risk for pain. Consequently, awareness of the factors associated with pain in NH residents becomes critical and may support risk stratification.

Understanding factors associated with risk of pain allows residents and clinicians to plan care and set priorities. However, factors associated with pain in NH residents have not been conclusively studied. In four recent US based studies of pain, factors associated with greater pain reports were female gender, White race, younger age, intact cognition, depression, arthritis, and sleep problems.[1, 6, 12, 51] The relationships between pain and other resident characteristics were equivocal or findings were based on only a single study. Additionally, the association between pain and diabetes or obesity, common conditions associated with pain, has been under evaluated.[80-82] Therefore, the aim of this study was to evaluate the association between pain and resident demographic and clinical characteristics including pain management strategies.

Methods

Design

The Minimum Data set (MDS) 3.0 data used in this analysis were originally used as part of a Centers for Medicare and Medicaid Services (CMS) demonstration project, Optimizing Patient Transfers, Impacting Medical quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC). Briefly, OPTIMISTIC was designed to reduce potentially avoidable hospitalizations of long-stay nursing home residents. The details and methodologies used during the original project are described elsewhere.[83-85] We conducted a retrospective analysis of MDS 3.0 data using a sample of nursing home

residents who resided in 44 OPTIMISTIC nursing homes between September 27, 2011, to December 16, 2019. This analysis was approved as exempt by the Indiana University Institutional Review Board.

The MDS is a source of assessment information for residents in nursing homes certified to participate in the Medicare and/or Medicaid programs. Residents are assessed within 14 days of admission, annually and with a change in condition using the MDS 3.0 comprehensive item set. Residents are further assessed quarterly using the MDS 3.0 quarterly item set, which contains a subset of items. Finally, MDS 3.0 entry and discharge reporting assessments and tracking records are used to track residents and gather important quality data at transition points, such as when entering a nursing home, leaving a nursing home, or death in the facility. The cycle of assessments generally follows a comprehensive, quarterly, quarterly, quarterly, comprehensive pattern unless interrupted by a change in condition or discharge.

The MDS was originally conceived to monitor resident health and improve the care plan process through improving resident assessment.[46] The MDS 3.0 was updated in 2010 from the prior version, MDS 2.0, to include direct resident interview, including the resident's self-report of pain.[28] Moreover, this update comprised the addition of established measures with demonstrated reliability and validity such as the patient health questionnaire-9 (PHQ-9) and pain numeric rating scale (NRS).[28, 52, 86]

Sample

Data represented 56,994 nursing home residents. Residents were excluded if the data indicated they had 1) no assessment of pain within the dataset (n=37,399); 2) length of stay <100 days (n=5,986); 3) no comprehensive assessment within the dataset,

necessary because not all variables and disease conditions (comorbidities) are assessed when the quarterly item set is used (n=2,872); or 4) no subsequent MDS, necessary to measure persistent pain (n=1,677). The final analytic sample was thus 9,060 residents (Figure 3-1). The first MDS assessment for each resident was selected and identified as the index assessment. Because some residents in this analysis were already living in the NH when the data was retrieved, not all residents index assessment was an admission or comprehensive assessment.

Measurements

For residents who were able to self-report, pain was assessed with the following items. *Pain presence* was measured with the question, "Have you had pain or hurting at any time in the last 5 days?" (yes/no). Residents who responded yes were then asked about their *pain frequency*, "How much of the time have you experienced pain or hurting over the last 5 days?" Resident responses were recorded as almost constantly, frequently, occasionally, rarely, or unable to answer. *Pain intensity* was measured by asking residents to rate their pain using either a numeric rating scale ranging from 0 "no pain" to 10 "worst pain you can imagine" or a 4-item verbal descriptor scale ranging from "mild" to "very severe, horrible." Reliability and validity of the numeric rating and the verbal descriptor scales have been extensively tested in older adults.[23, 87-91]

For residents unable to complete the pain interview, a proxy assessment by trained nursing staff was conducted. Staff recorded observations corresponding to pain indicators such as non-verbal sounds, vocal complaints of pain, facial expressions (grimacing, wincing), and protective body movements (guarding) in the previous 5 days.

Staff-assessed pain was categorized as no pain, infrequent pain (1-2 days), or frequent pain (>=3 days).

Pain severity is a composite scale of pain intensity and pain frequency calculated and classified using the criteria designed to serve as the CMS quality measure addressing pain.[27] First, MDS self-report pain assessment data collected using the numeric rating scale were categorized into verbal descriptor scale equivalents using a cross walk provided by Edelen and Saliba.[92] Next, pain severity was identified and categorized using the CMS quality measure algorithm as no pain, mild/infrequent pain (mild to severe pain occurring rarely or occasionally), or moderate to severe/frequent pain (moderate to severe pain occurring frequently or almost constantly or very severe/horrible pain occurring at any frequency). For our analyses, we combined the staff-assessed pain into the self-reported pain based upon reported frequency.

Persistent pain was defined as pain of any frequency or intensity that persisted from the index assessment to the subsequent assessment.

Pain treatment was assessed with a three-question item using a 5-day look-back period for scheduled pain medication administration, as needed pain medication administration, and non-medication intervention for pain (yes/no). Pain medication was defined as a pharmacological agent used for the relief or prevention of pain. Although not evaluated in this analysis, it was possible for residents to receive combinations of these pain treatments such as receiving pain medication on a routine basis and pain medication on an as needed basis.

Cognitive function was assessed using the cognitive function scale (CFS).[93] CFS is a measure of cognition calculated from variables available in MDS 3.0 and provides a

detailed description of cognitive status. CFS was categorized as intact cognition, mildly impaired cognition, moderately impaired cognition, and severely impaired cognition.

Resident demographic and clinical characteristics including pain treatment were assessed using the index assessment.

Data Analysis

We summarized the characteristics of the study cohort, as well as prevalence of pain, mild/infrequent pain, moderate to severe/frequent pain, and persistent pain. Chi-square tests were used to compare the proportions of residents by pain severity and persistent pain among demographic and clinical covariates. Any characteristic with a p value < 0.05 were included in the logistic regression analysis. Significance for the multinomial and multivariable logistic regression analyses were set at $p < .05$. All analyses were performed using IBM SPSS Statistics for Windows version 28.

Results

Sample Characteristics

The final analytic sample was 9,060 NH residents. At the index assessment, 68.9% were female. The sample age ranges were <60 (6.6%), 60-69 (11.1%), 70-79 (22.2%), 80-89 (38.0%), and >= 90 (22.1%) Most were White (84.8%) or Black (13.8%) with few being Hispanic (0.7%) or other race/ethnicities (0.6%). Most (78.6%) lived in an urban area. Body mass index ranged from underweight (5.4%), normal (35.8%), overweight (28.7%), to obese (27.4%). Additional resident characteristics are shown in Table 3-1.

No pain vs. Mild/Infrequent Pain vs. Moderate to Severe/Frequent Pain (n=9060)

As shown in Table 3-1, of the total sample, 23.7% of residents experienced pain in the previous five days with 17.0% reporting mild/infrequent pain and 6.7% reporting moderate to severe/frequent pain. Of the residents who experienced pain at the index assessment (n=2150), 71.8% reported mild/infrequent pain and 28.2% reported moderate to severe/frequent pain.

Also shown in Table 3-1, there were significant differences among the pain severity subgroups with respect to resident demographic and clinical characteristics. In the chi-square analyses, significant positive associations with pain were female gender, age, living in a rural location, body mass index, receiving hospice care, cognitive function, and comorbidities of arthritis, fracture (other than hip), contracture, diabetes, anxiety, depression, heart failure, and PVD/PAD. Whereas residents with Alzheimer's disease or dementia and stroke were less likely to report pain. In addition, compared to those with no pain, NH residents with mild/infrequent and moderate to severe/frequent pain were significantly more likely to receive 1) pain medication on a routine basis ($p < .001$), 2) as needed pain medications ($p < .001$) and 3) non-medication interventions for pain ($p < .001$). Finally, all covariates with a p value <.05 were retrained for the regression analysis.

Table 3-2 shows the adjusted multinomial logistic regression analysis results of resident characteristics by pain severity subgroups. Relative to residents with no pain, risk factors for mild/infrequent pain were female gender (AOR 1.52, CI 1.32-1.74, p<.001), living in a rural setting (AOR 1.51, CI 1.32-1.74, p<.001), receiving hospice care (AOR 1.74, CI 1.28-2.36, p<.001), having intact (AOR 3.47, CI 2.36-5.09, p<.001),

mildly impaired (AOR 2.30, CI 1.57-3.38, p<.001) or moderately impaired cognition (AOR 1.58, CI 1.08-2.31, p=.018), and comorbidities of arthritis (AOR 1.16, CI 1.03-1.31, p=.018), fracture (other than hip) (AOR 1.30, CI 1.04-1.62, p=.020), contracture (AOR 1.23, CI 1.07-1.41, p=.004), anxiety (AOR 1.15, CI 1.01-1.30, p=.030), and depression (AOR 1.40, CI 1.23-1.61, p<.001). Relative to residents with no pain, residents with normal weight (AOR 0.85, CI 0.73-0.99, p=.047) and Alzheimer's disease or dementia (AOR 0.60, CI 0.52-0.69, p<.001) were less likely to report mild/infrequent pain.

Also shown in Table 3-2, relative to no pain, moderate to severe/frequent pain was positively associated with female gender (AOR 1.48, 1.20-1.83, p<.001), living in a rural setting (AOR 1.89, CI 1.55-2.31, p<.001), receiving hospice care (AOR 2.97, 1.99-4.41, p<.001), having intact (AOR 7.29, CI 3.33-15.97, p<.001), mildly impaired (AOR 3.77, CI 1.72-8.30, p<.001) or moderately impaired cognition (AOR 2.47, CI 1.13-5.40, p=.024). With respect to clinical comorbidities, moderate to severe/frequent pain was positively associated with arthritis (AOR 1.52, CI 1.27-1.83, p<.001), contracture (AOR 1.86, CI 1.53-2.26, p<.01), anxiety (AOR 1.41, CI 1.17-1.70. p<.001), depression (AOR 1.63, CI 1.31-2.03, p<.01) and heart failure (AOR 1.29, 1.07-1.56, p=.007). In contrast stroke (AOR 0.71, CI 0.56-0.90, p=.005) and diagnosis of Alzheimer's disease or dementia (AOR 0.54, CI 0.43-0.66, p<.001) were negatively associated with moderate to severe/frequent pain.

Non-Persistent vs. Persistent Pain (n=2150)

As shown in Table 3-3, of the residents who experienced pain at the index assessment (n=2150), 45.4% had pain that did not persist and 54.6% reported persistent

pain. There were several differences in the presence of persistent pain by resident age (p<.001), race (p=.026), location (p=.011), body mass index (p<.001), cognitive function (p<.001), and comorbid conditions. Residents <60 years old were more likely to be in the persistent pain group (11.5%) than the no persistent pain group (6.3%) while ≥90 years old were less likely to be in the persistent pain group (15.8%) than the no persistent pain group (22.7%). Blacks were more likely to be in the persistent pain group (14.9%) than the no persistent pain group (10.7%) while Whites were less likely to be in the persistent pain group (84.0%) than the no persistent pain group (88.5%). Residents with obesity were more likely to be in the persistent pain group (40.9%) than the no persistent pain group (31.1%) while residents with normal body mass index were less likely to be in the persistent pain group (26.3%) than the no persistent pain group (34.4%). Residents with a diagnosis of Alzheimer's disease or dementia were less likely to be in the persistent pain group (47.9%) than the no persistent pain group (62.3%). In addition, significantly more residents with persistent pain than non-persistent pain received 1) pain medication on a routine basis (67.8% vs 59.6%, p < .001), 2) as needed pain medications (73.4% vs. 56.6%, p < .001) and 3) non-medication interventions for pain (39.5% vs 31.0%, p < .001). Finally, all covariates with a p value <.05 were retained for the multivariate logistic regression.

Table 3-4 shows the results of the adjusted multivariate logistic regression analysis of resident characteristics by persistent pain. Relative to no persistent pain, factors positively associated with persistent pain were age <60 (AOR 1.89, CI 1.25-2.85, p=.002), age 60-69 (AOR 1.67, 1.17-2.37, p=.004), Black race (AOR 1.47, CI 1.10-1.96, p=.009), living in a rural setting (AOR 1.60, CI 1.29-1.98, p<.001) intact cognition (AOR

2.64, CI 1.29-5.43, p=.008), contracture (AOR 1.27, CI 1.03-1.55, p=.025) and depression (AOR 1.44, CI 1.16-1.79. p<.001). There were no factors that were negatively associated with persistent pain.

Discussion

It is important to identify factors that increase the likelihood of NH residents experiencing pain to enhance the ability to anticipate, identify, and treat pain. In this study, the overall pain prevalence among NH residents was 23.7%. Of those with pain, 28.0% experienced moderate to severe/frequent pain and 54.6% experienced persistent pain.

Overall, factors that were associated with mild/infrequent pain include female gender, living in a rural setting, receiving hospice care, intact, mildly impaired, and moderately impaired cognition, arthritis, fracture (other than hip), contracture, anxiety, and depression. In contrast Alzheimer's disease or dementia was negatively associated with mild/infrequent pain. Factors that were associated with moderate to severe/frequent pain include female gender, living in a rural setting, hospice care, intact, mildly impaired, and moderately impaired cognition, and the comorbidities of arthritis, contracture, Alzheimer's disease or dementia, anxiety, depression, and congestive heart failure. Factors that were associated with persistent pain include age <70, Black race, living in a rural location, intact cognitive function, contracture, and depression.

These findings are important because they provide clinically relevant evidence that can improve recognition of risk factors associated with pain severity and pain persistence in nursing home residents. This is particularly important for the subset of nursing home residents with impaired cognition, limiting their ability to report pain.

Notably we present three main findings which may have implications for the way that pain is identified, assessed, and managed among NH residents: 1) prevalent comorbidities in NH residents associated with pain, 2) racial and rural disparities in pain, and 3) sub-optimal pain management practices.

For comorbidities, residents with depression were more likely to have moderate to severe/frequent pain and persistent pain. Depression in older adults is common with prevalence rates among NH residents ranging from 42.6% of short-stay residents to 53.0% of long-stay residents.[20] Pain is known to exacerbate depression but the mechanistic link between pain and depression remains elusive. Possible mechanisms include that depression may reduce the pain threshold and sensitize pain perception, or that chronic pain can lead to an altered emotional state, including depression.[60] Regardless of the mechanism, tricyclic and selective serotonin-norepinephrine reuptake inhibitor (SNRI) antidepressants are effective in treating widespread musculoskeletal and neuropathic pain and are commonly prescribed.[61, 62] Use of antidepressant (psychoactive) medications in the NH can be limited by survey guidance and NH regulations including the need to receive gradual dose reductions.[29] Finally, the therapeutic benefit of antidepressant medications for pain management should be weighed carefully against potential adverse effects.

