A Latent Approach to Understanding Pain in Nursing Home Residents Who are Unable to Self-Report Pain

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Context: Pain assessment in people with cognitive impairment is challenging.

Objective: The study sought to 1) identify pain subgroups based on staff-assessed pain, agitated and reactive behavior, functional status, and symptoms of depression; and 2) understand if cognitive impairment was associated with transitions between pain subgroups at nursing home admission, 3 months, and 6 months.

Methods: Using national Minimum Data Set 3.0 data (2011–2016), we included 26,816 newly admitted residents with staff-assessed pain at admission, 3 months, and 6 months. Pain subgroups were identified by latent class analysis at each time point. Transitions between pain subgroups were described using latent transition analysis.

Results: Five latent statuses of pain were identified at admission: “Behavioral and Severe Depression” (prevalence stable, severe or worsening cognitive impairment: 11%, mild/moderate or improved cognitive impairment: 10%), “Functional” (21%; 25%), “Physical” (22%; 23%), “Behavioral” (23%; 19%), and “Low” (23%; 24%). Regardless of change in cognitive status, most residents remained in the same pain latent class. Among residents with stable, severe or worsening cognitive impairment, 11% in the “Behavioral” class transitioned to the “Behavioral and Severe Depression” class by 3 months. Fewer residents transitioned between latent classes in the 3- to 6-month period (>80% remained in their 3-month class).

Conclusion: For nursing home residents unable to self-report pain, consideration of additional indicators including functioning, depressive symptoms, and agitation may be useful in identifying pain subgroups. Longitudinal changes in the pain subgroups over 6 months post-admission highlight that residents with severe cognitive impairment may be at risk for worsening pain.

Keywords: latent transition analysis, dementia, depressive symptoms, agitation, long-term care

Introduction

In nursing homes, residents commonly experience pain. Despite similar frequencies of painful conditions across levels of cognitive impairment, residents with worse cognitive function have decreased pain documented in nursing homes. Among residents with moderate to severe dementia, 45% experienced moderate to severe pain at some point in the previous week. Yet, nursing home direct care staff may fail to recognize pain in residents unable to self-report pain owing to dementia or may confuse indicators of pain with behavioral and psychological symptoms of dementia.

Pain assessment in people with cognitive impairment is challenging, as alterations in speech/language and memory often worsen as disease progresses.
Observational pain scales have been developed for use in people with cognitive impairment such as the Pain Assessment in Advance Dementia (PAINAD), visual analog scales, the Discomfort in Dementia Scale and Protocol, the checklist of non-verbal pain indicators, and proxy pain questionnaires. Among patients who are unable to self-report pain, facial expressions and behavioral symptoms are often included in scales designed to assess pain. Restlessness, rubbing, guarding, rigidity, and physical aggression show strong evidence as body movement indicators for pain while bracing, decreased mobility, flinching, and pacing show moderate evidence. The assessment of pain in those with dementia is further complicated by the well-documented relationships between pain and depression and dementia and depression. Among those who are unable to self-report pain, disentangling pain and depression can be challenging.

Pain affects quality of life, mental health, and activities of daily living. Understanding the non-traditional ways that pain may be exhibited and the relationship between pain and depression symptoms is important to ensure adequate treatment. This study sought to identify pain subgroups among residents unable to self-report pain and to understand if cognitive impairment was associated with movement between pain subgroups at admission, 3 months, and 6 months among residents. We hypothesized that 1) pain would be expressed through non-verbal sounds, vocal complaints of pain, facial expressions, protective body movements, behavioral symptoms, and that the relationship of pain to depression and functional status would result in distinct pain subgroups and 2) the level of cognitive impairment would affect how residents move between subgroups at 3- and 6-months post admission.

Methods
This study was approved by the University of Massachusetts Medical School Institutional Review Board (IRB ID: H00011964). In accordance with our Data Use Agreement with the Centers for Medicare and Medicaid Services, the Minimum Data Set resource used in the study complies with data protection and privacy regulations.

