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## 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.

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### Author information

### Abstract

**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, semiannually, 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.