In addition, we hypothesized an association among pain and obesity and diabetes. Our findings indicate a high prevalence of moderate to severe/frequent pain and persistent pain among residents with these comorbidities. Although statistically significant in the chi-square analysis, neither diabetes nor obesity were significant in the regression model. These findings are important due to the increasing prevalence of

obesity[94] and diabetes[20] within the nursing home setting and the risk for diabetic neuropathy or weight related joint arthropathies.[80-82] The association between obesity and diabetes is complex and may confound the relationship with pain, more research in this area is needed.

Consistent with prior studies, we identified an inverse relationship between cognitive impairment and pain.[12, 13, 51] This finding likely represents both the under assessment and under reporting of pain among cognitively impaired nursing home residents. Pain assessment for residents unable to self-report pain, relies on the ability of staff to infer pain from behaviors such as grimacing, yelling out, or guarding a body part, but inferring pain is difficult. To improve quality of life and pain management for residents with cognitive impairment a change in pain assessment such as the movement-based pain assessment in older adults may be necessary.[24] Future directions in this area are exciting, but research is needed to support practice changes.

Racial disparities including less opioid prescribing,[95, 96] lower hospice utilization,[97] and poor-quality end-of-life care[98, 99] have been well documented in Black Americans.[100] Consistent with this growing body of research, we identified racial disparities among NH residents with pain. Findings from our study indicate that Blacks were 1.5 times more likely to report persistent pain than Whites. In recent years there has been an expansion of interest in exploring disparities in pain assessment and treatment in the general population and our findings suggest additional work is needed to eliminate disparities in the NH setting.

Americans living in a rural setting experience unique health disparity with higher incidence of disability, increased mortality, lower life expectancy, and higher prevalence

of pain.[101, 102] In this analysis we found that living in a rural location was a significant predictor of moderate to severe/frequent pain and persistent pain. Reasons for this may be due to decreased resources available outside of large urban centers to identify and treat pain. Most pain specialty practices, and palliative care practices are located within an urban setting, necessitating great effort involved in obtaining a specialty consultation to reduce pain in those living in rural settings in Indiana.[103-105]Alternatively, it has been reported that rural residents are more likely to have pain and not request pain medication.[106] This provides an important area for future research.

Sub-optimal pain management is another important area for future focus. Clinical practice guidelines recommend the use of a multifaceted approach to treating pain including both pharmacological and nonpharmacological treatment for individuals with chronic pain.[61, 62, 107] In the present study, most residents with moderate to severe/frequent pain (74.0%) or persistent pain (67.8%) received scheduled pain medication or as needed pain medication (70.5%, 73.4% respectively). However, nonpharmacological treatment for pain was limited to 35.6% of residents with moderate to severe/frequent pain and 39.5% of residents with persistent pain. It is unclear if this indicates NH residents' preference, lack of availability, or lack of staff knowledge of nonpharmacological measures for pain management. Deeper examination of this issue is needed.

Finally, 42.9% of residents in the no pain group received routine pain medication. It is unclear from our study whether this reflects effective pain management, under-reporting of pain, or over-prescribing of analgesics. CMS removed the quality measure for pain in October 2019 to avoid potential conflict where performance on pain quality

measures could inappropriately contribute to opioid use.[108] This is an important area for future research because nursing home residents are susceptible to polypharmacy and analgesic-related side effects.

Strengths and Limitations

Despite the significance of this analysis, some limitations should be taken into consideration when interpreting the results. First, the lower pain prevalence in our sample compared to previous reports[1, 6, 12] may be in part because our sample included only long-stay residents with a length of stay greater than 100 days. Short stay residents (≤ 100 days) are more likely to be admitted following hospitalization for rehabilitation and complex nursing services and medical care for a limited time before returning to the community.[109] Thus, short stay residents tend to be sicker and still recovering from acute illness for which they were initially hospitalized.[110] Long stay residents by contrast tend to have increased prevalence of cognitive impairment[20, 21] which has been associated with a decreased reporting of pain.[12, 13, 51] Furthermore, the cross-sectional study design means it is not possible to make causal inferences about the data. Finally, the use of a sample of nursing home residents that were part of a clinical demonstration project providing enhanced geriatric care, potentially limit the generalizability of these findings. Despite these limitations, this analysis has several strengths. First our analysis included a large and diverse sample. In addition, our use of comprehensive standardized measures (MDS) facilitates comparison with other clinical studies conducted in the NH setting. Finally, we included NH residents with various levels of cognition. Many times, NH residents with cognitive impairment are excluded from studies due to difficulties in assessing their pain

and obtaining informed consent. Use of previously collected MDS data allowed us to overcome this issue.

Conclusion

Pain remains a pressing problem for NH residents. In this study we identified the demographic and clinical characteristics associated with pain including depression and cognitive impairment. Furthermore, we identified racial disparities and sub-optimal pain management practices as important areas for future focus. Knowledge of factors associated with greater pain for NH residents has the potential for improving the ability to predict, prevent and provide better pain assessment thereby leading to improved pain management in NH residents.

Figure 3-1: Cohort creation flow diagram

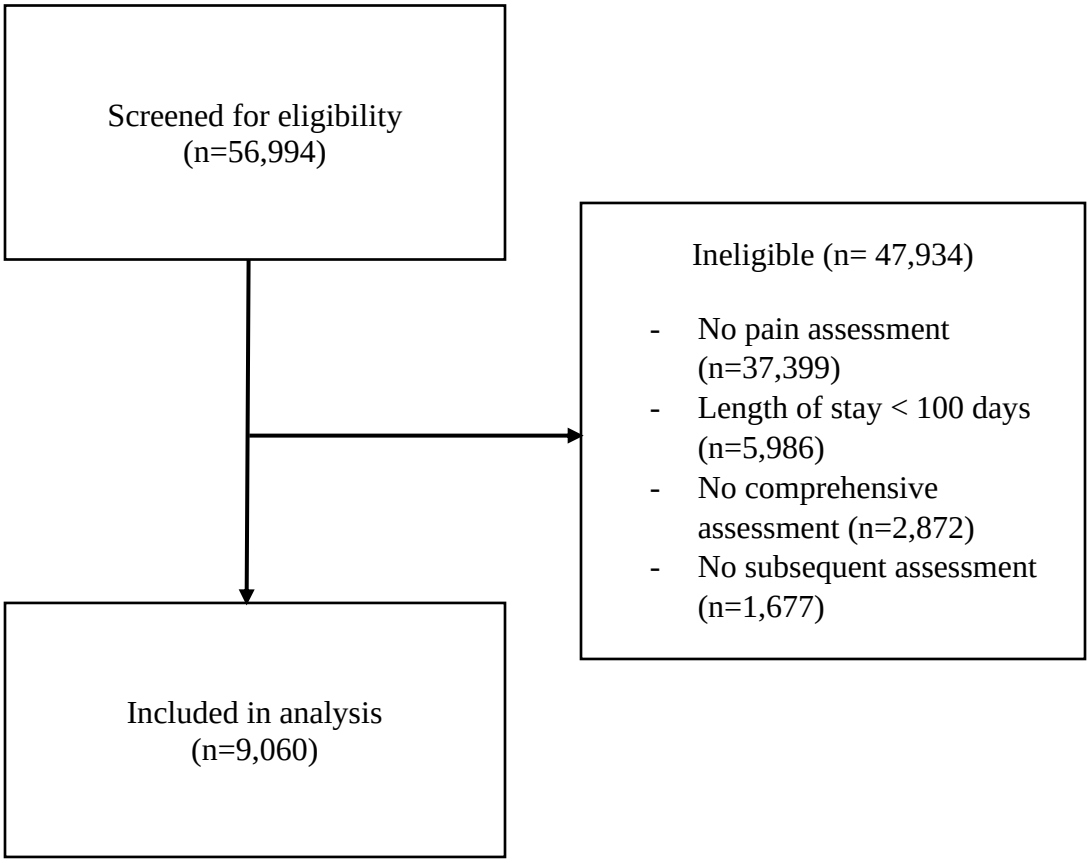


Table 3-1: Frequencies of individual-level characteristics and comparisons across pain groups

	Total Cohort % (n)	No pain % (n)	Mild/Infrequent Pain % (n)	Mod/Severe Frequent Pain % (n)	p Value -
Total	N=9060	76.3% (n=6910)	17.0% (n=1543)	6.7% (n=607)	
Gender					
Female	68.9% (6245)	67.4% (4658)	73.9% (1140)	73.6% (447)	p<.001
Age (years)					
<60	6.6% (602)	5.9% (406)	8.6% (132)	10.5% (64)	p<.001
60-69	11.1% (1006)	10.3% (710)	13.5% (209)	14.3% (87)	
70-79	22.2% (2009)	22.0% (1521)	22.2% (343)	23.9% (145)	
80-89	38.0% (3440)	38.8% (2678)	35.8% (553)	34.4% (209)	
90+	22.1% (2003)	23.1% (1595)	19.8% (306)	16.8% (102)	
Race					
White	84.8% (7640)	83.9% (5798)	84.8% (1308)	88.0% (534)	p=.087
Black	13.8% (1254)	14.1% (976)	13.8% (213)	10.7% (65)	
Hispanic	0.7% (60)	0.7% (50)	0.6% (9)	0.2% (1)	
Other	0.6% (51)	0.6% (41)	0.3% (5)	0.8% (5)	
Location					
Rural	21.4% (1937)	19.4% (1342)	26.7% (412)	30.1% (183)	p<.001
Medicaid Status					
Medicaid	74.1% (6369)	73.5% (4818)	75.6% (1094)	77.9% (457)	p=.100
Body mass index (BMI)					
Underweight	5.4% (490)	5.6% (386)	5.1% (79)	4.1% (25)	p<.001
Normal Weight	35.8% (3239)	37.8% (2611)	30.5% (470)	26.0% (158)	
Overweight	28.7% (2596)	28.9% (1996)	28.8% (445)	25.5% (155)	

	Total Cohort % (n)	No pain % (n)	Mild/Infrequent Pain % (n)	Mod/Severe Frequent Pain % (n)	p Value -
Obese	27.4% (2478)	24.8% (1714)	33.6% (518)	40.5% (246)	
Hospice Care	3.8% (339)	3.4% (237)	4.2% (64)	6.3% (38)	p=.001
Life expectancy <6 months	2.8% (257)	2.7% (187)	2.9% (45)	4.1% (25)	p=.130
Mental and physical function					
Cognitive Function Scale (CFS)					
Intact Cognition	31.4% (2817)	25.8% (1763)	46.5% (711)	56.7% (343)	p<.001
Mildly Impaired	25.0% (2238)	25.3% (1726)	25.0% (382)	21.5% (130)	
Moderately Impaired	38.6% (3460)	43.0% (2938)	26.0% (398)	20.5% (124)	
Severely Impaired	5.0% (452)	5.9% (406)	2.5% (38)	1.3% (8)	
Activities of Daily Living (ADL)					
No impairment	1.9% (175)	1.9% (128)	2.2% (34)	2.2% (13)	p=.083
Moderate impairment	93.3% (8389)	93.1% (6378)	93.8% (1440)	94.9% (571)	
Severe impairment	4.8% (428)	5.1% (348)	4.0% (62)	3.0% (18)	
Comorbid conditions associated with pain					
Arthritis	35.4% (3203)	33.6% (2322)	39.0% (601)	46.1% (280)	p<.001
Osteoporosis	20.1% (1820)	19.7% (1363)	21.1% (326)	21.6% (131)	p=.294
Hip fracture	3.8% (340)	3.5% (245)	4.3% (67)	4.6% (28)	p=.170
Fracture (other than hip)	6.4% (583)	5.9% (410)	8.4% (130)	7.1% (43)	p=.001
Contracture	24.4% (2192)	22.6% (1543)	27.9% (426)	37.1% (223)	p<.001
Diabetes	36.1% (3271)	34.4% (2374)	40.1% (619)	45.8% (278)	p<.001
Alzheimer's/Dementia	70.7% (6403)	75.7% (5233)	56.9% (878)	48.1% (292)	p<.001
Stroke	18.7% (1695)	19.4% (1342)	16.5% (254)	16.3% (99)	p=.008
Anxiety	39.9% (3613)	38.0% (2627)	44.2% (682)	50.1% (304)	p<.001

	Total Cohort % (n)	No pain % (n)	Mild/Infrequent Pain % (n)	Mod/Severe Frequent Pain % (n)	p Value -
Depression	67.3% (6100)	65.2% (4505)	72.9% (1125)	77.4% (470)	p<.001
Heart Failure	32.1% (2910)	30.2% (2085)	37.0% (571)	41.8% (254)	p<.001
PVD/PAD	13.6% (1234)	12.9% (894)	15.0% (232)	17.8% (108)	p<.001
Cancer	6.9% (622)	6.6% (454)	8.1% (125)	7.1% (43)	p=.097
Pain Treatment					
Scheduled Pain med in last 5 days	47.9% (4343)	42.9% (2965)	60.2% (929)	74.0% (449)	p<.001
As needed Pain med in last 5 days	24.8% (2242)	12.0% (831)	63.9% (984)	70.5% (427)	p<.001
Nonmedication intervention for pain in last 5 days	18.8% (1677)	13.6% (926)	35.7% (540)	35.6% (211)	p<.001

Table 3-2: Demographic and clinical correlates of mild/infrequent pain and moderate to severe/frequent pain compared to no pain, in a multinomial logistic regression model

	Mild/infrequent pain			**Moderate to severe frequent pain**		
	AOR$^{\Phi}$	95% CI	P Value	AOR$^{\Phi}$	95% CI	P Value
Gender						
Female	1.52	1.32-1.74	p<.001	1.48	1.20-1.83	p<.001
Age (years)						
<60	1.24	0.95-1.63	p=.115	1.48	0.99-2.21	p=.051
60-69	1.16	0.92-1.46	p=.213	1.22	0.86-1.75	p=.262
70-79	1.05	0.87-1.27	p=.602	1.17	0.86-1.58	p=.316
80-89	1.06	0.89-1.25	p=.509	1.19	0.91-1.57	p=.195
90+*	-	-	-	-	-	-
Location						
Rural	1.51	1.32-1.74	p<.001	1.88	1.55-2.31	p<.001
Body mass index (BMI)						
Underweight	0.97	0.72-1.27	p=.757	0.80	0.50-1.24	p=.309
Normal Weight	0.85	0.73-0.99	p=.047	0.73	0.58-0.92	p=0.10
Overweight	0.99	0.86-1.17	p=.979	0.83	0.66-1.06	p=.124
Obese*	-	-	-	-	-	-
Hospice Care	1.74	1.28-2.36	p<.001	2.97	1.99-4.41	p<.001
Cognitive Function Scale						
Intact Cognition	3.47	2.36-5.09	p<.001	7.29	3.33-15.97	p<.001
Mildly Impaired	2.30	1.57-3.38	p<.001	3.77	1.72-8.29	p<.001
Moderately Impaired	1.58	1.08-2.31	p=.018	2.47	1.13-5.40	p=.024
Severely Impaired*	-	-	-	-	-	-

	Mild/infrequent pain			Moderate to severe frequent pain		
Comorbid conditions associated with pain						
Arthritis	1.16	1.03-1.31	p=.018	1.52	1.27-1.82	p<.001
Fracture (other than hip)	1.30	1.04-1.62	p=.020	1.48	0.74-1.48	p=.792
Contracture	1.23	1.07-1.41	p=.004	1.86	1.53-2.26	p<.001
Diabetes	1.09	0.96-1.24	p=.204	1.21	0.99-1.46	p=.055
Alzheimer's/Dementia	0.59	0.52-0.69	p<.001	0.54	0.43-0.66	p<.001
Stroke	0.73	0.62-0.86	p=.728	0.71	0.56-0.90	p=.005
Anxiety disorder	1.15	1.01-1.29	p=.030	1.41	1.17-1.70	p<.001
Depression	1.40	1.23-1.61	p<.001	1.63	1.31-2.03	p<.001
Heart Failure	1.13	0.99-1.29	p=.052	1.29	1.07-1.56	p=.007
PVD/PAD	1.11	0.93-1.31	p=.243	1.19	0.93-1.51	p=.162

Overall referent is no pain group. $^{\Phi}$adjusted for all factors in the table. *denotes referent for that characteristic.