Conceptual Framework Guiding Research
Our study was guided by the seminal multidimensional pain model, which conceptualized pain as the result of a complex interaction between physiological, emotional, cognitive, and behavioral domains. Pain is a multidimensional construct with sensory, behavioral, emotional, and cognitive components. The dominant theories regarding pain are applicable to those with dementia. We have modified the model as the original model views mood as an outcome and we will consider it a symptom in our analyses.

Data Source
The Minimum Data Set (MDS) 3.0 contains information on comprehensive assessments of the health and functional status of every nursing home resident in Medicare/Medicaid certified nursing homes in the United States. Most US nursing homes are Medicare/Medicaid certified (~96%). The MDS assessment includes demographic information, diagnosed chronic conditions, self-reported depressive symptoms, staff-assessed pain, cognitive function, and behavioral and functional symptoms. A comprehensive MDS assessment is completed at admission. Thereafter, a subset of items is collected on quarterly assessments. The MDS is completed by multiple members of the care team, and includes information on self-reported and staff-observed symptoms and behaviors. All participant assessments were completed in-person at the nursing home.

Sample Selection
We identified 1,222,705 skilled nursing facilities or long-stay residents aged ≥65 years newly admitted to US nursing homes between 2011 and 2016, without a cancer diagnosis, non-comatose, and having 3- and 6-month assessments (Figure 1). Newly admitted residents were selected because they could be compared to each other in relation to time since admission. Residents with cancer were excluded because their pain was likely different from those with non-malignant pain. Our study focused on residents unable to self-report pain. The MDS manual provides explicit instructions on whether a staff assessment for pain should be conducted; staff assessment occurs only if the self-reported pain assessment interview is not completed. The study sample included 26,816 residents.

Measures
Staff assessment of pain was carried out based on information from the 5 days preceding the admission assessment (restricted to time in the nursing home) through the MDS Pain Behavior Scale. Staff assessment of four behavioral pain indicators included review of medical records, interviews with staff, and direct observation. The four pain
behaviors were 1) nonverbal sounds (eg, crying, whining, groaning); 2) vocal complaints (eg, ouch, stop); 3) facial expressions (eg, grimaces, winces); and 4) protective body movements (eg, bracing, rubbing, clutching a body part during movement). Medical records were reviewed, and information was confirmed with the direct care staff working most closely with the resident during activities of daily living (across all shifts). The direct care staff were asked about the presence of each pain indicator. Direct observation was conducted during care activities. The average agreement (kappa) for staff observed pain behaviors was between 0.94 and 0.96. The frequency of pain behaviors within the past 5 days was documented (ie, 1–2 days, 3–4 days, daily). We calculated Cronbach’s alpha as 0.63 in our sample. Pain was dichotomized as absent (none of the signs were observed or documented in the last 5 days) or present (any of the indicators of pain were present in the last 5 days).

The 10-item Patient Health Questionnaire Observational Version (PHQ-9 OV) and adaptation of the original PHQ-9 were used to screen for depression among residents who could not complete an interview (range: 0–30). Cronbach’s alpha for the PHQ-9 in primary care was 0.89. We calculated Cronbach’s alpha at 0.71 for the PHQ9-OV in our sample. We only used data from participants who were unable to self-report the PHQ-9. Anhedonia, hopelessness, insomnia/hypersomnia, poor appetite/overeating, worthlessness, impaired concentration, and psychomotor agitation/retardation, but not suicidal ideation (<1%) were included.

Functional status was assessed with the activities of daily living (ADL) hierarchy scale based on personal hygiene, toilet use, locomotion, and eating, which adapts the common measurements of ADLs to the MDS dataset. Cronbach’s alpha was 0.94 in the MDS validation study and 0.85 in our sample. The scale is scored 0–6 with 0 indicating independence in all four ADLs, 3 indicating at least extensive help needed in personal hygiene or toilet use, and 6 indicating total dependence in all four ADLs. We dichotomized the scale (1 = dependence (scores of 5 or 6); 0 = independent through extensive assistance).

The Agitated and Reactive Behavior Scale is a composite measure of physical and verbal behavioral symptoms directed at other people, other behavioral symptoms not directed at other people (eg, disrobing, pacing), and rejection of care that was updated from the original Aggressive Behavior Scale. Cronbach’s alpha in the validation study for newly admitted residents was 0.71 and 0.73 in our sample. The ARBS score range is 0 (behavior not exhibited on any item) to 12 (behavior...
occurs daily on all 4 items), but we dichotomized the scale (1 = any behavioral symptoms present, 0 = no behavioral symptoms present).

