Original Article

Dying With Dementia: Symptoms, Treatment, and Quality of Life in the Last Week of Life

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Abstract

Context. Burdensome symptoms present frequently in dementia at the end of life, but we know little about the symptom control provided, such as type and dosage of medication.

Objectives. To investigate symptom prevalence and prescribed treatment, explore associations with quality of life (QOL) in the last week of life, and examine symptom prevalence by cause of death of nursing home residents with dementia.

Methods. Within two weeks after death, physicians completed questionnaires about symptoms and treatment in the last week for 330 nursing home residents with dementia in the Dutch End of Life in Dementia study (2007–2011). We used linear regression to assess associations with QOL, measured by the Quality of Life in Late-Stage Dementia scale. Causes of death were abstracted from death certificates.

Results. Pain was the most common symptom (52%), followed by agitation (35%) and shortness of breath (35%). Pain and shortness of breath were mostly treated with opioids and agitation mainly with anxiolytics. At the day of death, 77% received opioids, with a median of 90 mg/24 hours (oral equivalents), and 21% received palliative sedation. Pain and agitation were associated with a lower QOL. Death from respiratory infection was associated with the largest symptom burden.

Conclusion. Symptoms are common in dementia at the end of life, despite the large majority of residents receiving opioids. Dosages may be suboptimal with regard to weighing of effects and side effects. Future research may employ observation on a day-to-day basis to better assess effectiveness of symptom control and possible side effects. J Pain Symptom Manage 2014;47:710–720. © *2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words
Dementia, end-of-life care, palliative care, symptoms, symptom control, treatment, opioids, palliative sedation

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Introduction

Worldwide mortality rates of death with dementia have increased and so has awareness that patients with dementia need palliative care in the last phase of life. This has generated a considerable research interest in end-of-life care for patients with dementia.[1] A high symptom burden and inappropriate treatment at the end of life have been reported.[1,2] However, these reports lack detail on how specific symptoms are being treated, for example, which pharmacological treatment is being provided to relieve pain and shortness of breath at the end of life. Moreover, many reports are limited to nursing home residents with advanced dementia, whereas about half of patients may die before having reached this stage.[3]

Burdensome symptoms present frequently in the last phase of life, as Mitchell et al.[2] reported. Pain and shortness of breath are the most prevalent symptoms at some point in the process of dementia, with a peak when death approaches. The rates of these symptoms vary widely, from 12% to 76% for pain, and from 8% to 80% for shortness of breath.[1] Agitation is less frequently studied but was reported in 20%–54% of nursing home residents with advanced dementia at the end of life.[2,4,5]

We know little about types of medication administered to treat burdensome symptoms, and more specifically, the use and dosages of opioids and palliative sedation in residents with dementia at the end of life. Symptom control is an important factor in maintaining or improving quality of life (QOL) in end-of-life care.[6–8] So far, treatment has been mostly empirical or based on general palliative care guidelines, which are not tailored to dementia.[1,2,9,10]

In this study, we report on burdensome symptoms and on specific pharmacological and nonpharmacological treatments provided for the most important symptoms in the last week of life of nursing home residents in variable stages of dementia. We report on the use of opioids as important drugs to treat pain and shortness of breath and explore associations with QOL in the last week of life and symptom prevalence related to direct causes of death.

Methods

Data Collection

Data were collected as part of the Dutch End of Life in Dementia (DEOLD) study.[3] The primary aims of the study were to describe quality of dying and end-of-life care and assess associated factors. This observational study employed both prospective (on admission) and retrospective (after death) recruitment of residents. Data were collected between 2007 and 2011 in 34 long-term care facilities. The mean number of beds per facility was 82, ranging from 11 to 210 beds. Dutch nursing homes employ elderly care physicians, certified after three years of training,[11] who were responsible for data collection in nursing homes and affiliated residential homes. The residents had a physician's diagnosis of dementia of any stage and a family representative able to understand and write Dutch or English.

Prospectively, 372 residents were enrolled on admission; 218 (59%) died within the data collection period, resulting in 213 cases with complete physician after-death assessments. Retrospectively, 119 of 121 eligible residents were enrolled, resulting in 117 physician assessments. For analyses, we selected the 330 residents with complete physician after-death reports, involving 103 physicians. No longer than two weeks after death, written questionnaires were completed by physicians or, in part, by nurses under supervision of the physician. The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center in Amsterdam.

Measurements

The diagnosis of dementia was based on international guidelines.[12–15] Type of dementia was assessed with a prestructured item comprising the categories Alzheimer's disease, vascular dementia, Lewy body/Parkinson's disease, and other. Advanced dementia (vs. less advanced dementia) was defined as a Global Deterioration Scale score of 7[16] and a Cognitive Performance Scale score of 5 or 6.[17]

The level of consciousness that most frequently occurred during the last week was scored as: awake and alert, awake, awake but drowsy looking, falling asleep, light sleep, or deep looking sleep. The physicians scored this

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