Table 3-3: Frequencies of individual-level characteristics for residents with pain as well as crosstabs comparisons for those experiencing persistent pain

	Total Cohort % (n)	Pain did not persist % (n)	Persistent Pain % (n)	p Value -
Total	N=2150	45.4% (976)	54.6% (1174)	
Gender				
Female	73.8% (1587)	72.5% (708)	74.9% (879)	p=.221
Age (years)				
<60	9.1% (196)	6.3% (61)	11.5% (135)	p<.001
60-69	13.8% (296)	10.5% (102)	16.5% (194)	
70-79	22.7% (488)	22.0% (215)	23.3% (273)	
80-89	35.4% (762)	38.5% (376)	32.9% (386)	
90+	19.0% (408)	22.7% (222)	15.8% (186)	
Race				
White	86.1% (1842)	88.5% (585)	84.0% (984)	p=.026
Black	13.0% (278)	10.7% (104)	14.9% (174)	
Hispanic	0.5% (10)	0.3% (3)	0.6% (7)	
Other	0.5% (10)	0.4% (4)	0.5% (6)	
Location				
Rural	27.7% (595)	25.0% (244)	29.9% (351)	p=.011
Medicaid Status				
Medicaid	72.1% (1551)	70.3% (686)	73.7% (865)	p=.081
Body mass index (BMI)				
Underweight	5.0% (104)	5.5% (52)	4.5% (52)	p<.001
Normal Weight	30.0% (628)	34.4% (327)	26.3% (301)	

	Total Cohort % (n)	Pain did not persist % (n)	Persistent Pain % (n)	p Value -
Overweight	28.6% (600)	29.0% (276)	28.3% (324)	
Obese	36.5% (764)	31.1% (296)	40.9% (468)	
Hospice Care	4.8% (102)	4.6% (45)	4.9% (57)	p=.793
Life expectancy <6 months	3.3% (70)	3.4% (33)	3.2% (37)	p=.765
Mental and physical function				
Cognitive Function Scale (CFS)				
Intact Cognition	49.4% (1054)	39.8% (385)	57.4% (669)	p<.001
Mildly Impaired	24.0% (512)	25.0% (242)	23.2% (270)	
Moderately Impaired	24.5% (522)	32.2% (312)	18.0% (210)	
Severely Impaired	2.2% (46)	3.0% (29)	1.5% (17)	
Activities of Daily Living (ADL)				
No impairment	2.2% (47)	1.6% (15)	2.7% (32)	p=.040
Moderate impairment	94.1% (2011)	93.9% (907)	94.2% (1104)	
Severe impairment	3.7% (80)	4.6% (44)	3.1% (36)	
Comorbid conditions associated with pain				
Arthritis	41.0% (881)	40.4% (394)	41.5% (487)	p=.601
Osteoporosis	21.3% (457)	24.1% (235)	18.9% (222)	p=.004
Hip fracture	4.4% (95)	5.3% (52)	3.7% (43)	p=.061
Fracture (other than hip)	8.0% (173)	8.4% (82)	7.8% (91)	p=.581
Contracture	30.5% (649)	26.9% (260)	33.4% (389)	p<.001
Diabetes	41.7% (897)	36.8% (359)	45.8% (538)	p<.001
Alzheimer's/Dementia	54.4% (1170)	62.3% (608)	47.9% (562)	p<.001
Stroke	16.4% (353)	15.5% (151)	17.2% (202)	p=.280

	Total Cohort % (n)	Pain did not persist % (n)	Persistent Pain % (n)	p Value -
Anxiety	45.9% (986)	44.0% (429)	47.4% (557)	p=.106
Depression	74.2% (1595)	70.3% (686)	77.4% (909)	p<.001
Heart Failure	38.4% (825)	35.8% (349)	40.5% (476)	p=.023
PVD/PAD	15.8% (340)	15.6% (152)	16.0% (188)	p=.781
Cancer	7.8% (168)	8.4% (82)	7.3% (86)	p=.355
Pain Treatment				
Scheduled Pain med in last 5 days	64.1% (1378)	59.6% (582)	67.8% (796)	p<.001
As needed Pain med in last 5 days	65.8% (1411)	56.6% (551)	73.4% (860)	p<.001
Nonmedication intervention for pain in last 5 days	35.7% (751)	31.0% (296)	39.5% (455)	p<.001

Table 3-4: Demographic and clinical correlates of persistent pain compared to no persistent pain in a multivariable logistic regression model

	Persistent pain		
	AOR$^{\Phi}$	95% CI	P Value
Age (years)			
<60	1.89	1.25-2.85	p=.002
60-69	1.67	1.17-2.37	p=.004
70-79	1.19	0.88-1.59	p=.258
80-89	1.19	0.91-1.55	p=.198
90+*	-	-	-
Race			
White*	-	-	-
Black	1.47	1.09-1.96	p=.009
Hispanic	2.64	0.62-11.26	p=.189
Other	1.42	0.37-5.37	p=.610
Location			
Rural	1.59	1.29-1.98	p<.001
Body mass index (BMI)			
Underweight	0.90	0.58-1.41	p=.658
Normal Weight	0.87	0.68-1.11	p=.254
Overweight	1.04	0.82-1.32	p=.729
Obese*	-	-	-
Mental and physical function			
Cognitive Function Scale (CFS)			
Intact Cognition	2.64	1.29-5.43	p=.008

	Persistent pain		
	AOR[Φ]	95% CI	P Value
Mildly Impaired	1.88	0.92-3.85	p=.514
Moderately Impaired	1.27	0.62-2.59	p=.514
Severely Impaired*	-	-	-
Activities of Daily Living (ADL)			
No Impairment*	-	-	-
Moderate Impairment	0.69	0.36-1.32	p=.261
Severe Impairment	0.63	0.27-1.44	p=.272
Comorbid conditions associated with pain			
Osteoporosis	0.83	0.66-1.04	p=.101
Contracture	1.27	1.03-1.55	p=.025
Diabetes	1.13	0.93-1.38	p=.215
Alzheimer's/Dementia	0.85	0.69-1.05	p=.149
Depression	1.44	1.16-1.79	p<.001
Heart Failure	1.09	0.89-1.32	p=.384

Note: Overall referent is no persistent pain group. [Φ]adjusted for all factors in the table.
*denotes referent for that characteristic.

CHAPTER FOUR: GROUP BASED TRAJECTORY MODELING OF NURSING HOME RESIDENT PAIN SCORES

Introduction

Pain in nursing home (NH) residents is common and negatively impacts outcomes. Up to 80.0% of older adults living in a NH experience pain[4, 33, 111, 112] and up to 32.0% have substantial pain.[3] Pain in NH residents is associated with poor quality of life and higher likelihood of depression,[5, 8, 9, 12, 51] decreased happiness,[5, 10, 11] decreased life satisfaction,[11] greater ADL dependency,[8, 9, 12-14] and more sleep problems.[5, 6, 49, 51]

Approaches to improving recognition of pain in NH residents have aimed to identify factors associated with pain in NH residents,[6, 12, 51] develop improved pain assessment tools[25, 66, 67, 113, 114] and improve staff pain assessment knowledge.[68, 71, 72] Although many researchers are working to ameliorate pain in NH residents, most have done so using a cross sectional approach. The use of a cross sectional design fails to consider how the course or trajectory of pain changes over time. Understanding the trajectory of pain experience may provide opportunities to alter the course of illness, prevent adverse outcomes, and provide supportive therapies to improve quality of life.

Trajectories of pain in NH residents have not been well-described or characterized. Using five measurement points within a 14-day period, Landmark et al, identified and characterized four distinct pain trajectories in a sample of 201 Norwegian NH residents.[16] Pain trajectories based upon frequency and intensity included low or no pain (38.0%), persistent moderate pain (36.0%), persistent intense pain (11.0%), and fluctuant pain (14.0%).[16] The trajectory beyond 14 days is unknown. In another study of 962 NH residents in Western Canada, Thompson et al identified pain trajectories during

the 6 months before death.[17] Pain trajectories were stratified by severe cognitive impairment but the general trend in pain trajectories were similar across cognitive groups. Pain trajectories were generally described (consistent low or mild pain [60.1%]; substantially high or increasing pain [34%]) but not characterized.[17] It is unknown whether resident sociodemographic and clinical characteristics were associated with these different trajectory patterns. In addition, the identified trajectories were not generalizable to residents not in the final 6 months of life.

In addition, the impact of pain trajectories on mortality has not been described for a general sample of NH residents. Using two longitudinal population cohorts of adults ages 50 and older living in private households, Smith et al, identified that individuals who were "often troubled with pain" or reported pain interference with normal work activities (including both work outside the home and housework) were at increased risk of mortality.[115] It is unclear if this association is applicable to older adults living in nursing homes.

Understanding how NH resident pain changes over time will provide a more informed perspective, allowing opportunities to alter the course of illness, plan care and set priorities, prevent adverse outcomes, and provide supportive therapies to improve quality of life. Therefore, the purpose of this analysis was to characterize clinically meaningful, dynamic pain trajectories in NH residents. The main goals were to 1) define pain trajectories based on the presence of pain using group-based trajectory modeling, 2) identify demographic and clinical correlates, and 3) examine associations between trajectories and mortality.

Methods

Design

The MDS 3.0 data used in this analysis were originally used as part of a CMS demonstration project, Optimizing Patient Transfers, Impacting Medical quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC). Briefly, OPTIMISTIC was designed to reduce potentially avoidable hospitalizations of long-stay nursing home residents. The details and methodologies used during the original project are described elsewhere.[83-85] We conducted a longitudinal analysis of MDS 3.0 data using a sample of nursing home residents who resided in 44 OPTIMISTIC nursing homes between September 27, 2011, to December 16, 2019. This analysis was approved as exempt by the Indiana University Institutional Review Board.

The MDS is a source of assessment information for residents in NHs certified to participate in the Medicare and/or Medicaid programs. Comprehensive MDS assessments are completed upon admission, annually, and with any significant change in condition. A subset of questions is administered quarterly. Originally conceived to monitor resident health and improve the care plan process through improving resident assessment,[46] the MDS is a rich source of standardized clinical data obtained from nearly every NH resident in the United States. The MDS 3.0 was updated in 2010 from the prior MDS 2.0 version to include direct resident interview, including residents' *self-report* of their pain.[28]

Sample

OPTIMISTIC data administrators provided a de-identified dataset of 56,994 NH residents who were admitted to and living in one of 44 Indiana nursing facilities during

the study period. Residents who had an admission MDS assessment (completed within 14 days of NH admission) within the dataset were selected for this analysis (n=23,167). Residents were excluded from this analysis if data indicated they had 1) length of stay <100 days (n=13,622); or 2) less than three pain observation time points (n=4,681).

Measurements

The MDS data contains assessment of *pain presence* measured over the previous 5 days with the question, "Have you had pain or hurting at any time in the last 5 days?" (yes/no). For residents unable to complete the interview for pain, such as those with severe dementia, standard procedure was to use a proxy assessment. This included observations corresponding to pain indicators such as non-verbal sounds, vocal complaints of pain, facial expressions (grimacing, wincing) and protective body movements (guarding) in the previous 5 days. We have included all available pain presence measurement scores from the time of admission to discharge, or a maximum of 28 assessment time periods.

Cognitive function is assessed using the cognitive function scale (CFS).[93] CFS is a measure of cognition calculated from variables available in MDS 3.0 and provides a detailed description of cognitive status. CFS is categorized as intact cognition, mildly impaired cognition, moderately impaired cognition, and severely impaired cognition, using information extracted from MDS assessments.

Demographic variables and clinical comorbidities were assessed using the admission assessment. These defined variables were selected for inclusion in this analysis based on published studies that showed evidence of associations between these variables and pain in nursing home residents.

Mortality during the study time frame was collected from the last MDS in the analysis time period for each individual resident. Mortality was defined as death from any cause and recorded as a binary variable (yes/no).

Data Analysis

We conducted descriptive analyses to describe the characteristics of the study cohort. Pain trajectories were identified using group-based trajectory modeling (GBTT), a flexible and easily applied method for identifying subgroups within a population that follow distinctive trajectories.[116] GBTT allows for the estimate of several homogeneous trajectories instead of a single population mean as in traditional regression.[116-119] Length of stay for each assessment was used as a measure of time due to the de-identified nature of this dataset. Residents who experienced study attrition (defined as either death or discharge during the study population) were included in the GBTT analysis using an enhanced version of the methodology that jointly estimates the outcome of interest, pain, and the probability of dropping out of observation due to mortality.[120] To avoid obscuring the analysis based on a small set of surviving residents, we restricted the maximum observations per resident to 28, reducing the influence of outlying observations. The maximum likelihood method was used to fit a semiparametric or discrete-mixture model to the longitudinal data. Analyses were conducted using *traj*[119] in Stata 17.

Trajectories were modeled as a binary distribution using pain presence (yes/no). The optimal number of trajectories (one to six) and shape (constant, linear, quadratic, cubic, or quartic terms) were selected using the Bayesian information criterion (BIC). The model with the highest BIC (least negative) that also demonstrated a BIC change of

≥ 10 was selected. For each trajectory, the shapes were varied until the best-fitting model was identified using the maximum BIC. The fit was confirmed by evaluating the average of the posterior probability of trajectory assignment (with <0.70 considered a poor fit[116]) and odds of correct classification (≥5.0[116]). The model with the highest average posterior probability was selected.

To characterize trajectories, we assessed associations between trajectories and cognitive function, demographic, clinical comorbidities, and mortality using chi-square tests. Any characteristic with a p value < 0.05 were included in the logistic regression analysis. Descriptive statistics, chi-square analysis, and logistic regression analysis were performed using IBM SPSS Statistics for Windows version 28.

