Pain in U.S. nursing homes: Validating a pain scale for the minimum data set

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Abstract:
The aim of this study was to validate a pain scale for the Minimum Data Set (MDS) assessment instrument and examine prevalence of pain in major nursing home subpopulations, including type of admission and cognitive status. A four-group scale was highly predictive of VAS pain scores (variance explanation 56%) and therefore quite valid in detecting pain.

Full Text:

[Headnote]

Purpose: The aim of this study was to validate a pain scale for the Minimum Data Set (MDS) assessment instrument and examine prevalence of pain in major nursing home subpopulations, including type of admission and cognitive status. Design and Methods: This study considered validation of the MDS pain items and derivation of scale performed against the Visual Analogue Scale (VAS), using Automatic Interaction Detection. The derivation data describe 95 postacute care nursing home patients who are able to communicate. The scale is then used in retrospective analysis of 34,675 Michigan nursing home residents. Results: A four-group scale was highly predictive of VAS pain scores (variance explanation 56%) and therefore quite valid in detecting pain. In the prevalence sample, only 47% of postacute patients compared to 63% of postadmission patients reported no pain, and these percentages rose with increasing cognitive impairment. Implications: Pain is prevalent in nursing home residents, especially in those with cognitive dysfunction, and often untreated.
Key Words: Care planning, Comprehensive assessment, Long-term care

The Omnibus Budget Reconciliation Act of 1987 mandated that a comprehensive and uniform resident assessment system be implemented nationwide in all United States nursing homes. The Resident Assessment Instrument (RAI) system, with its Minimum Data Set (MDS) assessment, was implemented in 1991 (Morris et al., 1990). The purpose of the RAI was mandated in the original law: to improve care. It was assumed that improved, individualized assessment of a resident's condition would lead to better care planning that would, in turn, lead to better care and improved outcomes. This logic of achieving improved care requires at least that the assessment is accurate and valid.

In this context, pain is a domain acknowledged to be critical yet underrecognized in older people. Prevalence estimates of pain among nursing home residents range from 26% to 66% (Sengstaken & King, 1993; Won et al., 1999). Physicians frequently fail to identify symptoms of pain among nursing

home residents and when symptoms are observed, they are often inconsistently documented (Ferrell, Ferrell, & Rivera, 1995; Won et al., 1999). Furthermore, pain among nursing home residents is often untreated (Bernabei et al., 1998), and is a critical issue in terminally ill individuals where it is "one of the most feared complications of growing older and the worst source of suffering for most patients" (Hazzard, Blass, Ettinger, Halter, & Ouslander, 1999, p. 433).

Research on the detection and assessment of pain among cognitively impaired elders is limited. Existing studies with cognitively impaired elders have found an association with less frequent self-reports of pain (Parmelee, 1996; Scherder, Bouma, Borkent, & Rahman, 1999). Some have explained the inverse relationship between cognitive function and reported pain by suggesting that elders with dementia respond differently to pain than nondemented individuals (Porter et al., 1996). Hadjistavropoulos and colleagues have shown that verbal and nonverbal measures of pain can improve the assessment of pain among cognitively impaired individuals (Hadjistavropoulos, LaChapelle, MacLeod, Snider, & Craig, 2000).

Greater pain intensity and more localized complaints of pain have also been reported among elderly nursing home residents with major depressive symptoms, compared with those with minor or no depressive symptoms (fasten, Parmelee, Kleban, Lawton, & Katz, 1995; Parmelee, Katz, & Lawton, 1991). Others have found that after controlling for age, gender, race, and cognitive and health status, pain in nursing home residents is associated with activity of daily living (ADL) impairment and with decreased involvement in activities (Won et al., 1999).

The current study considered the validity of MDS items describing pain in contrast to a standard measure of pain and derived a simple but effective pain scale. It then proceeded to use this scale to describe the prevalence of pain in a representative state's nursing home population, and in particular to examine differences in pain levels by type of admission and cognitive status.

