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Original Study

Dying in a Nursing Home: Treatable Symptom Burden and its Link to Modifiable Features of Work Context

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A B S T R A C T

Importance: High-quality care at the end of life supports freedom from pain and other potentially burdensome symptoms. Lowering symptom burden at the end of life is an urgent and achievable goal in delivering services in nursing home settings. Few published reports describe symptom burden among older adults in nursing homes; none examine links between symptom burden and modifiable features of nursing home organizational context (work environment).
Objectives: To examine the influence of organizational context on symptom burden and to compare symptom burden in the last year of life between nursing home residents with and without dementia.
Design: Retrospective analysis of longitudinal survey data.
Setting: A stratified random sample of 36 nursing homes in the Canadian provinces of Alberta, Manitoba, and Saskatchewan.
Participants: A total of 2635 residents with dementia and 1012 without dementia; 1381 front-line care staff.
Measurements: (1) Trajectories of 6 symptoms (dyspnea, pain, pressure ulcers, urinary tract infections, challenging behavior, delirium), assessed with the Resident Assessment Instrument-Minimum Data Set, version 2.0, between 2008 and 2012. All residents received assessments in each quarter of the year before death. (2) Modifiable organizational context, assessed with the Alberta Context Tool. Hierarchical mixed model, repeated measures regression, to simultaneously evaluate effects of time, dementia, and context on symptom trajectories.
Results: For all residents, prevalence of symptoms increased over time. In the last quarter before death, challenging behavior was the most frequent symptom in the dementia group (40.2%), delirium the most frequent symptom in the nondementia group (31.0%), and urinary tract infections least frequent (9.0% to 10.0%). Facilities with more favorable context had significantly higher prevalence of challenging behavior and delirium and significantly lower use of antipsychotics without diagnosis of psychosis.
Conclusion: Symptom burden increases as the end of life approaches but differs between high- and low-context facilities and between residents with and without dementia. Trajectories of treatable, burdensome symptoms at the end of life in nursing homes should be a priority focus for quality improvement. Modifiable features of organizational context that are linked to symptom burden offer new potential strategies and interventions for quality improvement.

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Symptoms from diseases and chronic conditions put a significant physiologic and psychological burden of suffering on the rapidly growing population of seniors, particularly at the end of life. Of Canada's population of 35 million, 350,000 adults older than 65 years live in a special care facility (nursing home, chronic care, long-term care hospital, residence for seniors) at any given time.[1] Demand for facilities is expected to almost double by 2038.[2] As is typical of many developed countries, most residents will die in the nursing home. The most comprehensive work on burden of symptoms at the end of life was conducted by Mitchell and colleagues in the United States.[3–5] They reported that during the last year of life, the proportion of nursing home residents with dyspnea and pressure ulcers more than tripled to more than 30%, pain more than doubled to more than 25%, and the prevalence of aspiration increased from almost 10% to almost 40%.[5] These are unacceptably high rates of modifiable symptoms. They cause unnecessary distress and significantly increase health care costs. Strategies to reduce suffering and address this quality and cost issue must be based on better knowledge of modifiable symptom burden, and of the links between symptom burden and modifiable features of nursing home work environments.

Over the past decade, a key factor in increasing symptom burden is individuals entering nursing homes at more advanced ages and stages of disease trajectories, in particular the trajectory of dementia.[6] As the population ages, the prevalence of dementia also rises. At least two-thirds of residents in Canadian nursing homes have a diagnosis of dementia.[7–9] In the United States, the proportion of persons with dementia who will die in a nursing home is 70%[10] and ranges from 50% (Wales) to 92% (NL) in Europe.[11] A number of researchers have studied single symptoms at the end of life for nursing home residents with dementia, but we identified only 10 studies addressing the broad range of symptoms that cause burden over time.[3–5,12–18] Mitchell and colleagues' 2009 study[5] was the first to provide a comprehensive picture of symptom burden in advanced dementia at the end of life, based on a sample of 323 US nursing home residents.

Characteristics of an organization's context (work environment), such as leadership, culture, feedback mechanisms, and available information resources, are increasingly seen as important for quality and safety in health care.[19,20] These factors are modifiable. However, we know relatively little about the role of organizational context in the nursing home environment in general, and in end-of-life care specifically. We used data collected in the longitudinal Translating Research in Elder Care (TREC) study[21] conducted in the Canadian provinces of Alberta, Manitoba, and Saskatchewan. These data permitted a unique focus on the influence of nursing home organizational context on distressing symptoms in residents at the end of life.