Results

The final analytic sample was 4,864 NH residents and 46,103 total pain assessments. At admission, 63.9% were female. The sample age ranges were < 60 (8.8%), 60-69 (11.9%), 70-79 (21.9%), 80-89 (37.0%), and ≥ 90 (20.4%). Most were White (87.3%) or Black (11.6%) with few being Hispanic (0.6%) or other race/ethnicities (0.5%). Most (76.7%) lived in an urban area. BMI ranged from underweight (8.5%), normal (38.8%), overweight (27.8%) to obese (24.9%). Very few residents were on hospice (2.1%) or had a life expectancy of < 6 months (1.8%). Cognitive function varied from intact (31.9%) to impaired mildly (25.9%), moderately (37.2%) or severely (3.3%). Less than half the sample died within the analysis time period (40.4%).

Pain Trajectories

As shown in Figure 4-1, four distinct pain trajectories emerged: 1) consistent pain absence (48.9%) [pain consistently absent]; 2) decreasing-increasing pain presence

(21.8%) [pain presence initially decreased, held steady, then increased over time]; 3) increasing-decreasing pain presence (15.3%) [pain presence initially increased, held steady, then decreased]; and 4) persistent pain presence (14.0%) [pain consistently present]. Rationale for the 4 trajectories is provided via model selection and fit statistics in Tables 4-1 and 4-2.

Characterizing Pain Trajectories

Table 4-3 shows the results of the characterization of the four trajectories by demographic and clinical variables, and mortality based on chi-square analyses. For gender a greater proportion of women was in the decreasing-increasing trajectory ($p<.001$). For age, greater proportions of ages <60 and 60-69 and smaller proportions of ages 80-89 and 90+ were in the persistent pain presence trajectory ($p<.001$). For location, a greater proportion of residents living in a rural location were in the persistent pain trajectory ($p<.001$). For body mass index, greater proportion of residents with obesity and smaller proportions of residents with normal body mass index were in any of the trajectory groups with pain ($p<.001$). Regarding cognitive function a larger proportion of residents with intact cognition were in the persistent pain presence trajectory (61.8%) versus the consistent pain absence trajectory (21.3%). Whereas smaller proportions of residents with moderately or severely impaired cognition were in any of the trajectory groups with pain ($p<.001$). All comorbid conditions except for stroke and Alzheimer's disease or dementia were positively associated with being in one of the trajectory groups with pain. Whereas Alzheimer's disease or dementia was negatively associated with being in one of the trajectory groups with pain. Stroke was not significantly associated with the pain trajectories in this analysis ($p=.800$).

Table 4-4 shows adjusted multinomial model results for pain trajectories. In the adjusted analysis, compared to residents in the consistent pain absence trajectory, residents in the decreasing-increasing pain presence trajectory were more likely to be female (AOR 1.43, CI 1.20-1.70, p<.001), live in a rural location (AOR 1.41, CI 1.16-1.71, p<.001), with intact (AOR 2.73, CI 1.69-4.42, p<.001) or mildly impaired cognition (AOR 1.67, CI 1.03-2.69, p=.036), arthritis (AOR 1.29, CI 1.08-1.55, p=.006), hip fracture (AOR 5.64, CI 3.78-8.43, p<.001), fracture (other than hip) (3.34, CI 2.49-4.49, p<.001), and contracture (AOR 1.31, CI 1.11-1.55, p<.001). In contrast residents with Alzheimer's disease or dementia were less likely to be in the decreasing-increasing pain presence trajectory (AOR 0.57, CI 0.47-0.68, p<.001).

Compared to residents in the consistent pain absence trajectory, residents in the increasing-decreasing pain presence trajectory were more likely to be female (AOR 1.34, CI 1.10-1.62, p=.003), live in a rural location (AOR 1.94, CI 1.59-2.36, p<.001), underweight (AOR 1.41, CI 1.02-1.93, p=.035) or obese (AOR 1.37, CI 1.08-1.74, p=.009) with intact (AOR 2.94, CI 1.62-5.36, p<.001), mildly impaired (AOR 3.16, CI 1.75-5.71, p<.001), or moderately impaired cognition (AOR 2.05, CI 1.14-3.67, p=.016), contracture (AOR 1.63, CI 1.36-1.95, p<.001), diabetes (AOR 1.31, CI 1.08-1.59, p=.007), anxiety disorder (AOR 1.34, CI 1.08-1.65, p=.007), depression (AOR 1.25, CI 1.00-1.51, p=.015), and cancer (AOR 1.51, CI 1.09-2.08, p=.013). In contrast residents with Alzheimer's disease or dementia were less likely to be in the increasing-decreasing pain presence trajectory (AOR 0.73, CI 0.59-0.89, p=.002).

Compared to residents in the consistent pain absence trajectory, residents in the persistent pain presence trajectory were more likely to be female (AOR 1.52, CI 1.24-

1.88, p<.001), rurally located (AOR 2.75, CI 2.20-3.43, p<.001), obese (AOR 1.32, CI 1.02-1.71, p=.037) with intact (AOR 6.70, CI 3.21-13.78, p<.001), or mildly impaired cognition (AOR 2.79, CI 1.34-5.82, p=.006), arthritis (AOR 1.49, 1.19-1.86, p<.001), hip fracture (AOR 4.29 CI 2.61-7.04, p<.001), fracture (other than hip) (AOR 2.89, CI 2.03-4.11, p<.001), contracture (AOR 1.75, CI 1.43-2.13, p<.001), anxiety disorder (AOR 1.55, CI 1.23-1.95, p<.001), heart failure (AOR 1.37, CI 1.07-1.75, p=.011), PVD/PAD (AOR 1.51, CI 1.01-2.25, p=.045). In contrast residents with Alzheimer's disease or dementia were less likely to be in the persistent pain presence trajectory (AOR 0.34, CI 0.27-0.44, p<.001).

Relative to the consistent pain absence trajectory, the odds of being in any one of the other three trajectories with pain was higher for residents who were living in a rural location (AORs range 1.41 to 2.75), obese (AORs range 1.248 to 1.37), with hip fracture (AORs range 1.26 to 5.64), fracture (other than hip) (AORs range 1.38 to 3.34), or contracture (AORs range 1.31 to 11.75). In addition, also relative to the consistent pain absence trajectory, the odds of being in any one of the other three trajectories was lower for residents with a diagnosis of Alzheimer's disease or dementia (AORs range 0.34 to 0.73).

Pain Trajectories and Mortality

For mortality a greater proportion of residents that died during the analysis time period were in the increasing-decreasing trajectory (45.6%) compared to the consistent pain absence trajectory (41.3%), decreasing-increasing trajectory (39.2%), or persistent pain presence trajectory (33.4%). After controlling for all covariates in the model,

residents in the increasing-decreasing trajectory were at 42.0% greater risk of mortality (AOR 1.42, CI 1.19-1.70, p<.001) versus the consistent pain absence trajectory.

Discussion

In this analysis, we present the first evidence of four distinct pain trajectories among NH residents using group-based trajectory modeling. Pain trajectories capture the complex and dynamic (temporal) nature of pain and have implications for both clinical assessment and research. After pain trajectories emerged, we characterized them in terms of demographics, clinical variables, and mortality.

Pain Trajectories

The four pain trajectories identified in this analysis tended to represent contrasting pain patterns, either steady state (consistent pain absence; persistent pain presence) or changing over time (increasing-decreasing pain presence; decreasing-increasing pain presence). All four pain trajectories exhibit a period of stability. The two dynamic groups tend to have a change at the beginning and end of the trajectory separated by a period of stabilization. After this period of stabilization, both trajectories tend to return toward their initial pain level. For example, the decreasing-increasing pain presence trajectory starts with a high occurrence of pain, declines, stabilizes, and then trends toward an increasing occurrence of pain. A similar pattern repeats with the increasing-decreasing pain presence trajectory, although this trajectory begins and ends with a lower occurrence of pain. The source of this period of stabilization is unclear although it may indicate an associated period of time in which physical, emotional and cognitive comorbidities remain stable. Understanding the source of this stabilization may be important in driving change to reduce pain in this population.

Characterizing Pain Trajectories

Compared to the consistent pain absence trajectory, the common factors associated with pain across all three trajectories with pain were female gender, living rurally, intact cognition, and contracture. Residents with normal BMI or a diagnosis of Alzheimer's disease or dementia were less likely to be in any of the three pain trajectories. Younger, female residents who lived rurally, were obese, had fracture (hip or other) or contracture were more likely to be in the persistent pain presence trajectory. Our findings are important because they provide clinically relevant evidence that can improve recognition of risk factors associated with pain persistence in nursing home residents.

Hip fracture in our study was associated with a five-fold increased risk for persistent pain. In the United States, nearly 32,000 NH residents fracture their hip each year,[121] leading to functional decline,[122, 123] poor quality of life,[123] and increased risk of mortality.[124] Acute fracture is commonly associated with increased acute pain, but no prior studies have evaluated how this pain changes over time. Hip fracture in our study was associated with a five-fold increased risk for persistent pain presence over time. Understanding this increased risk for persistent pain allows residents and clinicians to plan care and set priorities.

Living in a rural location was also identified as a significant predictor of persistent pain presence. This may be due to decreased resources available outside of large urban centers to identify and treat pain. Most pain specialty practices, and palliative care practices are located within an urban setting, necessitating great effort to obtain a specialty consultation to reduce pain for those living in rural settings in Indiana.[103-105] Alternatively, rural residents are more likely to have pain and not request pain

medication.[106] Rural disparities in pain management for nursing home residents provides an important area of future research and intervention.

Pain Trajectories and Mortality

Incorporating mortality into analysis of pain trajectories is an important step because those who survive across periods of observation and those who die in the interim may follow distinctly different pain trajectories. The group-based trajectory modeling approach is well suited to summarizing large numbers of individual trajectories and allows for the inclusion of the experience of both survivors and decedents. Limiting the analysis to survivors would have resulted in substantially different pain trajectories that do not truly reflect the experience of nursing home residents, many of whom are approaching death. In this analysis, the increasing-decreasing trajectory was at significantly greater risk for mortality. This group consisted of a higher proportion of residents who were underweight or diagnosed with Alzheimer's disease or dementia, possibly indicating increased frailty. Unfortunately, a frailty measure was not included in the MDS dataset. Further research is needed to evaluate this association further.

Strengths and Limitations

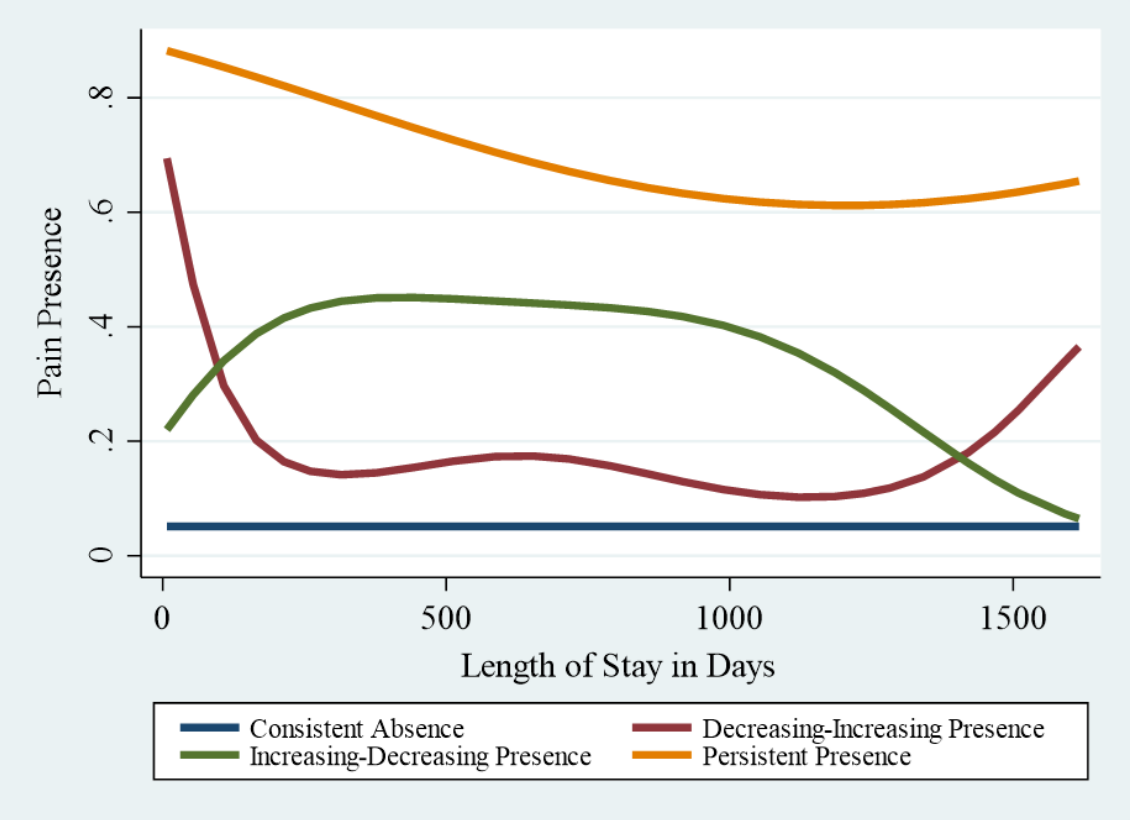
Some limitations should be taken into consideration when interpreting the results. First, we were unable to use age in determining trajectory groups. For residents aged 90 years and above, the age in the de-identified dataset was categorized as 90 or older. This age limitation may obscure some important dynamic relationships that vary based upon age in the oldest old. For this reason, future work is recommended to model age-based pain trajectories. In addition, this analysis does not account for comorbid conditions that change over time (dementia) or the use of pain treatments (analgesics) meant to improve

pain. Future refinements and expansion of our analysis should include investigating time-varying covariates such as cognitive function and use of analgesic medications. Finally, the use of a sample of NH residents that were part of the OPTIMISTIC demonstration project, that provided enhanced geriatric care, potentially limit generalizability of findings. Despite these limitations, this study included a large and diverse sample. Furthermore, we included NH residents with various levels of cognition. Many times, NH residents with cognitive impairment are excluded from studies due to difficulties in assessing their pain and obtaining informed consent. Use of previously collected MDS data allowed us to overcome this issue.

Conclusion

We identified four pain trajectories among nursing home residents, including persistent pain presence which was associated with several resident characteristics and clinically relevant diagnoses. Using residents' characteristics associated with persistent pain, such as hip fracture or contracture, may improve care planning based on early identification or risk stratification and can improve mitigation of persistent pain. Further research to examine the biological underpinnings of each trajectory may elucidate unique genetic and biomarker profiles, leading to further refinement of dynamic pain trajectories.

Figure 4-1: Trajectories of pain presence in nursing home residents



Legend: Figure 4-1 shows the four trajectories of pain presence that emerged from the MDS dataset (n=4,864). 1) consistent pain absence (48.9%) [pain consistently absent]; 2) decreasing-increasing pain presence (21.8%) [pain presence initially decreased, held steady, then increased over time]; 3) increasing-decreasing pain presence (15.3%) [pain presence initially increased, held steady, then decreased]; and 4) persistent pain presence (14.0%) [pain consistently present].