Background

The National Resident Assessment Instrument/Minimum Data Set. -Under congressional mandate, the RAI is performed on every resident in all nursing facilities that meet conditions of participation for federal funding under Medicare or Medicaid-virtually all nursing homes in the United States. The primary purpose of the embedded assessment instrument, the MDS, is to enable improved care planning. Residents are assessed on admission, on significant change, and at least annually; there is, as well, a quarterly review using a reduced subset of items. Assessments are coordinated (although not necessarily performed) by registered nurses and assessors, and are to use all sources of information (e.g., the resident, facility staff, the resident's physician, the medical chart) in determining the most appropriate response for each item. MDS items assess a broad range of domains, including physical and cognitive function, continence, mood, medical diagnoses and conditions (including pain), activity patterns, medications, and so forth. Since June 1998, the Health Care Financing Administration (HCFA) has mandated submission of the MDS in electronic form.

Over the nine years since its implementation, a variety of studies have evaluated the MDS for reliability and for the validity of specific items or domains. The reliability studies have examined interobserver reliability, which is the agreement (interclass correlation) between two assessors, independently evaluating the same resident (Hawes et al., 1995; Morris et al., 1990, 1997; Sgadari et al., 1997). These studies found adequate to good reliability for all but a few items (such as delirium) that are difficult to assess. Other studies have examined the validity of selected domains of the MDS. Several of us (Morris et al., 1997) demonstrated that five MDS items could be encoded in a Cognitive Performance Scale (CPS) that was highly predictive of "gold standard" measures of cognition: the Folstein and colleagues' (Folstein, Folstein, & McHugh, 1975) Mini-Mental State Examination score and the Albert Test of Severe Impairment (Albert & Cohen, 1992). Others have validated scales in the domains of psychosocial function (Mor et al., 1995), activities of daily living (Morris, Fries, & Morris, 1999), nutrition (Blaum, O'Neill, Clements, Fries, & Fiatarone, 1997), and depression (Burrows, Morris, Simon, Hirdes, & Phillips, 2000). In addition, a national evaluation of the full RAI system has shown the system's effectiveness in improving care (Fries et al., 1997; Hawes et al., 1997; Mor et al., 1997; Phillips et al., 1997).

There are two major purposes for developing scales. The first is to establish further validity, by demonstrating that some combination of MDS items accurately predicts standard, externally validated, and independently assessed measures of a domain. In this manner, we add assurance to our clinical views that these MDS items address the concept at hand. Second, a scale permits efficient amalgamation of multiple MDS items, each describing a different aspect of the domain. Thus, a scale such as the CPS summarizes succinctly the cognitive status of a resident. This scale can have direct clinical utility, can permit summarization of a group of assessments (e.g., of a facility or population) for multiple purposes such as quality measurement or policy formulation, and can serve in statistical models to adjust for preexisting conditions in populations for which we would want to analyze outcomes.

The MDS measures of pain fit into this context. The original MDS promulgated in 1991 had only two pain items, each coded yes/no: "Resident complains or shows evidence of pain daily or almost daily," and the very specific "Mouth pain." While no direct validation study has been performed to date, the national RAI evaluation referenced earlier found that residents' pain was more prevalently reported after implementation of the RAI, perhaps due to increased attention to this item or changes in the patient population not handled by statistical adjustments. This implied that there might be insufficient pain assessment (items) in the MDS and that the RAI system lacked a care planning module that specifically addressed pain. In view of the increasing importance of pain control in these populations, Version 2.0 of the RAI/MDS, issued in 1995, included more numerous and specific pain items (Health Care Financing Administration, 1995). The current items from this new version are displayed in Table 1. Two items address the general characteristics of pain: "Pain Frequency" and "Pain Intensity," with three levels each. The remaining pain items are checklisted to indicate the site of pain. A "skip pattern" instructs the coder to skip items after the first (frequency) if there is no pain.

With these several items now available in the RAI/ MDS Version 2.0, we were interested in the creation of a summary pain scale and to examine whether it was a valid predictor of a "gold standard" measure of pain-the best-studied and validated measure currently available.

Choosing a Pain Scale for Validation.- Assessment of pain is complex because it is based on an individual's perception of pain. Thus, measurement of pain poses a challenge to clinicians, especially in older people-whether or not they have cognitive problems. Pain should be assessed from the patient's perspective, with the knowledge that their current level of pain may be affected by both clinical and personal factors (Flaherty, 1996). In selecting an instrument for this study, we recognized the subjective nature of pain and the potential limitations of the older population targeted.