The Cognitive Function Scale (CFS), a measure of cognitive status based on MDS items, integrates information from the Brief Interview for Mental Status (score range 0–15, lower score indicates worse cognition, 3 items total) and the Cognitive Performance Scale (score range 0–6, higher score indicates worse cognition, 5 items total). The internal consistency (Cronbach’s alpha) of the CPS was 0.70 in a validation study. The CFS classifies residents as intact (able to complete BIMS and scored 13–15), mildly impaired (8–12 BIMS score or 0–2 CPS score), moderately impaired (0–7 BIMS score or 3–4 CPS score, or severely impaired (could not complete BIMS and 5–6 CPS score). The scale has four items total and a score range of 0–6, but we created a dichotomized variable that indicated change in cognitive impairment from admission to 6 months. Residents who had severe cognitive impairment at nursing home admission and who remained severely impaired at 6 months were included in the “worse” category.

Analyses

Descriptive statistics characterized the sample overall and by change in level of cognitive impairment. To identify pain subgroups and understand how cognitive impairment affects resident transition between pain groups, we used latent transition analysis (LTA), a longitudinal extension of latent class analysis (LCA). LTA includes a measurement component and a structural component. The first step in the analysis is to complete a cross-sectional LCA at each time point (ie, admission, 3 months, and 6 months). LCA produces posterior probabilities or the likelihood of a resident endorsing an item given their membership in a class which makes up the measurement component. The structural component consists of the class prevalence at each time point and the conditional probability of transition from one class to another at each time point given the class membership at the previous time point.

Separate LCAs were completed to determine the ideal number of classes at admission, 3 months, and 6 months. Twelve dichotomous indicators measuring pain, behavioral symptoms, ADLs, and depression (interest, feeling down, sleep, energy, appetite, feeling like a failure, concentration, psychomotor retardation, and temper) were included in each model. Fit indices (AIC, BIC, Lo-Mendell Rubin [LMR], and Bootstrapped Likelihood Ratio [BLRT] tests) were obtained for models with classes ranging from 2 to 8 for each time point. Next, LTA was used to measure transition probabilities from admission to 3 months to 6 months. We ran an overall LTA with the full sample and an LTA in which change in cognitive status was used as a grouping variable to influence the transitions.

Results

Sample Characteristics

Table 1 shows that most were aged ≥75 years and the sample majority was unmarried, White, and women. More than 90% had moderate to severe cognitive impairment as measured by the CFS. Fifty-two percent of residents had either stable severe cognitive impairment or worsened cognitive impairment over the 6 months since nursing home admission.

Latent Class Analyses at Nursing Home Admission, 3 Months, and 6 Months

Separate LCAs at admission, 3 months, and 6 months were examined to determine the optimal number of classes at each time point. We examined the bivariate residuals to check the assumption of conditional independence. Conditional independence assumes that all indicators are independent of one another after conditioning on the latent class. We found that the indicators for feeling like a failure and psychomotor retardation remained dependent after conditioning on the latent class and neither indicator distinguished between latent classes, so we removed them as indicators. The final LCA included 10 indicators. The AIC and BIC indicated a six-class solution at each time point while the BLRT and LMR indicated a five-class solution at each time point. We selected the five-class solution because six-class solution did not add pertinent information to the model. Figure 2 displays the indicators and their conditional probabilities within each class. The “Low” class had probabilities of 0.20 or less for all indicators. The “Behavioral and Severe Depression” class showed high probability of behavioral symptoms as well as high probabilities of all depression symptoms. The “Behavioral” class also had high probability of behavioral symptoms but only a high probability of being short-tempered or easily annoyed, a behavioral symptom of depression. The “Functional” class had a high probability of being dependent or totally dependent while the “Physical” class had a high probability of being dependent...
or totally dependent and a high probability of feeling tired or having little energy, a physical depression symptom. Based on the initial LCA, we conducted the LTA with five classes and 10 indicators.