Table 4-1: Model selection statistics

			# Pain Assessments Over Time (n=46,103)		# of Unique NH Residents (N=4,864)	
Model	K	Order	BIC	BIC Δ	BIC	BIC Δ
1	1	5	-25383.82		-25377.07	
2	2	5 5	-21944.61	3439.21	-21929.99	3447.08
3	3	5 5 5	-21523.95	420.66	-21501.45	428.54
4	4	5 5 5 5	-21338.89	185.06	-21308.53	192.92
5	5	5 5 5 5 5	-21255.92	82.97	-21217.69	90.87
6	6	5 5 5 5 5 5	-21230.77	25.15	-21184.66	33.03
7	7	5 5 5 5 5 5 5	Failed convergence			

Note:
K= number of trajectories
Order = chosen polynomial for model
BIC = Bayesian Information Criterion.
BIC Δ = Change in the BIC
Model with highest BIC (least negative) was selected that also demonstrated a BIC Δ of $\geq$ 10. Models with highest BIC were then evaluated based on average posterior probability

Table 4-2: Average posterior probabilities for 6-, 5-, and 4-trajectory models

Model	Trajectory #1	Trajectory #2	Trajectory #3	Trajectory #4	Trajectory #5	Trajectory #6
6-trajectory model	.640	.770	.717	.646	.679	.714
5-trajectory model	.843	.740	.726	.643	.726	
4-trajectory model	.866	.779	.734	.868		
Odds of Correct Classification	7.3	11.8	13.4	44.7		
The model with the highest average posterior probability was selected (4 Trajectories).						

Model Evaluation Statistics: 6-trajectory Order (0 5 5 5 5 5) Dropout (1 1 1 1 1 0); 5-trajectory Order (0 5 4 3 5) Dropout (1 1 1 1 0); 4-trajectory Order (0 5 5 2) Dropout (1 1 1 0).

Table 4-3: Characterization of the four trajectories: demographics, clinical variables, and mortality based on chi-square analyses

	Consistent Pain Absence	Decreasing-Increasing	Increasing-Decreasing	Persistent Pain Presence	p Value
	% (n)	% (n)	% (n)	% (n)	
Total	48.9% (n=2379)	21.8% (n=1059)	15.3% (n=743)	14.0% (n=683)	
percentage(n)					
Gender					
Female	61.1% (1454)	68.6% (726)	65.4% (486)	64.6% (441)	p<.001
Age (years)					
<60	7.1% (168)	7.8% (83)	8.5% (63)	16.5% (113)	p<.001
60-69	11.0% (262)	10.4% (110)	10.9% (81)	18.6% (127)	
70-79	20.8% (494)	21.0% (222)	24.4% (181)	24.9% (170)	
80-89	39.0% (928)	38.3% (406)	37.1% (276)	27.7% (189)	
90+	22.2% (527)	22.5% (238)	19.1% (142)	12.3% (84)	
Race					
White	86.5% (1970)	88.6% (895)	88.5% (630)	86.8% (566)	p=.313
Black	12.1% (275)	10.3% (104)	10.7% (76)	12.7% (83)	
Hispanic	0.7% (17)	0.8% (8)	0.4% (3)	0.3% (2)	
Other	0.7% (16)	0.3% (3)	0.4% (3)	0.2% (1)	
Location					
Rural	19.0% (452)	23.1% (245)	29.5% (219)	32.1% (219)	p<.001
Body mass index (BMI)					
Underweight	8.4% (194)	8.0% (81)	9.9% (70)	8.3% (55)	p<.001
Normal Weight	43.1% (991)	37.5% (381)	35.2% (249)	29.7% (197)	

	Consistent Pain Absence	Decreasing-Increasing	Increasing-Decreasing	Persistent Pain Presence	p Value
Overweight	28.2% (649)	28.5% (290)	26.8% (190)	26.2% (174)	
Obese	20.2% (465)	26.0% (264)	28.1% (199)	35.8% (238)	
Hospice Care	2.4% (57)	1.5% (16)	1.7% (13)	2.0% (14)	p=.351
Life expectancy <6 months	2.2% (52)	1.0% (11)	1.6% (12)	1.9% (13)	p=.132
Cognitive Function Scale (CFS)					
Intact Cognition	21.3% (506)	39.2% (415)	28.3% (210)	61.8% (422)	p<.001
Mildly Impaired	25.5% (606)	25.2% (267)	32.0% (238)	21.7% (148)	
Moderately Impaired	46.5% (1106)	31.5% (334)	37.0% (275)	14.1% (96)	
Severely Impaired	4.7% (111)	2.6% (28)	1.9% (14)	1.3% (9)	
Comorbid Conditions					
Arthritis	21.7% (516)	29.1% (308)	24.6% (183)	31.8% (217)	p<.001
Hip fracture	1.8% (42)	9.8% (104)	2.4% (18)	6.3% (43)	p<.001
Fracture (other than hip)	3.8% (90)	13.4% (142)	5.9% (44)	12.2% (83)	p<.001
Contracture	36.7% (874)	49.5% (524)	48.5% (360)	55.2% (377)	p<.001
Diabetes	26.0% (618)	29.3% (310)	34.1% (253)	38.9% (266)	p<.001
Alzheimer's/Dementia	62.8% (1494)	43.2% (458)	51.3% (381)	21.7% (148)	p<.001
Stroke	12.2% (291)	11.4% (121)	11.8% (88)	11.0% (75)	p=.800
Anxiety	20.0% (476)	20.9% (221)	25.7% (191)	29.7% (203)	p<.001
Depression	40.7% (967)	41.4% (438)	47.8% (355)	47.1% (322)	p<.001
Heart Failure	15.5% (368)	19.5% (206)	18.6% (138)	24.3% (166)	p<.001
PVD/PAD	4.4% (105)	5.6% (59)	4.7% (35)	7.8% (53)	p=.005
Cancer	6.2% (147)	5.5% (58)	8.7% (65)	9.4% (64)	p=.001
Death	41.3% (983)	39.2% (415)	45.6% (339)	33.4% (228)	p<.001

Table 4-4: Adjusted odds of belonging to a pain trajectory relative to the consistent pain absence trajectory

	Decreasing-Increasing			Increasing-Decreasing			Persistent Pain Presence		
	AOR$^{\Phi}$	CI	p Value	AOR$^{\Phi}$	CI	p Value	AOR$^{\Phi}$	CI	p Value
Gender									
Female	1.43	1.20-1.70	p<.001	1.34	1.10-1.62	p=.003	1.52	1.24-1.88	p<.001
Age (years)									
<60	0.98	0.68-1.40	p=.896	1.35	0.90-2.03	p=.141	3.11	2.06-4.69	p<.001
60-69	0.80	0.64-1.21	p=.423	1.04	0.73-1.49	p=.833	2.30	1.57-3.37	p<.001
70-79	1.10	0.85-1.42	p=.466	1.42	1.07-1.88	p=.015	2.21	1.57-3.10	p<.001
80-89	1.16	0.93-1.44	p=.191	1.18	0.92-1.51	p=.182	1.52	1.12-2.08	p=.008
90+*	-	-	-	-	-	-	-	-	-
Location									
Rural	1.41	1.16-1.71	p<.001	1.94	1.59-2.36	p<.001	2.75	2.20-3.43	p<.001
Body mass index (BMI)									
Underweight	0.98	0.73-1.33	p=.912	1.41	1.02-1.93	p=.035	1.26	0.87-1.83	p=.216
Normal Weight*	-	-	-	-	-	-	-	-	-
Overweight	1.14	0.94-1.39	p=.179	1.11	0.89-1.38	p=.369	1.15	0.90-1.48	p=.270
Obese	1.24	.99-1.54	p=.053	1.37	1.08-1.74	p=.009	1.32	1.02-1.71	p=.037
Cognitive Function Scale									
Intact Cognition	2.73	1.69-4.42	p<.001	2.94	1.62-5.36	p<.001	6.7	3.21-13.78	p<.001
Mildly Impaired	1.67	1.03-2.69	p=.036	3.16	1.75-5.71	p<.001	2.79	1.34-5.82	p=.006
Moderately Impaired	1.25	0.78-2.01	p=.348	2.05	1.14-3.67	p=.016	1.41	0.67-2.96	p=.363
Severely Impaired*	-	-	-	-	-	-	-	-	-
Comorbid Conditions									
Arthritis	1.29	1.08-1.55	p=.006	1.13	0.89-1.36	p=.351	1.49	1.19-1.86	p<.001

	Decreasing-Increasing			Increasing-Decreasing			Persistent Pain Presence		
Hip fracture	5.64	3.78-8.43	p<.001	1.26	0.69-2.28	p=.444	4.29	2.61-7.04	p<.001
Fracture (other than hip)	3.34	2.49-4.49	p<.001	1.38	0.93-2.03	p=.106	2.89	2.03-4.11	p<.001
Contracture	1.31	1.11-1.55	p=.001	1.63	1.36-1.95	p<.001	1.75	1.43-2.13	p<.001
Diabetes	1.03	0.86-1.24	p=.743	1.31	1.08-1.59	p=.007	1.19	0.96-1.47	p=.119
Alzheimer's/Dementia	0.57	0.47-0.68	p<.001	0.73	0.59-0.89	p=.002	0.34	0.27-0.44	p<.001
Anxiety disorder	1.10	0.90-1.35	p=.342	1.34	1.08-1.65	p=.007	1.55	1.23-1.95	p<.001
Depression	1.04	0.88-1.23	p=.653	1.25	1.00-1.51	p=.015	1.19	0.97-1.46	p=.089
Heart Failure	1.12	0.91-1.38	p=.289	1.15	0.91-1.46	p=.227	1.37	1.07-1.75	p=.011
PVD/PAD	1.21	0.84-1.73	p=.302	1.03	0.68-1.56	p=.887	1.51	1.01-2.25	p=.045
Cancer	0.85	0.60-1.19	p=.329	1.51	1.09-2.08	p=.013	1.22	0.98-1.52	p=.052
Death	1.07	0.90-1.27	p=.455	1.43	1.18-1.72	p<.001	1.22	0.98-1.55	p=.074

Note: Overall referent is no consistent pain absence trajectory. $^{\Phi}$adjusted for all factors in the table. *denotes referent for that characteristic.

CHAPTER FIVE: DISCUSSION

This dissertation focused on pain and associated factors in nursing home (NH) residents culminating in the identification, quantification, and characterization of NH resident pain trajectories. Results of the three interconnected studies included in this dissertation expand the scientific knowledge of pain in NH residents.

Summary of Key Findings

Chapter Two

Chapter two presents the results of a systematic review of the literature focused on pain prevalence and associated factors in NH residents. Per the inclusion criteria, 26 studies were included in this review. Findings indicate that 22.0% to 85.0% of NH residents experience pain, 20.0% to 56.0% experience persistent pain, and approximately 56.0% experience chronic pain. Pain prevalence was highly variable and influenced by length of pain detection time (minutes, days, months), source of pain data (self-report, proxy, chart review), intensity of pain assessed (mild, moderate, severe), and sample characteristics (cognition, pain related conditions). Depression, cognitive impairment, and dementia were associated with pain across multiple studies, whereas evidence for an association between pain and other factors was equivocal or limited.

Chapter Three

Chapter three presents the results of a retrospective analysis of Minimum Data Set (MDS) 3.0 data using a sample of Indiana NH residents. The purpose of this analysis was to evaluate the association between pain and resident demographic and clinical characteristics including pain management strategies. In this study, the overall pain prevalence among NH residents was 23.7%. Of those with pain, 72.0% experienced

mild/infrequent pain, 28.0% experienced moderate to severe/frequent pain and 54.6% experienced persistent pain.

Risk factors for mild/infrequent pain were female gender, living in a rural setting, receiving hospice care, cognitive status (intact, mildly, or moderately impaired), arthritis, fracture (other than hip), contracture, anxiety, and depression. In contrast, normal BMI and Alzheimer's disease or dementia were associated with decreased risk of mild/infrequent pain. Risk factors for moderate to severe/frequent pain were female gender, living in a rural setting, receiving hospice care, cognitive status (intact, mildly, or moderately impaired), arthritis, contracture, anxiety, depression, and heart failure. In contrast, stroke and Alzheimer's disease or dementia were associated with decreased risk of moderate to severe/frequent pain. Risk factors for persistent pain included age <70, Black race, living in a rural location, intact cognition, contracture, and depression.

Most residents with moderate to severe/frequent pain (74.0%) or persistent pain (67.8%) received scheduled pain medication. However, non-pharmacological treatment for pain was limited to 35.6% of residents with moderate to severe/frequent pain and 39.5% of residents with persistent pain.

Chapter Four

Chapter four presents the results of a retrospective longitudinal analysis of MDS 3.0 data using a sample of Indiana NH residents to identify, quantify, and characterize NH resident pain trajectories. The findings from this analysis comprise the first evidence of four distinct pain trajectory groups among NH residents using group-based trajectory modeling. The four pain trajectories identified in this analysis include: 1) consistent pain

absence (48.9%), 2) decreasing-increasing pain presence (21.8%), 3) increasing-decreasing pain presence (15.3%), and 4) persistent pain presence (14.0%).

Relative to residents in the consistent pain absence trajectory, the likelihood of being in the persistent pain presence trajectory was more than twice as high for those living in a rural location, over 4 times higher for those with hip fracture, nearly 3 times higher for those with a fracture other than hip, and almost twice as high for those with contracture. In addition, relative to the residents in the consistent pain absence trajectory, those at greater risk for being in one or more of the trajectory groups with pain were female gender, living in a rural location, intact cognition, and contracture. In contrast, residents with normal weight or a diagnosis of Alzheimer's disease or dementia were less likely to be in any of the three trajectories with pain.

Lastly, in this analysis, the Increasing-Decreasing trajectory group was significantly related to increased mortality. This group consisted of a higher proportion of residents who were underweight or with diagnosis of Alzheimer's disease or dementia, possibly indicating increased frailty. Unfortunately, a frailty measure was not included in the MDS dataset. Further research is needed to evaluate this association further.

Summary

The findings from this dissertation are important because they provide clinically relevant evidence that can improve the recognition of risk factors associated with pain in NH residents. This is especially important for residents with impaired cognition which limits their ability to report pain. Overall, across the three studies comprising this dissertation, there are several notable findings which may have implications for the way that pain is identified, assessed, and managed among NH residents.

First, the results of this dissertation highlights the evidence for the association between pain and resident demographic and clinical characteristics. This is particularly true for age, impaired cognition, obesity, contracture, and heart failure which were identified in the systematic review of the literature as having mixed or limited research. NH residents with depression were at greater risk for mild/infrequent pain, moderate to severe/frequent pain, persistent pain, and having pain that followed an increasing-decreasing pain presence trajectory. Similarly, NH residents with contracture were at greater risk for mild/infrequent pain, moderate to severe/frequent pain, persistent pain, and belonging to a pain trajectory other than the consistent pain absence trajectory. Finally, across all three studies in this dissertation, the inverse relationship between cognitive impairment and pain was noted.