Table 1. Minimum Data Set (Version 2.0) Pain Items

Item J2: Code the highest level of pain present in the last 7 days:
- J2a. FREQUENCY with which resident complains or shows evidence of pain
  - 0. No pain (skip other pain items)
  - 1. Pain less than daily
  - 2. Pain daily
- J2b. INTENSITY of pain
  - 1. Mild pain
  - 2. Moderate pain
  - 3. Times when pain is horrible or excruciating

Item J3: If pain present, check all sites that apply in last 7 days:
- J3a. Back pain
- J3b. Bone pain
- J3c. Chest pain while doing usual activities
- J3d. Headache
- J3e. Hip pain
- J3f. Incisional pain
- J3g. Joint pain (other than hip)
- J3h. Soft tissue pain (e.g., lesion, muscle)
- J3i. Stomach pain
- J3j. Other

Source: Health Care Financing Administration. (1995).

Table 1

The process of instrument selection began with a review of the literature. A number of well-validated instruments exist, including the Pain Thermometer, the Numeric Rating Scale, the Visual Analogue Scale (VAS), and the Verbal Descriptor Scale. Our selection criteria for a pain assessment included consideration of cost, ease of use, and evidence that the instrument has been tested and validated. As participants in this study were all over the age of 65, we wanted to be sure that it would be specifically applicable. We were also committed to using a self-report instrument. The VAS was chosen as the external standard for its demonstrated sensitivity to pick up a continuum of pain severities and efficiency of administration (Herr & Mobily, 1993). The vertical version of the VAS (v-VAS) is preferred by older adults (Herr & Mobily, 1991, 1993) and was chosen for use in this project. It is acknowledged that this measure cannot be expected to work on individuals with severe cognitive impairment or who are unable to understand or communicate.

Methods

Our approach was to develop a scale, based on MDS (Version 2.0) items, that would both make reasonable clinical sense and be predictive of a VAS score, independently assessed. The data collection

and analytic approach are discussed in this section.

Data Collection. -Data were collected from 25 Medicare-certified skilled nursing facilities in Massachusetts as part of a project to develop a postacute assessment system. Eligibility criteria were established to ensure that participants were receiving subacute services at the time assessments were completed. All participants (N = 95) had been admitted from an acute-care hospital, had already stayed in the nursing home more than 24 hours, were currently receiving daily skilled nursing or rehabilitation services, and were expected to return to a community-based setting (with or without home care services). Excluded from the study were patients either dying or with an expected discharge from the facility within 24 hours, and the relatively rare instances where the subject was unable to communicate.

Field study nurses visited the nursing facilities at least weekly, to meet with the nursing home staff and review which patients met the selection criteria. A nurse would approach any newly admitted patients meeting the criteria and ask them to participate in the study. After informed consent was obtained, the patient was enrolled in the study and a full MDS assessment was performed, in addition to the VAS.

In the version of the VAS used here, the resident was presented with a vertical line segment with bipolar anchoring labels: "no pain" (0) at one end and "worst pain possible" (10) at the other. Tick marks and values were placed uniformly along the line, representing the intermediate values 1, 2, ... 9. The research nurse asked the participants to place a mark somewhere on the continuum showing the intensity of their pain. The response was then coded as a number between 0 and 10, using 0.5 for responses recorded between the tick marks.

Standard training and assessment protocols for the MDS and VAS were employed. For the MDS, this included reliance on all sources of information for determining MDS assessment items. When information was conflicting or missing, the best judgment of the assessor determined the appropriate response. For the VAS, the research nurse explained the scale and the definition of pain (e.g., that pain is discomfort that may occur anywhere in the body, that it may have characteristics such as aching, hurt, pulling, tightness, burning, or pricking, and that it may be mild to severe). To verify that the participants understood how the word "pain" (or/and other word preferred by the subject) was being used, the participants were asked to describe the worst pain they had ever experienced and then asked to rate that pain on the VAS scale. The nurse went on to ask the patient about the pain that he or she was currently experiencing and either let the patient score directly on the VAS instrument or scored it herself, based on the patient's instructions.