### Latent Transitions from Nursing Home Admission to 6 Months

We examined transitions across classes from admission to 6 months. We ran both an overall LTA and an LTA with change in cognitive status (same/better versus worse) as a grouping variable so that we could examine the rates of transition across cognitive status groups. Among the full sample, the estimated prevalence of each class was similar at each time point. The only class that appeared to increase was the “Behavioral and Severe Depression” class which had estimated prevalence of 10%, 13%, and 14% at admission, 3 months, and 6 months, respectively. Class stability over time was similar within cognitive change groups (Table 2). The “Behavioral and Severe Depression” class increased from admission to 3 months and then stabilized for both groups. All other classes had similar prevalence at each time point. The main difference in class membership between groups can be seen in the differences in class membership in the “Low” class and the “Functional” class. Among those whose cognitive status did not worsen, about 30% are in the “Low” class compared to about 19% among those whose cognitive status did worsen or remained severe. Conversely, about 29% of those whose cognitive status worsened or remained severe were in the “Functional” class compared to about 19% in those whose cognitive status remained mild or moderate or improved.

Among the full sample, there was less stability from admission to month 3 than from month 3 to month 6 (Table 3). About 11% of the sample transitioned from the “Behavioral and Severe Depression” to “Physical” and 12% transitioned from “Behavioral and Severe Depression” to “Behavioral”. Similarly, 12% transitioned from “Physical” to “Functional” and 11% transitioned from “Behavioral” to “Low”. Class membership was more stable from 3 months to 6 months; class stability ranged from 90% for the “Physical” and “Low” classes to 95% for the “Functional” class.

Group-specific transitions followed a similar pattern. There was more movement from admission to 3 months.
and more stability from 3 to 6 months. From admission to 3 months, there were multiple transitions of 0.10 or higher among both cognitive change groups. Several transitions were similar between the two groups, such as transitions from the “Behavioral and Severe Depression” class to the “Behavioral” class, and from the “Behavioral and Severe Depression” class to the “Physical” class. Specific to the same/better cognitive change group, there were higher proportions of participants moving to the “Low” class from other classes (13%–14%). Among the stable severe cognitive impairment/worsening cognitive change group, only the “Behavioral” class had a higher proportion that moved to the “Low” class (10%). Unique to the stable severe cognitive impairment/worsening cognitive change

Table 2 Estimated Class Membership Across Time Points by 6-Month Change in Cognitive Impairment Among US Nursing Home Residents with Staff-Assessed Pain (2011–2016)

|                          | Behavioral and Severe Depression | Functional | Physical | Behavioral | Low |
|--------------------------|----------------------------------|------------|----------|------------|-----|
| **Stable, Severe Cognitive Impairment or Worsened in 6 Months Since Admission** |                                   |            |          |            |     |
| Admission                | 11%                              | 21%        | 22%      | 23%        | 23% |
| Three Months             | 15%                              | 21%        | 22%      | 21%        | 23% |
| Six Months               | 15%                              | 21%        | 22%      | 21%        | 22% |
| **Stable, Mild/Moderate Cognitive Impairment or Improved in 6 Months Since Admission** |                                   |            |          |            |     |
| Admission                | 10%                              | 25%        | 23%      | 19%        | 24% |
| Three Months             | 14%                              | 24%        | 23%      | 19%        | 24% |
| Six Months               | 14%                              | 24%        | 23%      | 19%        | 23% |
We found that consideration of additional measures to detect pain in nursing home residents unable to self-report pain has value. Among newly admitted nursing home residents unable to self-report pain, there were five pain symptom subgroups differentiated by dependence in ADLs, behavioral symptoms, and symptoms of depression. Three-quarters of residents had symptom profiles qualitatively similar across time periods (admission, 3 months, 6 months) and change in cognitive impairment, 3 months post nursing home admission. We noted transitions from "low" to "functional" increased by about 3% from 3 to 6 months compared to the first 3 months post nursing home admission.

