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Original Study

Pain Trajectories of Nursing Home Residents Nearing Death

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A B S T R A C T

Keywords:

Pain
nursing home
trajectories
end-of-life
Resident Assessment Instrument
RAI

Background/Objectives: Although examining point in time prevalence of pain among nursing home (NH) residents has value, there is a lack of evidence describing the actual changes (ie, trajectories) in pain that take place during their last 6 months of life. The main objective of this study is to describe the major pain trajectories experienced by NH residents during their last 6 months of life.

Design: Secondary analysis of Resident Assessment Instrument-Minimum Data Set (MDS) 2.0 data captured as part of the longitudinal Translating Research in Elder Care data repository.

Setting: Twenty-seven urban NHs in Western Canada.

Participants: A total of 962 NH residents who died, had an MDS assessment completed within 30 days of death, and resided in a NH for at least 6 months. Pain trajectories were stratified by residents who were not severely cognitively impaired [Cognitive Performance Scale (CPS) ≤ 3] and those with severe impairment (CPS ≥ 4) at death.

Measurements: MDS-Pain Scale; CPS.

Results: In the 6 months before death, 60.1% of residents without severe cognitive impairment experienced consistently low pain; 34.6% reported experiencing either moderate to severe pain or significant increases in pain during this same period of time, and only 5.3% experienced any degree of pain improvement. When the trajectories were examined, most residents without severe cognitive impairment experienced no to mild pain in the time before their death (65.5%); however, we identified a group of residents who exhibited a pattern of pain that worsened or remained consistently high right until death (38.2%). Although the proportion of residents with “low/mild” pain trajectories was statistically greater among those who were severely impaired vs those without severe cognitive impairment, across both cognitive impairment groups, the general trend in pain trajectories is similar; with about 60% of residents experiencing either consistent low or mild pain in their last 6 months of life, and about 34% experiencing either substantially high or increasing pain levels.

Conclusions: Although a majority of NH residents experienced consistently low or improved pain levels in their last 6 months of life, a substantial number experienced consistently high or substantially worsening pain levels during this same time period. These results highlight the need to better manage pain levels for some NH residents during this important period of time.

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The research was supported by a Canadian Institutes of Health Research (CIHR) grant in aid (MOP 53107). The funding agency had no role in the study design, data collection, data analysis, interpretation of the data, writing of the report, or decision to submit the article for publication.

The authors declare no conflicts of interest.

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<http://dx.doi.org/10.1016/j.jamda.2017.03.002>

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The prospect of dying in pain is a universal fear; evidence suggests that older adults are more fearful of experiencing physical distress such as pain during the dying process than of death itself.¹ Older adults living in nursing homes (NHs) may be at particular risk of chronic, unrelieved pain and its negative consequences. Many of these residents have multiple chronic conditions (eg, osteoporosis, rheumatoid arthritis, congestive heart failure, and diabetic neuropathy), which are often associated with significant pain.^{2–4} The intensity and

frequency in which pain is experienced as a result of these conditions may wax and wane throughout the disease course; some evidence suggests that people with osteoarthritis experience markedly different levels of pain intensity over the course of months, weeks, or even days.⁵

A hallmark of excellence in end-of-life care is the effective management of symptoms, including pain.^{6–9} However, pain in particular continues to be poorly managed and controlled among NH residents. The literature suggests that 45%–80% of residents suffer from persistent or daily pain that is moderate to severe in nature.^{10–16} Unrelieved pain has far reaching consequences affecting people's ability to perform activities of daily living; profoundly affecting their psychological well-being, sleep, and quality of life^{17–21}; and contributing to dying in distress.²² Unrelieved pain is anathema to quality of care and significantly increases suffering.²³ Such adverse outcomes are contrary to residents', family caregivers', and NH staff descriptions of a "good" death in this setting.^{22,24–26}

Although many scientists have investigated pain at the end of life,^{27–34} most have done so using point-in-time cross-sectional techniques. However, this "snap shot" evidence does not describe the actual changes (ie, trajectories) in pain that people experience during their final stages of life, contributing to the criticism that the state of the science regarding pain in older adults is weak.³⁵ A better understanding of pain trajectories experienced by NH residents during their last 6 months of life has value for further understanding residents' experiences with pain at their end of life, as a first step in better defining the need for more comprehensive pain management strategies. Understanding the pain experience as residents approach death is vital to proactively mitigate a significant source of distress and suffering and, thus, enhance quality care among NH residents nearing end of life. In this article, we begin to address this important gap in knowledge, by identifying and describing the different pain trajectories experienced by NH residents in their last 6 months of life.