The analyses to derive the pain scale used all observations with valid VAS scores (three observations were dropped due to uncodable responses). All MDS assessments retained had the appropriate skip pattern for pain items (see Table 1). In the analysis, we also utilized the MDS measures of ADL (6-level measures of functional performance in bed mobility, bed-chair transfer, locomotion off the unit and on the unit, walking in room and in unit, eating, toileting, dressing, and personal hygiene) and the five items that form the CPS scale (decision making, ability to make self understood, short-term memory, and eating performance; comatose was not an issue here as all patients in the sample were able to

communicate).

After the pain algorithm (described in Results) was developed, we used it to profile the prevalence of pain in all residents of Michigan nursing homes from October 1998 through October 1999. All data were collected using the new MDS Version 2.0. As there were multiple assessments for each resident, we used only the first; in total, we had assessments of 34,675 unique individuals. These assessments were then classified into three types: (a) postacute admission, as identified by the coded "reason for assessment"; (b) other admission; and (c) postadmission (i.e., all other assessments).

Analytic Approach. -Our initial analyses selected those MDS variables that would be useful in predicting high VAS scores. Given the small sample size, we restricted consideration to a limited number of independent variables that might help predict the VAS score. Based on clinical input, the items selected represented direct measures of pain (including site of pain) and the presence of diseases likely to have substantial pain (cancer, arteriosclerotic heart disease, congestive heart failure, deep vein thrombosis, peripheral vascular disease, multiple sclerosis, osteoporosis, pathological bone fracture, and arthritis). To these we added all MDS measures of physical function and the CPS scale, to identify dementia that could change perception of pain.

From these variables we developed an index predicting the VAS score, using the tree-generation approach of Automatic Interaction Detection (AID), as implemented by the PC-Group program (Austin Data Management, 1992). Tree-based splitting has a tactical advantage in the presence of strong statistical interactions (when one characteristic is important in explaining the dependent variable of interest only in the presence of other characteristics). An example would be that pain intensity was only predictive of VAS-measured pain when the pain was frequent. The PC-Group package has been used successfully for scale development in nursing home populations in creating both the RUG-Ill case-mix measurement systems (Fries et al., 1994) and the CPS (Morris et al., 1994) previously discussed. In using PC-Group, the VAS was the dependent variable and was treated as continuous even though the coding was limited to multiples of 0.5. PC-Group attempts to find subgroups of all observations in the sample, defined by the independent variables by a series of "splits." The rationale for considering splits is based on a combination of statistical and clinical criteria. From the statistical view, individual variables and the resulting index need to explain differences in the VAS pain measure. A primary measure of statistical adequacy is variance explanation (VE), a statistic that represents the percentage of all variation in the dependent variable (i.e., the VAS) that is explained by the independent variables) considered; VE ranges from 0 to 100%. Also, the derived system should make clinical sense (e.g., higher levels of VAS would be associated with the presence of a medical condition potentially associated with pain, such as cancer).

The distribution of Michigan residents across the pain scale was then examined, both by type of assessment (postacute, other admission, and postadmission) and by levels of the CPS. To test whether there were differences in the distribution of the pain scale values across the different populations, we used a chi-squared test.

Finally, we examined the reporting of pain by levels of cognitive functioning. Within each of the three

resident types indicated earlier, and for each level of the CPS, we computed the percentage of Michigan nursing home residents reported on the MDS as having no pain. To test whether there were differences across the levels of the CPS and population, we formed a logistic regression model of the presence of pain, with independent variables representing six CPS levels (intact as the reference group) and two types of residents (postadmission as the reference group).

Given the very large sample sizes for the reported analyses of the Michigan data, all results were significant at the $p < .0001$ level. We thus do not report statistical significance in the following section, and urge the reader to consider instead the substantiality of differences.

Results

Complete MDS and VAS data were collected from a total of 95 individuals. Overall, 71 % of the sample were women, and the average age was 81 years. Of the chosen medical conditions, arthritis was the most prevalent (27%), followed closely by congestive heart failure (25%). On the MDS pain assessment items, 30 (32%) patients indicated no pain, 15 (16%) had mild pain, 26 (27%) moderate pain, and 24 (25%) horrible pain. The most frequent site of pain was the back (see Table 2).