Second, the results of this dissertation include the identification of both rural and racial pain disparities among NH residents. Living in a rural versus urban setting was associated with nearly two times the likelihood of being in moderate to severe/frequent pain, 1.5 times the likelihood of being in persistent pain, and nearly three times the likelihood of being in the persistent pain presence trajectory. Racial disparities were also noted, as Black residents were 1.5 times more likely to report persistent pain than White residents. In contrast, race was not associated with membership in a pain trajectory subgroup. In the systematic review of the literature (chapter two), evidence of an association between pain and race and pain and rural location were limited. In recent years there has been an expansion of interest in exploring disparities in pain assessment and treatment in the general population. The findings of this dissertation suggest that

additional work is needed to identify, evaluate, and eliminate pain disparities in the NH setting.

Strengths and Limitations

Some limitations should be taken into consideration when interpreting the results of this dissertation. First, because this dissertation used secondary data, the analyses were limited to variables within the dataset. The MDS 3.0 pain variables measured the presence, frequency, and intensity of pain. However, information such as location and character of the pain may have improved characterization of resident pain trajectories. Second, due to use of de-identified data, we were unable to use age in determining trajectory groups. For residents aged 90 years and above, the age in the de-identified dataset was categorized as 90 or older. This limitation was overcome by using length of stay for each assessment as a measure of time. Nevertheless, the inability to use age as a measure of time may obscure some important dynamic relationships that vary based upon age, particularly in the oldest old. Third, the sample consisted of Indiana NH residents that were part of the OPTIMISTIC demonstration project that provided enhanced geriatric care, potentially limiting generalizability of findings.

Despite these limitations, this dissertation has several strengths. First, our analysis included a large and diverse sample. Second, our use of comprehensive standardized measures (Minimum Data Set assessments) facilitates comparison across other clinical studies conducted in the NH setting. Third, we included NH residents with various levels of cognition. Many times, NH residents with cognitive impairment are excluded from studies due to difficulties in assessing their pain and obtaining informed consent. Use of previously collected MDS data allowed us to overcome this issue. Finally, the use of a

stepped approach, using the findings from each prior study in the subsequent study, strengthen the findings of this dissertation and add to the scientific literature.

Implications

Nursing Implications

This dissertation identified factors associated with pain and four distinct pain trajectories among NH residents. Resident characteristics were associated with moderate to severe/frequent pain, persistent pain, or individual pain trajectories. If nurses are trained to recognize the association between these characteristics and pain, it may improve mitigation of pain based on early identification or risk stratification. For example, nurses may prioritize pain assessment for residents who are less likely to report pain due to cognitive impairment (e.g., Alzheimer's disease or dementia). In addition, nurses may prioritize preventive therapies for residents with comorbidities that increase risk for pain such as depression and contracture.

Future Research

Several areas were identified as important areas for future research. Future research is needed to examine the biological underpinnings of each trajectory and elucidate unique genetic and biomarker profiles, leading to further refinement of dynamic pain trajectories. This is a novel area of exploration that could provide information needed to form the foundation of personalized health strategies, helping to manage and relieve pain in NH residents.

Next, further research is needed to describe and understand the disparities in NH resident pain identified in this dissertation. In recent years there has been an expansion of interest in exploring disparities in pain assessment and treatment in the general

population and the findings from this dissertation suggest that additional work is needed to eliminate disparities in the NH setting.

Finally, the continued high pain prevalence identified in this dissertation provide impetus for more research to improve NH resident pain situation. One such approach would be increased integration of palliative care in the NH setting. Palliative care has been shown to increase quality of life, decrease distressing symptoms such as pain, and improve comfort. Despite these positive outcomes, NH residents are not receiving palliative care services in relation to their high prevalence of chronic life-limiting disease. While several barriers to palliative care in the NH have been identified, the most pressing barrier is a lack of validated instruments to identify individuals who would benefit most from palliative care. Findings from this dissertation would be useful in developing and validating such an instrument. Future research in this area is needed.

Conclusion

In conclusion, this dissertation adds to the science by providing important information regarding NH resident pain trajectories and the demographic and clinical characteristics associated with greater risk of pain. This work will be helpful for nurses, clinicians, and other healthcare leaders who are interested in improving pain among NH residents.

REFERENCES

1. Shen, X., I.H. Zuckerman, J.B. Palmer, and B. Stuart, *Trends in prevalence for moderate-to-severe pain and persistent pain among Medicare beneficiaries in nursing homes, 2006-2009.* The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 2015. 70(5): p. 598-603.
2. Takai, Y., N. Yamamoto-Mitani, and A. Ko, *Prevalence of and factors related to pain among elderly Japanese residents in long-term healthcare facilities.* Geriatrics & Gerontology International, 2014. 14(2): p. 481-489.
3. Boerlage, A.A., A.D. Masman, J. Hagoort, D. Tibboel, F.P.M. Baar, and M. van Dijk, *Is pain assessment feasible as a performance indicator for Dutch nursing homes? A cross-sectional approach.* Pain Management Nursing: Official Journal Of The American Society Of Pain Management Nurses, 2013. 14(1): p. 36-40.
4. Torvik, K., S. Kaasa, O. Kirkevold, and T. Rustøen, *Pain and quality of life among residents of Norwegian nursing homes.* Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 2010. 11(1): p. 35-44.
5. Tse, M.M.Y., V.T.C. Wan, and S.K.S. Vong, *Health-Related Profile and Quality of Life Among Nursing Home Residents: Does Pain Matter?* Pain Management Nursing, 2013. 14(4): p. e173-84.
6. Lapane, K.L., B.J. Quilliam, W. Chow, and M. Kim, *The association between pain and measures of well-being among nursing home residents.* Journal of the American Medical Directors Association, 2012. 13(4): p. 344-349.

7. Institute of Medicine, *Relieving pain in America: a blueprint for transforming prevention, care, education, and research*. 2011: National Academies Press.

8. Tarakcı, E., Y. Zenginler, and E. Kaya Mutlu, *Chronic pain, depression symptoms and daily living independency level among geriatrics in nursing home.* Agri : Agri (Algoloji) Dernegi'nin Yayin organidir = The journal of the Turkish Society of Algology, 2015. 27(1): p. 35-41.

9. Achterberg, W.P., G. Gambassi, H. Finne-Soveri, R. Liperoti, A. Noro, D.H.M. Frijters, . . . M.W. Ribbe, *Pain in European long-term care facilities: cross-national study in Finland, Italy and the Netherlands.* Pain, 2010. 148(1): p. 70-74.

10. Tse, M.M.Y., C. Lai, J.Y.W. Lui, E. Kwong, and S.Y. Yeung, *Frailty, pain and psychological variables among older adults living in Hong Kong nursing homes: can we do better to address multimorbidities?* Journal Of Psychiatric And Mental Health Nursing, 2016. 23(5): p. 303-311.

11. Tse, M., R. Leung, and S. Ho, *Pain and psychological well-being of older persons living in nursing homes: an exploratory study in planning patient-centred intervention.* Journal of Advanced Nursing, 2012. 68(2): p. 312-321.

12. Hunnicutt, J.N., C.M. Ulbricht, J. Tjia, and K.L. Lapane, *Pain and pharmacologic pain management in long-stay nursing home residents.* Pain, 2017. 158(6): p. 1091-1099.

13. Bae, S.H., S. Lee, and H. Kim, *Extent of and factors associated with pain among older residents in nursing homes in South Korea: A nationwide survey study.* Geriatrics & Gerontology International, 2020. 20(2): p. 118-124.

14. Björk, S., C. Juthberg, M. Lindkvist, A. Wimo, P.-O. Sandman, B. Winblad, and D. Edvardsson, *Exploring the prevalence and variance of cognitive impairment, pain, neuropsychiatric symptoms and ADL dependency among persons living in nursing homes; a cross-sectional study.* BMC Geriatrics, 2016. 16: p. 154-154.

15. Horgas, A.L., *Pain Assessment in Older Adults.* The Nursing clinics of North America, 2017. 52(3): p. 375-385.

16. Landmark, B.T., S.V. Gran, and H.S. Kim, *Pain and persistent pain in nursing home residents in Norway.* Research In Gerontological Nursing, 2013. 6(1): p. 47-56.

17. Thompson, G.N., M. Doupe, R.C. Reid, J. Baumbusch, and C.A. Estabrooks, *Pain trajectories of nursing home residents nearing death.* Journal of the American Medical Directors Association, 2017. 18(8): p. 700-706.

18. Vossius, C., G. Selbæk, J. Šaltytė Benth, and S. Bergh, *Mortality in nursing home residents: A longitudinal study over three years.* PloS one, 2018. 13(9): p. e0203480.

19. Patel, K.V., J.M. Guralnik, E.J. Dansie, and D.C. Turk, *Prevalence and impact of pain among older adults in the United States: findings from the 2011 National Health and Aging Trends Study.* Pain, 2013. 154(12): p. 2649-2657.

20. Harris-Kojetin, L.D., M. Sengupta, J. lendon, V. Rome, R. Valverde, and C. Caffrey, *Long-term care providers and service users in the United States, 2015-2016*, in *National Center for Health Statistics*. 2019.

21. Center for Medicare and Medicaid Services, *Nursing home data compendium 2015 edition*. 2015. p. 1-251.

22. Scher, C., L. Meador, J.H. Van Cleave, and M.C. Reid, *Moving Beyond Pain as the Fifth Vital Sign and Patient Satisfaction Scores to Improve Pain Care in the 21st Century.* Pain management nursing : official journal of the American Society of Pain Management Nurses, 2018. 19(2): p. 125-129.

23. Kang, Y. and G. Demiris, *Self-report pain assessment tools for cognitively intact older adults: Integrative review.* International journal of older people nursing, 2018. 13(2): p. e12170.

24. Booker, S.Q., K.A. Herr, and A.L. Horgas, *A Paradigm Shift for Movement-based Pain Assessment in Older Adults: Practice, Policy and Regulatory Drivers.* Pain management nursing : official journal of the American Society of Pain Management Nurses, 2021. 22(1): p. 21-27.

25. Herr, K., J.S. Sefcik, M.B. Neradilek, M.M. Hilgeman, P. Nash, and M. Ersek, *Psychometric Evaluation of the MOBID Dementia Pain Scale in U.S. Nursing Homes.* Pain management nursing : official journal of the American Society of Pain Management Nurses, 2019. 20(3): p. 253-260.

26. Herr, K., P.J. Coyne, E. Ely, C. Gélinas, and R.C.B. Manworren, *Pain assessment in the patient unable to self-report: clinical practice recommendations in support of the ASPMN 2019 position statement.* Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 2019. 20(5): p. 404-417.

27. Center for Medicare and Medicaid Services, *MDS 3.0 Quality measures user's manual*. 2016.

28. Saliba, D., M. Jones, J. Streim, J. Ouslander, D. Berlowitz, and J. Buchanan, *Overview of significant changes in the Minimum Data Set for nursing homes version 3.0.* Journal of the American Medical Directors Association, 2012. 13(7): p. 595-601.

29. Center for Medicare and Medicaid Services, *State operations manual: appendix PP - guidance to surveyors for long term care*. 2017.

30. Lapane, K.L., B.J. Quilliam, W. Chow, and M.S. Kim, *Impact of revisions to the F-Tag 309 surveyors' interpretive guidelines on pain management among nursing home residents.* Drugs & Aging, 2012. 29(5): p. 385-393.

31. Center for Medicare and Medicaid Services. *Revised quality of care guidance at F309, including pain management as part of appendix PP SOM*. 2009 [cited 2021 December]; Available from: https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/CMS1219650.

32. Center for Medicare and Medicaid Services. *List of revised FTags*. 2021 [cited 2021 December 24]; Available from: https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/List-of-Revised-FTags.pdf.

33. Takai, Y., N. Yamamoto-Mitani, Y. Okamoto, K. Koyama, and A. Honda, *Literature review of pain prevalence among older residents of nursing homes.* Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 2010. 11(4): p. 209-223.

34. Page, M.J., D. Moher, P.M. Bossuyt, I. Boutron, T.C. Hoffmann, C.D. Mulrow, . . . J.E. McKenzie, *PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews.* BMJ, 2021. 372: p. n160.

35. Munn, Z., S. Moola, K. Lisy, D. Riitano, and C. Tufanaru, *Methodological guidance for systematic reviews of observational epidemiological studies reporting revalence and incidence data.* Int J Evid Based Healthc, 2015. 13(3): p. 147-153.

36. Bauer, U., S. Pitzer, M.M. Schreier, J. Osterbrink, R. Alzner, and B. Iglseder, *Pain treatment for nursing home residents differs according to cognitive state - a cross-sectional study.* BMC Geriatrics, 2016. 16: p. 124-124.

37. Tan, E.C., R. Visvanathan, S.N. Hilmer, A. Vitry, T. Emery, L. Robson, . . . J.S. Bell, *Analgesic use and pain in residents with and without dementia in aged care facilities: A cross-sectional study.* Australasian Journal On Ageing, 2016. 35(3): p. 180-187.

38. Auer, S.R., E. Linsmayer, D. Prieschl, P. Ratajczak, M. Höfler, A. Beránková, . . . I. Holmerová, *Cross-sectional study of prevalence of dementia, behavioural symptoms, mobility, pain and other health parameters in nursing homes in Austria and the Czech Republic: results from the DEMDATA project.* BMC Geriatrics, 2018. 18(1): p. 1-13.

39. Tse, M.M.Y., V.T.C. Wan, and S.S.K. Ho, *Profile of pain and use of pharmacological and non-pharmacological methods for relieving pain in older persons in nursing homes.* Journal of Pain Management, 2010. 3(3): p. 309-317.

40. Tse, M.M.Y. and S.K.S. Vong, *Pain beliefs and pain-related profiles of older persons living in nursing homes.* Journal of Pain Management, 2012. 5(2): p. 141-151.

41. Altintas, H.K., G.K. Aslan, N.Y. Sısman, and M.T. Kesgin, *Effects of Pain and Sleep Quality on Falls Among Nursing Home Residents in Turkey.* Research in gerontological nursing, 2018. 11(5): p. 257-264.

42. Barbosa, M.H., A.F. Bolina, J.L. Tavares, A.L.P. de Carvalho Cordeiro, R.B. Luiz, and K.F. de Oliveira, *Sociodemographic and health factors associated with chronic pain in institutionalized elderly.* Revista Latino-Americana de Enfermagem, 2014. 22(6): p. 1009-1016.

43. Warden, V., A.C. Hurley, and L. Volicer, *Development and Psychometric Evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale.* Journal of the American Medical Directors Association, 2003. 4(1): p. 9-15.

44. Closs, S.J., B. Barr, M. Briggs, K. Cash, and K. Seers, *A comparison of five pain assessment scales for nursing home residents with varying degrees of cognitive impairment.* Journal of pain and symptom management, 2004. 27(3): p. 196-205.

45. Hawker, G.A., S. Mian, T. Kendzerska, and M. French, *Measures of adult pain: Visual Analog Scale for Pain (VAS Pain), Numeric Rating Scale for Pain (NRS Pain), McGill Pain Questionnaire (MPQ), Short-Form McGill Pain Questionnaire (SF-MPQ), Chronic Pain Grade Scale (CPGS), Short Form-36 Bodily Pain Scale (SF-36 BPS), and Measure of Intermittent and Constant Osteoarthritis Pain (ICOAP).* Arthritis care & research, 2011. 63 Suppl 11: p. S240-S252.