Table 3 Latent Transition Probabilities from Nursing Home Admission to 3 Months and 3 Months to 6 Months, by Cognitive Change Status

|                        | Behavioral and Severe Depression | Functional | Physical | Behavioral | Low | Behavioral and Severe Depression | Functional | Physical | Behavioral | Low |
|------------------------|---------------------------------|------------|----------|------------|-----|----------------------------------|------------|----------|------------|-----|
| **Stable, Severe Cognitive Impairment or Worsened** |                                 |            |          |            |     |                                  |            |          |            |     |
| Behavioral and Severe Depression | 0.69                            | 0.03       | 0.13     | 0.12       | 0.02 | 0.90                             | 0.01       | 0.06     | 0.03       | 0.01 |
| Functional             | 0.00                            | 0.82       | 0.09     | 0.02       | 0.06 | 0.00                             | 0.93       | 0.05     | 0.01       | 0.01 |
| Physical               | 0.02                            | 0.18       | 0.68     | 0.03       | 0.08 | 0.03                             | 0.08       | 0.85     | 0.01       | 0.03 |
| Behavioral             | 0.11                            | 0.04       | 0.05     | 0.70       | 0.10 | 0.07                             | 0.02       | 0.04     | 0.84       | 0.03 |
| Low                    | 0.03                            | 0.06       | 0.05     | 0.07       | 0.79 | 0.02                             | 0.09       | 0.04     | 0.02       | 0.83 |
| **Stable, Mild/Moderate Cognitive Impairment or Improved** |                                 |            |          |            |     |                                  |            |          |            |     |
| Behavioral and Severe Depression | 0.72                            | 0.02       | 0.11     | 0.12       | 0.03 | 0.91                             | 0.02       | 0.01     | 0.04       | 0.02 |
| Functional             | 0.01                            | 0.84       | 0.04     | 0.01       | 0.10 | 0.00                             | 0.96       | 0.03     | 0.00       | 0.01 |
| Physical               | 0.02                            | 0.11       | 0.74     | 0.04       | 0.09 | 0.00                             | 0.06       | 0.91     | 0.01       | 0.03 |
| Behavioral             | 0.04                            | 0.03       | 0.02     | 0.81       | 0.12 | 0.02                             | 0.02       | 0.01     | 0.93       | 0.02 |
| Low                    | 0.01                            | 0.05       | 0.03     | 0.02       | 0.89 | 0.05                             | 0.05       | 0.02     | 0.00       | 0.91 |

Discussion

We found that consideration of additional measures to detect pain in nursing home residents unable to self-report pain has value. Among newly admitted nursing home residents unable to self-report pain, there were five pain symptom subgroups differentiated by dependence in ADLs, behavioral symptoms, and symptoms of depression. Three-quarters of residents had symptom profiles qualitatively similar across time periods (admission, 3 months, 6 months) and change in cognitive impairment, 3 months post nursing home admission. We noted transitions from "low" to "functional" increased by about 3% from 3 to 6 months compared to the first 3 months post nursing home admission.

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symptom subgroup at 3 and 6 months, transitions across subgroups were more apparent in the 3 months post nursing home admission as compared to the 3 to 6 months post admission.

One-third of residents lacking the ability to self-report pain were aligned with latent classes defined by behavioral symptoms [Behavioral and Severe Depression" (~11–15%); “Behavioral” subgroups (~19–23%)]. Our findings are consistent with previous research supporting the notion that pain may be a root cause of behavioral disturbances as the links between pain, psychiatric symptoms, and depression onset have been shown. We also found that the prevalence of the “Behavioral and Severe Depression” class increased from admission to 3 months, and 1 in 10 residents with worsening or stable severe cognitive impairment transitioned from the “Behavioral” class to the “Behavioral and Severe Depression” class by 3 months post-admission. There are several plausible explanations for these findings. One explanation is that as nursing home staff get to know residents better over 3 months, documentation of depressive symptoms is more accurate. While no data exist specific to residents unable to self-report pain, previous work has shown little transition between depressive symptom subgroups within the first 3 months of a nursing home stay. Residents adjusting to their new setting may develop depressive symptoms during the 3-month transitional phase. While a recent study on suicidal ideation in nursing homes noted that the prevalence declined with time in the nursing facility, research on changes in depressive symptoms throughout the initial transition to nursing home among residents lacking the ability to report pain measures does not exist. Studies to further understand the patterns observed may provide greater direction to improve pain recognition and management in this population. We agree with others who endorse the need to evaluate the triggers of behavioral disturbances and identify appropriate strategies to intervene on modifiable triggers.

