



JAMDA

journal homepage: www.jamda.com

Original Study

From Admission to Death: Prevalence and Course of Pain, Agitation, and Shortness of Breath, and Treatment of These Symptoms in Nursing Home Residents With Dementia



Simone A. Hendriks MD^a, Martin Smalbrugge MD, PhD^a,
Francisca Galindo-Garre PhD^b, Cees M.P.M. Hertogh MD, PhD^a,
Jenny T. van der Steen PhD^{a,*}

^a Department of General Practice and Elderly Care Medicine and EMGO+ Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands

^b Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

A B S T R A C T

Keywords:
Dementia
palliative care
symptoms
pain
behavior
symptom control

Objectives: Burdensome symptoms frequently develop as part of the dementia trajectory and influence quality of life. We explore the course of symptoms and their treatment during nursing home stay to help target adequate symptom management.

Design: Data were collected as part of the Dutch End of Life in Dementia study, a longitudinal observational study with up to 3.5 years of follow-up. Physicians performed assessments at baseline, semi-annually, and shortly after death of pain, agitation, shortness of breath, and treatment provided for these symptoms.

Setting: Long-term care facilities (28) in the Netherlands.

Participants: Newly admitted nursing home residents (372) in variable stages of dementia.

Measurements: We described prevalence and course of symptoms, and treatment provided for these symptoms. We used generalized estimating equations to evaluate the longitudinal change in symptoms and their treatment, and the associations between the symptoms of pain and agitation, as well as between stage of dementia and symptoms.

Results: Pain was common (varying from 47% to 68% across the semiannual assessments) and frequently persistent (36%–41% of all residents); it increased to 78% in the last week of life. Agitation was the most common symptom (57%–71%), and also frequently persistent (39%–53%), yet it decreased to 35% in the last week of life. Shortness of breath was less common (16%–26%), but it increased to 52% at the end of life. Pain was not significantly associated with agitation. Advanced dementia was associated with more pain only. Treatment changed in particular at the end of life. Pain was treated mostly with acetaminophen (34%–52%), and at the end of life with parenteral opioids (44%). Agitation was mostly treated nonpharmacologically (78%–92%), and at the end of life anxiolytics were the most frequently prescribed treatment (62%). Overall, aerosolized bronchodilators were the most frequently prescribed treatment for shortness of breath (29%–67%), but at the end of life, this was morphine (69%).

Conclusion: Pain and agitation were common and frequently persisted in residents with dementia during nursing home stay, but symptom management intensified only at the end of life. Symptom control may be suboptimal from admission, and a stronger focus on symptom control is needed at an earlier stage than the end of life.

© 2015 AMDA – The Society for Post-Acute and Long-Term Care Medicine.

The authors declare no conflicts of interest.

This study was funded by a career award to Dr. van der Steen from the Netherlands Organisation for Scientific Research (NWO; Veni grant number 916.66.073); ZonMw The Netherlands Organisation for Health Research and Development, grant number 1151.0001; the VU University Medical Center, EMGO Institute for Health and Care Research, Department of General Practice and Elderly Care Medicine, and Department of Public and Occupational Health, Amsterdam, the

Netherlands; and by a grant from the SBOH (the employer for GP trainees and elderly care medicine trainees), the Netherlands.

* Address correspondence to Jenny T. van der Steen, PhD, Department of General Practice and Elderly Care Medicine, EMGO Institute for Health and Care Research, VU University Medical Center, Van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands.

E-mail address: j.vandersteen@vumc.nl (J.T. van der Steen).

<http://dx.doi.org/10.1016/j.jamda.2014.12.016>

1525-8610/© 2015 AMDA – The Society for Post-Acute and Long-Term Care Medicine.

Burdensome symptoms frequently occur in patients with dementia, while adequate symptom control is important to maintain or improve quality of life.¹ In the United States and Western Europe, most people with dementia are eventually admitted to, and die in long-term care facilities.^{2,3} Pain, agitation, and shortness of breath are the most prevalent and important symptoms at the end of life.⁴ At any given time, 12% to 76% of nursing home residents are in pain and prevalence may increase when death approaches,^{4,5} and up to 80% present with challenging behavior.^{6,7} More severe dementia may be associated with more pain^{8,9} and with more agitation.^{10,11} The rates of shortness of breath vary widely, from 8% to 80%.⁴ Optimal symptom control needs a holistic approach because symptoms may be interrelated; for example, pain may be associated with agitation.^{12–15}

These findings are from work that has several specific limitations. First, study populations are often limited to advanced dementia,⁵ whereas in the Netherlands, half of all patients with dementia may die before having reached this stage.¹⁶ Second, most studies are limited to the period shortly before dying,⁴ whereas symptoms present earlier.¹ Last, data collection is frequently limited to retrospective collection or fixed periods per individual.^{12,17} In addition, there are few studies on how specific symptoms are managed with pharmacological and nonpharmacological treatment.⁹

To achieve adequate symptom control in dementia, a better understanding is needed of the longitudinal course of symptoms and the treatment provided.¹⁸ Therefore, the objectives of this study were to explore changes in symptoms and provided treatment in Dutch nursing home residents in variable stages of dementia during their nursing home stay. We report on the prevalence and course of pain, agitation, and shortness of breath. We explore the longitudinal association between pain and agitation, and between stage of dementia and symptoms. Furthermore, we report on specific pharmacological and nonpharmacological treatment provided for pain, agitation, and shortness of breath during nursing home stay.