46. Morris, J.N., C. Hawes, B.E. Fries, C.D. Phillips, V. Mor, S. Katz, . . . A.S. Friedlob, *Designing the National Resident Assessment Instrument for Nursing Homes.* 1990.

47. Morris, J., K. Murphy, and S. Nonemaker, *Long term care facility Reident Assessment Instrument (RAI) user's manual version 2.0*. 1995, Baltimore: HCFA.

48. Xu, Y., N. Jiang, Y. Wang, Q. Zhang, L. Chen, and S. Ma, *Pain perception of older adults in nursing home and home care settings: evidence from China.* BMC Geriatrics, 2018. 18(1): p. 152-152.

49. Lukas, A., B. Mayer, D. Fialová, E. Topinkova, J. Gindin, G. Onder, . . . M.D. Denkinger, *Pain characteristics and pain control in European nursing homes: cross-sectional and longitudinal results from the Services and Health for Elderly in Long TERm care (SHELTER) study.* Journal of the American Medical Directors Association, 2013. 14(6): p. 421-428.

50. Onder, G., I. Carpenter, H. Finne-Soveri, J. Gindin, D. Frijters, J.C. Henrard, . . . R. Bernabei, *Assessment of nursing home residents in Europe: the Services and Health for Elderly in Long TERm care (SHELTER) study.* BMC health services research, 2012. 12: p. 5.

51. Brennan, P.L., M.A. Greenbaum, S. Lemke, and K.K. Schutte, *Mental health disorder, pain, and pain treatment among long-term care residents: Evidence from the Minimum Data Set 30.* Aging & Mental Health, 2019. 23(9): p. 1146-1155.

52. Saliba, D. and J. Buchanan, *Making the investment count: revision of the Minimum Data Set for nursing homes, MDS 3.0.* Journal of the American Medical Directors Association, 2012. 13(7): p. 602-610.

53. Takai, Y., N. Yamamoto-Mitani, Y. Chiba, Y. Nishikawa, Y. Sugai, and K. Hayashi, *Prevalence of pain among residents in Japanese nursing homes: a descriptive study.* Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 2013. 14(2): p. e1-e9.

54. Herr, K., K.F. Spratt, L. Garand, and L. Li, *Evaluation of the Iowa pain thermometer and other selected pain intensity scales in younger and older adult cohorts using controlled clinical pain: a preliminary study.* Pain medicine (Malden, Mass.), 2007. 8(7): p. 585-600.

55. Abbey, J., N. Piller, A. De Bellis, A. Esterman, D. Parker, L. Giles, and B. Lowcay, *The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia.* International journal of palliative nursing, 2004. 10(1): p. 6-13.

56. Herr, K.A., P.R. Mobily, F.J. Kohout, and D. Wagenaar, *Evaluation of the Faces Pain Scale for use with the elderly.* The Clinical journal of pain, 1998. 14(1): p. 29-38.

57. Hoedl, M. and S. Bauer, *The relationship between care dependency and pain in nursing home residents.* Archives of Gerontology & Geriatrics, 2020. 90: p. N.PAG-N.PAG.

58. Hemmingsson, E.-S., M. Gustafsson, U. Isaksson, S. Karlsson, Y. Gustafson, P.-O. Sandman, and H. Lövheim, *Prevalence of pain and pharmacological pain*

treatment among old people in nursing homes in 2007 and 2013. European Journal Of Clinical Pharmacology, 2018. 74(4): p. 483-488.

59. Cadogan, M.P., J.F. Schnelle, N. Yamamoto-Mitani, G. Cabrera, and S.F. Simmons, *A minimum data set prevalence of pain quality indicator: is it accurate and does it reflect differences in care processes?* The Journals Of Gerontology. Series A, Biological Sciences And Medical Sciences, 2004. 59(3): p. 281-285.

60. Nekovarova, T., A. Yamamotova, K. Vales, A. Stuchlik, J. Fricova, and R. Rokyta, *Common mechanisms of pain and depression: are antidepressants also analgesics?* Frontiers in behavioral neuroscience, 2014. 8: p. 99-99.

61. Arnstein, P., K.A. Herr, and H.K. Butcher, *Evidence-based practice guideline: persistent pain management in older adults.* Journal of Gerontological Nursing, 2017. 43(7): p. 20-31.

62. Fine, P.G., *Treatment guidelines for the pharmacological management of pain in older persons.* Pain Med, 2012. 13 Suppl 2: p. S57-66.

63. Wu, N., S.C. Miller, K. Lapane, J. Roy, and V. Mor, *Impact of cognitive function on assessments of nursing home residents' pain.* Medical care, 2005. 43(9): p. 934-939.

64. Ersek, M., P.V. Nash, M.M. Hilgeman, M.B. Neradilek, K.A. Herr, P.R. Block, and A.N. Collins, *Pain patterns and treatment among nursing home residents with moderate-severe cognitive impairment.* Journal of the American Geriatrics Society, 2019.

65. Dube, C.E., R.A. Morrison, D.S. Mack, B.M. Jesdale, A.P. Nunes, S.-H. Liu, and K.L. Lapane, *Prevalence of Pain on Admission by Level of Cognitive Impairment in Nursing Homes.* Journal of pain research, 2020. 13: p. 2663-2672.

66. Herr, K., H. Bursch, M. Ersek, L.L. Miller, and K. Swafford, *Use of pain-behavioral assessment tools in the nursing home: expert consensus recommendations for practice.* Journal of Gerontological Nursing, 2010. 36(3): p. 18-31.

67. Ersek, M., M.B. Neradilek, K. Herr, M.M. Hilgeman, P. Nash, N. Polissar, and F.X. Nelson, *Psychometric Evaluation of a Pain Intensity Measure for Persons with Dementia.* Pain Medicine, 2019. 20(6): p. 1093-1104.

68. Hadjistavropoulos, T., J. Williams, S. Kaasalainen, P.V. Hunter, M.L. Savoie, and A. Wickson-Griffiths, *Increasing the Frequency and Timeliness of Pain Assessment and Management in Long-Term Care: Knowledge Transfer and Sustained Implementation.* Pain research & management, 2016. 2016: p. 6493463.

69. Pieper, M.J.C., J.T. van der Steen, A.L. Francke, E.J.A. Scherder, J.W.R. Twisk, and W.P. Achterberg, *Effects on pain of a stepwise multidisciplinary intervention (STA OP!) that targets pain and behavior in advanced dementia: a cluster randomized controlled trial.* Palliative medicine, 2018. 32(3): p. 682-692.

70. Stein, C.M., R.G. Marie, A.T. Jo, W.P. James, D.B. Kenneth, and A.R. Wayne, *Educational program for nursing home physicians and staff to reduce use of non-steroidal anti-inflammatory drugs among nursing home residents: a randomized controlled trial.* Medical Care, 2001. 39(5): p. 436.

71. Baier, R.R., D.R. Gifford, G. Patry, S.M. Banks, T. Rochon, D. DeSilva, and J.M. Teno, *Ameliorating pain in nursing homes: a collaborative quality-improvement project.* Journal Of The American Geriatrics Society, 2004. 52(12): p. 1988-1995.

72. Horner, J.K., L.C. Hanson, D. Wood, A.G. Silver, and K.S. Reynolds, *Using quality improvement to address pain management practices in nursing homes.* Journal of pain and symptom management, 2005. 30(3): p. 271-277.

73. Chen, Y.-H. and L.-C. Lin, *Ability of the Pain Recognition and Treatment (PRT) Protocol to Reduce Expressions of Pain among Institutionalized Residents with Dementia: A Cluster Randomized Controlled Trial.* Pain management nursing : official journal of the American Society of Pain Management Nurses, 2016. 17(1): p. 14-24.

74. Kaasalainen, S., K. Brazil, N. Akhtar-Danesh, E. Coker, J. Ploeg, F. Donald, . . . A. Papaioannou, *The Evaluation of an Interdisciplinary Pain Protocol in Long Term Care.* Journal of the American Medical Directors Association, 2012. 13(7): p. 664.e1-8.

75. Ersek, M., M.B. Neradilek, K. Herr, A. Jablonski, N. Polissar, and A. Du Pen, *Pain Management Algorithms for Implementing Best Practices in Nursing Homes: Results of a Randomized Controlled Trial.* Journal of the American Medical Directors Association, 2016. 17(4): p. 348-356.

76. Kaasalainen, S., J. Ploeg, F. Donald, E. Coker, K. Brazil, R. Martin-Misener, . . . T. Hadjistavropoulos, *Positioning clinical nurse specialists and nurse practitioners as change champions to implement a pain protocol in long-term*

care. Pain management nursing : official journal of the American Society of Pain Management Nurses, 2015. 16(2): p. 78-88.

77. Kaasalainen, S., A. Wickson-Griffiths, N. Akhtar-Danesh, K. Brazil, F. Donald, R. Martin-Misener, . . . L. Dolovich, *The effectiveness of a nurse practitioner-led pain management team in long-term care: A mixed methods study.* International Journal of Nursing Studies, 2016. 62: p. 156-167.

78. Kehinde, J.O., *Instruments for measuring fall risk in older adults living in long-term care facilities: an integrative review.* J Gerontol Nurs, 2009. 35(10): p. 46-55.

79. Pancorbo-Hidalgo, P.L., F.P. Garcia-Fernandez, I.M. Lopez-Medina, and C. Alvarez-Nieto, *Risk assessment scales for pressure ulcer prevention: a systematic review.* J Adv Nurs, 2006. 54(1): p. 94-110.

80. Iqbal, Z., S. Azmi, R. Yadav, M. Ferdousi, M. Kumar, D.J. Cuthbertson, . . . U. Alam, *Diabetic Peripheral Neuropathy: Epidemiology, Diagnosis, and Pharmacotherapy.* Clin Ther, 2018. 40(6): p. 828-849.

81. Stone, A.A. and J.E. Broderick, *Obesity and pain are associated in the United States.* Obesity (Silver Spring), 2012. 20(7): p. 1491-5.

82. McCarthy, L.H., M.E. Bigal, M. Katz, C. Derby, and R.B. Lipton, *Chronic pain and obesity in elderly people: results from the Einstein aging study.* J Am Geriatr Soc, 2009. 57(1): p. 115-9.

83. Unroe, K.T., A. Nazir, L.R. Holtz, H. Maurer, E. Miller, S.E. Hickman, . . . G.A. Sachs, *The Optimizing Patient Transfers, Impacting Medical Quality, andImproving Symptoms:Transforming Institutional Care approach: preliminary*

data from the implementation of a Centers for Medicare and Medicaid Services nursing facility demonstration project. Journal of the American Geriatrics Society, 2015. 63(1): p. 165-169.

84. Unroe, K.T., N.R. Fowler, J.L. Carnahan, L.R. Holtz, S.E. Hickman, S. Effler, . . . G. Sachs, *Improving Nursing Facility Care Through an Innovative Payment Demonstration Project: Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care Phase 2.* Journal of the American Geriatrics Society, 2018. 66(8): p. 1625-1631.

85. Hickman, S.E., K.T. Unroe, M.T. Ersek, B. Buente, A. Nazir, and G.A. Sachs, *An interim analysis of an advance care planning intervention in the nursing home setting.* Journal of the American Geriatrics Society, 2016. 64(11): p. 2385-2392.

86. Saliba, D., S. DiFilippo, M.O. Edelen, K. Kroenke, J. Buchanan, and J. Streim, *Testing the PHQ-9 interview and observational versions (PHQ-9 OV) for MDS 3.0.* Journal of the American Medical Directors Association, 2012. 13(7): p. 618-625.

87. Herr, K.A., K. Spratt, P.R. Mobily, and G. Richardson, *Pain intensity assessment in older adults: use of experimental pain to compare psychometric properties and usability of selected pain scales with younger adults.* Clin J Pain, 2004. 20(4): p. 207-19.

88. Gagliese, L., N. Weizblit, W. Ellis, and V.W.S. Chan, *The measurement of postoperative pain: a comparison of intensity scales in younger and older surgical patients.* Pain, 2005. 117(3): p. 412-420.

89. Ware, L.J., C.D. Epps, K. Herr, and A. Packard, *Evaluation of the Revised Faces Pain Scale, Verbal Descriptor Scale, Numeric Rating Scale, and Iowa Pain Thermometer in older minority adults.* Pain Manag Nurs, 2006. 7(3): p. 117-25.

90. Taylor, L.J., J. Harris, C.D. Epps, and K. Herr, *Psychometric evaluation of selected pain intensity scales for use with cognitively impaired and cognitively intact older adults.* Rehabil Nurs, 2005. 30(2): p. 55-61.

91. Peters, M.L., J. Patijn, and I. Lamé, *Pain assessment in younger and older pain patients: psychometric properties and patient preference of five commonly used measures of pain intensity.* Pain Med, 2007. 8(7): p. 601-10.

92. Edelen, M.O. and D. Saliba, *Correspondence of verbal descriptor and numeric rating scales for pain intensity: an item response theory calibration.* Journals of Gerontology Series A: Biological Sciences & Medical Sciences, 2010. 65A(7): p. 778-785.

93. Thomas, K.S., D. Dosa, A. Wysocki, and V. Mor, *The Minimum Data Set 3.0 Cognitive Function Scale.* Medical care, 2017. 55(9): p. e68-e72.

94. Zhang, N., T. Field, K.M. Mazor, Y. Zhou, K.L. Lapane, and J.H. Gurwitz, *The Increasing Prevalence of Obesity in Residents of U.S. Nursing Homes: 2005-2015.* J Gerontol A Biol Sci Med Sci, 2019. 74(12): p. 1929-1936.

95. Pletcher, M.J., S.G. Kertesz, M.A. Kohn, and R. Gonzales, *Trends in opioid prescribing by race/ethnicity for patients seeking care in US emergency departments.* Jama, 2008. 299(1): p. 70-8.

96. Rambachan, A., M.C. Fang, P. Prasad, and N. Iverson, *Racial and Ethnic Disparities in Discharge Opioid Prescribing From a Hospital Medicine Service.* J Hosp Med, 2021. 16(10): p. 589-595.

97. Lepore, M.J., S.C. Miller, and P. Gozalo, *Hospice use among urban Black and White U.S. nursing home decedents in 2006.* Gerontologist, 2011. 51(2): p. 251-60.

98. Brown, C.E., R.A. Engelberg, R. Sharma, L. Downey, J.A. Fausto, J. Sibley, . . . J.R. Curtis, *Race/Ethnicity, Socioeconomic Status, and Healthcare Intensity at the End of Life.* J Palliat Med, 2018. 21(9): p. 1308-1316.

99. Mor, V., J. Zinn, J. Angelelli, J.M. Teno, and S.C. Miller, *Driven to tiers: socioeconomic and racial disparities in the quality of nursing home care.* The Milbank quarterly, 2004. 82(2): p. 227-256.

100. Jones, K.F., E. Laury, J.J. Sanders, L.T. Starr, W.E. Rosa, S.Q. Booker, . . . S.H. Meghani, *Top Ten Tips Palliative Care Clinicians Should Know About Delivering Antiracist Care to Black Americans.* J Palliat Med, 2021.