Using the VAS on this population, 39 (41%) indicated no pain (the difference from the 32% scored with no pain on the MDS is not significant, $p < .17$). There was good agreement between the MDS and the VAS on the presence of pain: of those who were assessed with no pain on the MDS, 93% had a VAS score of 0 (kappa = .707; not shown). The mean VAS score for the entire sample was 2.5.

The PC-Group analysis showed that the direct measures of pain-frequency (variance explanation [VE] = 53%) and intensity (VE = 42%)-were greatly superior in predicting VAS-scored pain to all other measures considered (the next largest, walking in room, had VE = 11%). Based on this finding, the initial split separated the sample into three subsample groups, based on the three levels of pain frequency (later experiments starting with pain intensity were not as successful in leading to systems with good overall VE). For the first two groups-those with no pain, and those with pain less than daily-- no additional variables were found to be effective in providing additional VAS variance explanation. In the highest group-daily pain-two ADLs (locomotion off the unit and toileting), back pain, and the MDS pain intensity item all had predictive capability. Interestingly, average VAS pain scores decreased with increasing ADL dysfunction.

Table 2.

The best MDS Pain Scale for predicting the VAS score is shown in Table 3. Patients with no pain or pain less than daily form the first two index groups. Then, those patients with daily pain are split into two groups based on pain intensity: Those with horrible/excruciating pain form the highest group, and all others form an intermediate group. This system, with four groups and using two MDS variables, achieved a variance explanation of 56%. The average VAS for the lowest group was 0.1, increasing to 5.0 for the highest group. Thus, this system was slightly better than one using only pain frequency, with a variance explanation of 53% and a range from 0.1 to 4.4. The next best alternative system (not shown) had five groups and was constructed using an index constructed of the two ADLs indicated earlier and pain intensity. It achieved only slightly higher VE (59%) but had no increased range and considerably more complexity.

Using the selected MDS Pain Scale in the validation sample of postacute patients, 32% were without pain, and 22% had excruciating pain. A different distribution was seen when the scale was applied to a more representative sample of all nursing home residents in Michigan. In this case, focusing on postacute admissions, 47% were without pain and only 4% in excruciating pain. In contrast, less pain was seen in other admissions (54% without pain) and even less in others seen after admission, including long-staying residents (63% without pain). To simplify comparisons, we also imputed an average VAS score for each type of patient, computed by multiplying the prevalence of each Pain Scale value by the groups' mean VAS (from the validation sample) and summing. Postacute admissions had the highest average VAS score (1.5), followed by other admissions (1.3); post-- admissions had a yet lower score (1.0).

The final analysis addressed the reporting of pain by those with cognitive impairment. The analysis was not performed in the validation sample, as this excluded residents cognitively impaired and unable to perform the VAS. In each of the three Michigan populations, the percentage of residents reporting no pain increased dramatically with increasing cognitive impairment. For example, in postacute admissions 31% of cognitively intact residents reported no pain compared to 69% of the most severely impaired; and

40% of cognitively intact residents compared to 79% of severely impaired in the longer-staying post--admission cohort (Table 4).

Discussion

Reports of pain, a common characteristic of post-- acute patients, are increasingly recognized as an important issue in the care of nursing home residents, particularly among those with terminal conditions. As pain symptoms are usually amenable to treatment, identification of pain is an imperative to the quality of care of these individuals. The MDS Pain Scale represents a simple method to summarize the reported presence and intensity of pain using routinely collected nursing home MDS data. The scale is rather simple and based on only two MDS items. However, we found high concordance rates and variance explanation between the MDS Pain Scale and the VAS among nursing home patients in postacute settings. While the VAS is recognized as a "gold standard" measurement of pain, the Pain Scale is easier to administer and the MDS is already available for all nursing home residents. With this validation, the Pain Scale can be used for epidemiological studies in the large MDS databases that are now accumulating. Both pain intensity and frequency were useful factors, a result that validates the revisions made (from a simply dichotomous indicator of the presence of pain) moving to Version 2.0 of the MDS. Perhaps equally important to the scale's simplicity is that no other MDS items were of use in predicting measured pain.