Our research objectives were to describe the trajectory of symptom burden at the end of life in a cohort of nursing home residents, and to determine if organizational context or dementia status influenced symptom prevalence. These are necessary first steps to improving quality and safety of care at the end of life in residential long-term care.

Methods

Our sample was 36 nursing homes in the 3 Canadian provinces that participated in the TREC (protocol described elsewhere).[22] We extracted symptom measures from the routinely collected Resident Assessment Instrument–Minimum Data Set 2.0 (RAI-MDS 2.0).[7,8,23,24] We measured organizational context with the Alberta Context Tool (ACT), a core component of a survey questionnaire administered to 1381 front-line care staff using structured in-person interviews with computer assistance.[21,22,25,26]

Symptom Burden

To construct trajectories of symptom burden, we used RAI-MDS 2.0 assessments (2008–2012). The RAI-MDS 2.0 has been examined extensively for reliability and validity, and is appropriate for research purposes (allowing for some weaknesses, notably around depression, which is not a focus here).[27–29] From the assessments, we built an analytic dataset of residents assessed in at least 4 quarterly periods before death. Date of death was determined by the administrative discharge record of the RAI-MDS 2.0 and could have occurred in the nursing home or in hospital. Nursing homes complete assessments only once in any calendar quarter, thus time varied between a resident's final assessment and death.

We extracted measures of selected symptoms in the 7-day period before assessment, unless otherwise noted. Dyspnea was recorded as present or not. Pain was recorded as daily pain that was at least moderate at its worst or that was horrible or excruciating at any time. The assessor used both resident reports of pain and other cues for residents not verbally communicative. Pressure ulcers of stage 2 or higher were recorded (partial loss of thickness in skin layers presenting clinically as an abrasion, blister, or shallow crater). Urinary tract infections in the 30 days before assessment were recorded. Challenging behavior was recorded as verbally abusive, physically abusive, or socially inappropriate/disruptive behavior on at least 1 day in the past week. Delirium was measured with 6 items (easily distracted, altered perception, disorganized speech, restlessness, lethargy, mental function varies over the day). Delirium was recorded if (1) any item was present and over the past 7 days appeared different from usual function or (2) any item was present and not of recent onset but differed from the previous assessment. Antipsychotic use without a diagnosis of psychosis was recorded if the resident either had no diagnosis of Huntington disease or schizophrenia, or had not experienced hallucinations in the past 7 days. A resident was classified as having dementia if either or both of the RAI-MDS 2.0 items, *Alzheimer's disease* or *dementia other than Alzheimer's disease*, were recorded at any time in the resident's assessment history.

Organizational Context

The ACT is a validated survey instrument for 10 modifiable elements of organizational context: (1) leadership, (2) culture, (3) evaluation (feedback processes), (4) formal team interactions, (5) informal team interactions, (6) social capital, (7) structural and electronic resources, (8) organization slack—time, (9) organization slack—staff, and (10) organization slack—space.[21,25] All items are scored on a 5-point Likert agreement scale (*strongly disagree* to *strongly agree*). The original validation was completed with 752 pediatric acute care nurses[21] and provided evidence for acceptability, internal consistency reliability (Cronbach $\alpha \geq 0.70$ for 10 of 13 concepts), and validity. We found statistically significant correlations between instrumental research utilization and all but one ACT concept. The psychometric testing of the nursing home version was based on responses from 645 care aides.[25] Results of confirmatory factor analyses were consistent with the factor structure theorized in the development of the ACT. For 8 ACT concepts, we found significant correlations with instrumental research utilization; internal consistency reliability (Cronbach's $\alpha \geq 0.70$ for 8 of 10 concepts) and acceptability (there was minimal missing data with 93.5% of the health care aides providing complete data on all ACT items and the time to complete the ACT survey was below target with a mean of 11.08 minutes and an SD of 2.93 minutes) were confirmed.[25] Validation of the ACT is an ongoing process and advanced psychometric assessments are ongoing.[30] Direct comparisons to other tools assessing context have not been reported or to our knowledge undertaken.