101. Meit, M., A. Knudson, T. Gilbert, A. Yu, E. Tanenbaum, E. Ormson, . . . S. Popat, *The 2014 update of the rural-urban chartbook*. 2014.

102. Coughlin, S.S., C. Clary, J.A. Johnson, A. Berman, V. Heboyan, T. Benevides, . . . V. George, *Continuing Challenges in Rural Health in the United States.* J Environ Health Sci, 2019. 5(2): p. 90-92.

103. Lewis, J.M., M. DiGiacomo, D.C. Currow, and P.M. Davidson, *Dying in the margins: understanding palliative care and socioeconomic deprivation in the*

developed world. Journal of pain and symptom management, 2011. 42(1): p. 105-118.

104. Suntai, Z., C.R. Won, and H. Noh, *Access Barrier in Rural Older Adults' Use of Pain Management and Palliative Care Services: A Systematic Review.* Am J Hosp Palliat Care, 2021. 38(5): p. 494-502.

105. Tedder, T., L. Elliott, and K. Lewis, *Analysis of common barriers to rural patients utilizing hospice and palliative care services: An integrated literature review.* J Am Assoc Nurse Pract, 2017. 29(6): p. 356-362.

106. Jones, K.R., R.M. Fink, L. Clark, E. Hutt, C.P. Vojir, and B.K. Mellis, *Nursing home resident barriers to effective pain management: why nursing home residents may not seek pain medication.* Journal of the American Medical Directors Association, 2005. 6(1): p. 10-17.

107. Levenson, S., B. Resnick, S. Cryst, R. Ferrini, R. Hogikyan, R. Ignacio, . . . N.K. Overstreet, *Pain Management in the Post-acute and Long-Term Care Setting: A Clinical Practice Guideline (CPG) from the Society for Post-acute and Long-Term Care Medicine (AMDA).* J Am Med Dir Assoc, 2021. 22(12): p. 2407.

108. Apold, J. *CMS removes two quality measures relating to pain*. 2019 [cited 2021; Available from: https://www.leadingagemn.org/news/cms-removes-two-quality-measures-relating-to-pain/.

109. Goodwin, J.S., S. Li, J. Zhou, J.E. Graham, A. Karmarkar, and K. Ottenbacher, *Comparison of methods to identify long term care nursing home residence with administrative data.* BMC health services research, 2017. 17(1): p. 376.

110. Li, S., A. Middleton, K.J. Ottenbacher, and J.S. Goodwin, *Trajectories Over the First Year of Long-Term Care Nursing Home Residence.* Journal of the American Medical Directors Association, 2018. 19(4): p. 333-341.

111. Won, A.B., K.L. Lapane, S. Vallow, J. Schein, J.N. Morris, and L.A. Lipsitz, *Persistent nonmalignant pain and analgesic prescribing patterns in elderly nursing home residents.* Journal of the American Geriatrics Society, 2004. 52(6): p. 867-874.

112. Zwakhalen, S.M.G., R.T.C.M. Koopmans, P.J.E.M. Geels, M.P.F. Berger, and J.P.H. Hamers, *The prevalence of pain in nursing home residents with dementia measured using an observational pain scale.* European Journal of Pain (London, England), 2009. 13(1): p. 89-93.

113. Ersek, M., K. Herr, M.B. Neradilek, H.G. Buck, and B. Black, *Comparing the psychometric properties of the Checklist of Nonverbal Pain Behaviors (CNPI) and the Pain Assessment in Advanced Dementia (PAIN-AD) instruments.* Pain Medicine, 2010. 11(3): p. 395-404.

114. Ersek, M., N. Polissar, M.B. Neradilek, M. Ersek, N. Polissar, and M.B. Neradilek, *Development of a composite pain measure for persons with advanced dementia: exploratory analyses in self-reporting nursing home residents.* Journal of Pain & Symptom Management, 2011. 41(3): p. 566-579.

115. Smith, D., R. Wilkie, P. Croft, and J. McBeth, *Pain and Mortality in Older Adults: The Influence of Pain Phenotype.* Arthritis Care Res (Hoboken), 2018. 70(2): p. 236-243.

116. Nagin, D., *Group-Based Modeling of Development*. 2005, Cambridge, MA: Harvard University Press.

117. Nagin, D.S. and C.L. Odgers, *Group-based trajectory modeling in clinical research.* Annual Review of Clinical Psychology, 2010. 6: p. 109-138.

118. Nagin, D.S., B.L. Jones, V. Lima Passos, and R.E. Tremblay, *Group-based multi-trajectory modeling.* 2018.

119. Jones, B.L. and D.S. Nagin, *A Note on a Stata Plugin for Estimating Group-based Trajectory Models.* Sociological Methods & Research, 2013. 42(4): p. 608-613.

120. Haviland, A.M., B.L. Jones, and D.S. Nagin, *Group-based trajectory modeling extended to account for nonrandom participant attrition.* Sociological Methods & Research, 2011. 40(2): p. 367-390.

121. Berry, S.D., Y. Lee, A.R. Zullo, D.P. Kiel, D. Dosa, and V. Mor, *Incidence of Hip Fracture in U.S. Nursing Homes.* The journals of gerontology. Series A, Biological sciences and medical sciences, 2016. 71(9): p. 1230-1234.

122. Dharmarajan, T.S., H. Tankala, B. Patel, M. Sipalay, and E.P. Norkus, *Outcome in ambulatory status immediately following hip fracture surgery in the acute setting: a comparison of nursing home residents and community older adults.* J Am Med Dir Assoc, 2001. 2(3): p. 115-9.

123. Beaupre, L.A., C.A. Jones, D.W. Johnston, D.M. Wilson, and S.R. Majumdar, *Recovery of function following a hip fracture in geriatric ambulatory persons living in nursing homes: prospective cohort study.* J Am Geriatr Soc, 2012. 60(7): p. 1268-73.

124. Neuman, M.D., J.H. Silber, J.S. Magaziner, M.A. Passarella, S. Mehta, and R.M. Werner, *Survival and functional outcomes after hip fracture among nursing home residents.* JAMA Intern Med, 2014. 174(8): p. 1273-80.

CURRICULUM VITAE

Connie Sue Cole

Education

2022	PhD, Indiana University, Indianapolis, IN Major: Nursing Minor: Geriatrics
2014	DNP, Purdue University, West Lafayette, IN Minor: Gerontology
2011	MSN, Adult Nurse Practitioner, Purdue University, Fort Wayne, IN
2009	BSN, Indiana Wesleyan University, Marion, IN
1995	ASN, Purdue University, Fort Wayne, IN
1987	LPN, Ivy Tech, Fort Wayne, IN

Research Experience

2019 - 2021	Research Assistant, Indiana University School of Nursing, Indianapolis Principal Investigator: Susan Hickman, PhD
2018 - 2019	Woltman Fellow, IUPUI Research in Palliative and End-of-Life Communication and Training (RESPECT) Signature Center, Advance Care Planning Education for Nursing Home Staff Leveraging Value Based Purchasing Indiana University School of Nursing, Indianapolis, IN Investigators: Susan Hickman, PhD and Kathleen Unroe, MD
2014	DNP Student Capstone Project, *"Preparing Future Health Professionals for an Aging Population"*

Academic Experience

2012-2019	Clinical Assistant Professor of Nursing, Indiana University/Purdue University School of Nursing, Fort Wayne, IN (Note: Purdue nursing department became part of Indiana University School of Nursing in 2018)
2012-2018	Program Director Adult-Gerontological Primary Care Nurse Practitioner Program, Purdue University, Fort Wayne, IN
2009-2012	Visiting Professor, Lecturer, Graduate Assistant, Nursing, Purdue University, Fort Wayne, IN

Clinical and Administrative Experience

2011 -	Adult Nurse Practitioner, Nursing Home Private Practice, Self Employed
2016-2018	Executive Director of Purdue University Fort Wayne Health Clinics, Fort Wayne, IN
2009-2014	Deputy Coroner, Noble County Coroner's Office, Albion, IN
2000-2009	Director of Nursing, Kendallville Healthcare Manor, Kendallville, IN
1997-2000	Utilization Review, Sacred Heart Home, Avilla, IN

Certifications and Licensure

Registered Nurse
Indiana State Board of Nursing
Nurse Practitioner
Indiana State Board of Nursing
Certified Adult Nurse Practitioner
American Academy of Nurse Practitioners
Certified Gerontological Nurse
American Nurses Credentialing Center

Honors and Awards

2022	IUPUI Chancellor's Scholar's Award, Honorable Mention
2020-2021	Luella McWhirter Internship/Fellowship
2020	Audrey S. Geisel Nursing Fellowship
2020	Ruth Deter Scholarship
2020	Lyons Dissertation Award
2019	IUPUI PhD Nursing Leadership Scholarship
2019	Michelle White Scholarship
2019	Class of 1966 Scholarship in Nursing Education
2019	Frank and Robin Newhouse Scholarship
2019	Daisy Faculty Award
2018	Woltman Communication in End-of-Life Fellowship
2018	Irene Aycock Scholarship
2018	IUPUI Leadership in Nursing Education Scholarship
2015	Golden Stethoscope Award
2013	Gerontological Advance Practice Nurses Association Health Policy Scholarship
2012-2013	Purdue Gerontology Trainee Scholarship
2011-2012	Helene Fuld Scholarship
2010	Parkview Tapestry Scholarship
2009	John and Joan Robinson Scholarship

Publications

Peer-Reviewed Journal Articles:

Hickman, S., Cole, C.S., Unroe, K.T., (2022). Leveraging Value-Based Purchasing to Improve Advance Care Planning. *Journal of Gerontological Nursing*, 2022. 48(2): p. 31-35.

Cole, C., & Zimmerman, R. (2017). Anticoagulant options in atrial fibrillation: When novel treatments become standard practice. *The Nurse Practitioner Journal*.

Bane, T., & Cole, C. (2015). Prevention of Alzheimer's disease: The roles of nutrition and primary care. *The Nurse Practitioner Journal*

Cole, C. (2012). A Closer look at mission nursing: Perspectives from an experience abroad. *Imprint*, 76-79.

Cole, C. (2012). Know your WBCs. *Nursing Made Incredibly Easy*, 11-15.

Accepted Abstracts and Presentations:

Cole, C., Hickman, S., Carpenter, J., Chen, C., Blackburn, J. (2022) Group-based Trajectory Modeling of Nursing Facility Resident Pain Scores. *Midwest Nursing Research Society*. Annual Research Conference. (Poster Presentation)

Cole, C., Hickman, S., Carpenter, J., Chen, C., Blackburn, J. (2022) Group-based Trajectory Modeling of Nursing Facility Resident Pain Scores. *American Geriatrics Society*. Annual Scientific Meeting. (Poster Presentation)

Cole, C., Lum, H., Koch, S., Hickman, S. (2022) Nursing Facility Provider Perceptions of Appropriate Use of POLST. *American Geriatrics Society*. Annual Scientific Meeting. (Poster Presentation)

Cole, C., Lum, H., Koch, S., Hickman, S. (2022) Nursing Facility Provider Perceptions of Appropriate Use of POLST. *American Academy of Hospice and Palliative Medicine*. State of the Science in Hospice and Palliative Care Conference. (Poster Presentation)

Cole, C., Hickman, S., Carpenter, J., Chen, C., Blackburn, J., (2021) Nursing home resident pain prevalence and associated factors: An integrative review of the literature. *Midwest Nursing Research Society*. Annual Research Conference. IUSON Student Poster Competition Winner (Poster Presentation)

Cole, C., (2020) Does nursing home resident pain differ between nursing homes implementing the OPTIMISTIC clinical/payment model combination and nursing homes implementing the OPTIMISTIC payment only model? *OPTIMISTIC Annual Stakeholder Meeting*. (Poster accepted but not presented due to COVID-19 restrictions)

Pinkerton A, Cole, C.S., (2017) A Comprehensive overview of end-of-life care and hospice: Implications for advanced practice nurses. *Purdue Fort Wayne Teaching Seminar*, Fort Wayne, IN. (Podium presentation)

Heidenreich, C, Cole, C.S., (2016) Palliative care and end of life issues. *Purdue Fort Wayne Teaching Seminar*, Fort Wayne, IN. (Podium presentation)

Cole, C., (2014) Preparing Future Health Professionals for an Aging Population. *Purdue University* (Podium presentation)

Works in Progress:

Hickman, S., Cole, C., Koch, S., Lum, H., (Manuscript in Progress). Nursing facility provider decision making about which residents are appropriate or inappropriate for POLST.

Cole, C., Hickman, S., Carpenter, J., Blackburn, J., Chen, C. (Manuscript in Progress) Prevalence and associated factors of pain in nursing home residents: A systematic review of the literature.

Cole, C., Hickman, S., Carpenter, J., Blackburn, J., Chen, C. (Manuscript in Progress) Pain and associated factors in nursing home residents.

Cole, C., Hickman, S., Carpenter, J., Blackburn, J., Chen, C. (Manuscript in Progress) Group based trajectory modeling of nursing home resident pain scores.

Professional Memberships

2021 -	Member, Palliative Care Research Cooperative Group, University of Colorado (5U2CNR014637-08)
2021 -	Member, United States Association for the Study of Pain (USASP)
2021 -	Executive Committee Member, USASP Pain and Aging Committee
2020 - 2021	Member, American Pain Management Nurses Association
2020 - 2021	Member, Midwest Pain Society
2020 -	Member, Emerging Scholars Network, Hospice and Palliative Care Nurses Association
2019 -	Society for Post-Acute and Long-Term Care Medicine
2017-	Member, Midwest Nursing Research Society, End-of-Life Research Interest Group, Symptom Science Research Interest Group, & Gerontological Nursing Research Interest Group
2017 -	Hospice and Palliative Care Nursing Association
2012 - 2019	American Nurses Credentialing Center, Geriatric Content Expert Registry
2011 -	Gerontological Advanced Practice Nurses Association
2011-	Health Policy Committee, Member, Gerontological Advanced Practice Nurses Association
2010 -	American Academy of Nurse Practitioners
2009 -	Sigma Theta Tau

Select Professional Development

2022	Annual Investigator Conference, Palliative Care Research Cooperative, Virtual conference, March 2022
2022	American Academy of Hospice and Palliative Care Medicine, State of the Science Conference, Virtual
2021	Group Based Trajectory Modeling Workshop, Inter-university Consortium for Political and Social Research (ICPSR) University of Michigan, Virtual workshop, May 2021

2021	Annual Investigator Conference, Palliative Care Research Cooperative, Virtual conference, March 2021
2021	Midwest Nursing Research Society Annual Conference, Virtual, March 2021
2020	Introduction to Grant Proposal Development, IUPUI Office of Vice Chancellor for Research, Virtual workshop
2020	Integrated Pain Management, IUPUI Project ECHO, twice monthly meetings beginning September 2020
2020	Clinical Data Science for Beginners, Midwest Nursing Research Society Annual Conference Pre-Workshop, Virtual
2020	Midwest Nursing Research Society Annual Conference, Virtual