Given that pain can often be alleviated, the results of analyzing the Michigan nursing home population are disquieting. Symptoms of daily pain are seen in 16% of current residents and as many as 28% of postacute patients, prevalences somewhat consistent with other research in chronic settings, such as Won and colleagues (1999), who found 26% of patients in daily pain in a sample of more than 49,000 nursing home patients.

Still more disturbing is that cognitive impairment appears to diminish the reporting of pain. Those with higher cognitive impairment will, on average, be sicker. Yet, pain is substantially less reported for those with even moderate impairment. This finding is in concert with our other finding that reported levels of pain decreased with increasing ADL dysfunction. Clinicians need to be especially vigilant in looking for indicators of pain in impaired individuals.

This study has a number of limitations that may impede the generalizability of our findings. The validation sample was relatively small, and the distributions of reported pain is relevant only for the sample that was able to give consent. It is important to note that our sample was predominantly cognitively alert, with 60% scoring as cognitively intact on the CPS. Clearly, the VAS cannot be performed on those unable to communicate or severely cognitively impaired, and we cannot assume that the Pain Scale will work for those individuals. It remains a question (and an area for improvement) whether assessors using the MDS are able to identify signs of pain in those who are unable to report it. Finally, we may not be able to generalize our findings to particular subpopulations seen in nursing homes, such as those of particular cultures, genders, ages, or particular conditions (such as terminal illness); we did not have a sufficiently large sample to test the Pain Scale on these subsamples.

We already have begun studies that will improve both the content and the generalizability of the results reported here. In moving from Version 1 to Version 2.0 of the MDS pain items, reliability increased, prevalence estimates doubled, and barriers to accurate assessment by facility staff were greatly reduced. As part of the interRAI-HCFA effort to create the third generation of the MDS for nursing homes, we are examining the issue of pain measurement for both verbal and nonverbal patients near the end of life. Under consideration are supplemental assessment items that address whether the pain is new (i.e., first arose in the prior 3 days), whether the pain has worsened in the prior 3 days, and whether the pain is present with movement and at rest. In addition, InterRAI-HCFA is looking at the issue of nonverbal markers that could and should be relied upon in assessing pain. When sufficient data are available, we will be able to assess how this will affect the Pain Scale described here and our understanding of pain prevalence.

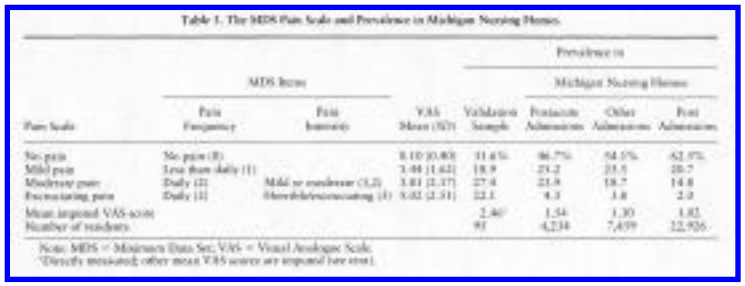

Table 3.

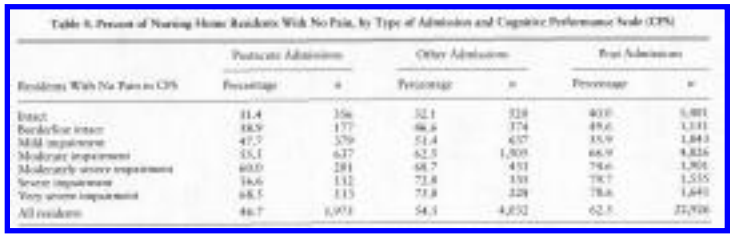

Table 4.

The strengths of this study include the relative psychometric properties of the MDS and the VAS, both measures having been tested elsewhere (Hawes et al., 1995; Herr & Mobily, 1991; Sgadari et al., 1997). The MDS pain frequency and pain intensity, in particular, achieve interrater reliabilities of 0.73 and higher. Further, the ability to use a full state's nursing home population in research strengthens our expectation that the results will be valid for the U.S. institutionalized population.

Given the correlates of pain among nursing home residents and the existing treatment options for pain, we believe the use of the MDS Pain Scale will enable clinicians better to identify and treat pain, with a concomitant reduction of comorbid mood symptoms and ADL impairment.

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