Methods

This study uses Resident Assessment Instrument (RAI)-Minimum Data Set (MDS) 2.0 data, captured and stored as part of the longitudinal Translating Research in Elder Care (TREC) data repository.³⁶ This repository provides data from 27 urban NHs in Western Canada, selected using a random stratified (health region, owner-operator model, and size) sampling technique. RAI-MDS 2.0 profiles NH residents by their various demographic, clinical, functional, diagnostic, psychosocial, and cognitive status domains, initially at NH admission and quarterly thereafter; it is the also the only system used in Canada at present. Details of the TREC research program and its data collection methods have been published previously.³⁶

Selection of Cohort

Our initial cohort consisted of all residents reported to have died using the RAI-MDS 2.0 discharge assessment (item R3a coded as deceased) between the dates of October 1, 2007 and March 31, 2012 (N = 5050; Figure 1). Prior to analysis, several residents were excluded from this cohort, such as those for whom MDS 2.0 was completed more than 30 days preceding death (N = 3280 residents were removed; this decision was made to ensure that we assessed resident pain close to their time of death), and residents with fewer than three MDS 2.0 assessments in total (N = 414). Our goal in this article was to assess pain trajectories during NH residents' last 6 months of life; given that MDS assessments are completed about every 90 days, we required 3 such assessments (1 associated with "death" plus 2 previous) to assess pain trajectories during this time. Our Results section (Table 1) demonstrates that this strategy accurately captures pain levels during the last 6 months of a resident's life.

Differences in pain levels between the index (third last) and the final MDS assessment were used to create a pain trajectory, for each

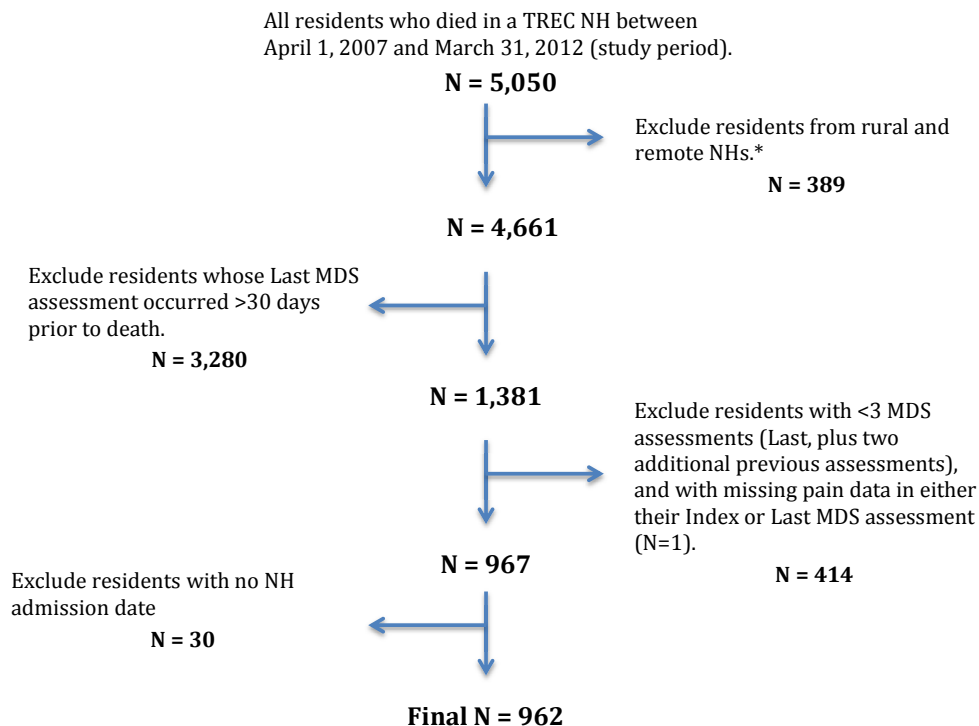


Fig. 1. Study exclusion and inclusion criteria.* These were from the 5 rural facilities (all located in Saskatchewan) and, therefore, removed to ensure focus on an urban sample.

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