Most residents remained in their admission latent class at 3 months and further research is needed to understand the reasons why. In a medically supervised setting, we had hoped to see improvements in pain subgroups with time. Use of analgesics and antidepressants may reduce pain. Our study was not designed to evaluate the role of pharmacologic interventions. Whether the residents in our study received treatments for pain and/or depression and the extent to which such treatments reduce symptom burden needs to be carefully evaluated in future research.

We had expected greater change in latent classes earlier in the nursing home stay and the data confirmed this expectation. For those transitioning between the latent classes, we observed more change in the first 3 months, with greater stability between 3- and 6-months post nursing home admission. It is well known that the initial period in the nursing home corresponds with major adjustments. Nevertheless, the stability observed in the 3- to 6-month period is troublesome. In nursing homes, each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care.

In March 2009, changes to surveyor guidance provided in F-Tag 309 gave explicit direction about the nursing home’s responsibility regarding effectively identifying specific pain type and pain management. Although data in the immediate post-implementation period suggested positive changes in response to the surveyor guidance with respect to recognition and management of pain, these findings did not extend to nursing home residents with severe cognitive impairment. If regulations and administrative initiatives do not meet the needs of residents who cannot report pain, research on how best to implement effective pain assessment and management strategies in this setting is warranted. Clinical implications include the need to ensure that pain in cognitively impaired populations is being managed adequately and recognition that the adjustment period after entering a nursing home and the unique pain and psychosocial needs of patients. Our findings of stable pain classes from 3 to 6 months indicate that this pain may not be adequately managed in this population.

Strengths and Limitations

We used a national data resource that included virtually all US nursing home residents. Doing so allowed for a large sample size of residents unable to self-report pain and provides a “real-world” look at the symptoms experienced by this population. Because we wanted our findings to be informative for all residents unable to self-report pain in nursing home settings, we did not limit our sample to specific populations likely to experience pain (eg, cancer or post-surgical populations). Our study provides a longitudinal evaluation of pain subgroups within the
first 6 months of the nursing home stay. Previous cross-sectional research has provided a snapshot of pain at admission, and only included residents with self-reported pain. Our study demonstrates that latent transition analysis is a useful tool to harness the power of longitudinal, high dimensional data for pain symptom science in an under-studied setting.

Our study is limited to the first 6 months of the nursing home stay, a critical time in the nursing home stay. Additional study is required to evaluate the extent to which our findings extend to longer stays. Evaluating pain subgroups throughout the entire nursing home stay may yield greater insights about the course of symptoms. Such insights may help develop processes of care to improve pain recognition and management. Our decision to focus on newly admitted residents with assessments at 3 and 6 months may have introduced selection bias as residents may have been excluded if they died or were discharged during the first 6 months. We recognize that studies using administrative data resources are limited to items collected. Our study lacked measures of specific domains of cognitive function. As recommended when using administrative data, we had a clear rationale regarding which indicators to include that was guided by a relevant conceptual model.

Conclusions
Our longitudinal study supports the notion that pain subgroups may be differentiated by pain itself, depressive symptoms, and behavioral manifestations. Broadening the perspective pain expressions in those unable to self-report to include physical, behavioral, and psychological components may lead to better recognition of pain in nursing homes. Leveraging existing data and applying person-centered analytic approaches to identify residents in pain is an important first step towards improving pain recognition in those unable to voice their suffering. Algorithms to identify pain residents unable to express their suffering coupled with pharmacological (e.g., scheduled analgesics and/or adjuvants) and non-pharmacological (e.g., massage, heating pad) treatments may improve pain management in nursing homes.

Key Message
This article describes longitudinal changes in pain subgroups differentiated by physical functioning, depressive symptoms, and agitation for nursing home residents unable to self-report pain. Longitudinal changes in the pain subgroups over 6 months post-admission highlight that residents with severe cognitive impairment may be at risk for worsening pain.

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