Methods

Data Collection

Data were collected as part of a longitudinal observational study, the Dutch End of Life in Dementia study. Between 2007 and 2011, data were prospectively and retrospectively collected on 491 residents in 34 long-term care facilities, nursing homes, and affiliated residential homes. In this article, we used only prospectively collected data from 28 facilities (23 nursing homes and 5 residential care facilities that the physicians visit from their nursing home practice) on 372 newly admitted residents. Elderly care physicians, who are certified after 3 years of training, employed by the nursing homes were responsible for data collection. The residents had a physician's diagnosis of dementia in all possible stages. A total of 372 residents were enrolled on admission between January 2007 and July 2009; during the study period, 218 residents died before summer 2010.¹⁶

Individual assessments were performed for a maximum period of 3.5 years (January 2007–July 2010; and survival was monitored for an additional year, until summer 2011). The baseline measurement was carried out 8 weeks after admission, and it was followed by a maximum of 5 semiannual assessments. We refer to the baseline measurement and the semiannual assessments as regular assessments. In case of death during the study period, a questionnaire about the last week of life was completed within 2 weeks after death, and we refer to this questionnaire as the after-death assessment. The study protocol was approved by the Medical Ethics Review Committee of the (VU University Medical Center in Amsterdam), and written consent was obtained from all participants or their families.

Measurements

The diagnosis of dementia was based on international guidelines.^{19–22} Type of dementia was assessed with a prestructured item comprising the categories Alzheimer disease, vascular dementia, Alzheimer disease and vascular dementia, Lewy body/Parkinson disease, and other. Advanced dementia (versus less advanced dementia) was defined as a maximum score of 7 on the Global Deterioration Scale (GDS)²³ and a score of 5 or 6 on the Cognitive Performance Scale (CPS, range 0–6).²⁴

The physicians assessed frequency of pain and shortness of breath as “never,” “rarely” (<5 days a month), “sometimes” (5–10 days per month), “often” (11–20 days/month), and “almost daily” (>20 days per month). The frame of reference was the previous month for the baseline assessments, and the 3 months before the semiannual assessments (frequency on average per month over last 3 months). During the last week of life, the physicians assessed frequency of pain and shortness of breath as “never,” “rarely” (≤1 day), “sometimes” (2–3 days), “often” (4–5 days), and “almost daily” (6–7 days). We dichotomized into “never” versus “other” for all assessments. Prevalence of agitation, such as restlessness, calling out, resistance to care, verbal aggression, or physical aggression was assessed as present or not, during the month before baseline, the 3 months before the semiannual assessments, and during the last week of life.

Treatment provided for pain, agitation, and shortness of breath was assessed using prestructured items. The categories for pain treatment were nonpharmacological (eg, physiotherapy, occupational therapy, transcutaneous electrical neurostimulation, massage); acetaminophen (paracetamol); nonsteroidal anti-inflammatory drugs (NSAIDs); oral narcotic; parenteral narcotic (including transdermal patch), each separately assessed as PRN (“as needed”) only or scheduled dose; other; and no therapy. Treatment provided for agitation comprised nonpharmacological treatments (eg, 1:1 sitter, separate, involve family to participate in care), trunk or limb restraints, antipsychotic medication, anxiolytic or hypnotic medication, other, and no therapy. Finally, treatment of shortness of breath was prestructured as oxygen, morphine, aerosolized bronchodilators, diuretics, other, and no therapy.

Analyses

We analyzed the results by taking 2 perspectives, one prospective, reporting on consecutive regular follow-up assessments, and the other retrospective, anchoring the after-death assessment and following back to the last regular assessment. For the follow-back analyses, we selected the last regular assessment before death from the assessments 1 through 6. For each assessment, we described symptom prevalence. To investigate the individual course of symptoms in more detail, we calculated the following frequency parameters for each consecutive assessment: persistence of a symptom and persistence of no symptom, incidence, and resolution of a symptom relative to the total number of residents at the assessments concerned. A symptom persisted if it occurred on 2 consecutive assessments, or a symptom was persistently absent if it did not. Incidence was defined as a symptom present at one assessment but not present at the previous assessment. We defined resolution as presence of a symptom at one assessment but not at the next assessment. For each assessment, we described the targeted treatment and for the most frequently provided treatments we calculated the proportion of continued treatment in case of a persistent symptom.

To evaluate the longitudinal associations (change in symptoms, and change in treatment), we used the generalized estimating equation (GEE) model, with an exchangeable correlation structure. We evaluated 5 models of longitudinal associations. Three models used assessment as the independent predictor with repeated contrast

Download English Version:

<https://daneshyari.com/en/article/6050068>

Download Persian Version:

<https://daneshyari.com/article/6050068>

[Daneshyari.com](https://daneshyari.com)