The Use and Costs of Formal Care in Newly Diagnosed Dementia: A Three-Year Prospective Follow-Up Study

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Objective: *To investigate the use of formal care during the first three years after diagnosis of mild dementia and identify cost-predicting factors.* **Design:** *Prospective longitudinal study over three years.* **Setting:** *An incidence-based bottom−up cost-of-illness study where information about formal health care services was drawn from the municipalities' registers during the first three years after the diagnosis of mild dementia.* **Participants:** *109 patients with mild dementia at baseline, diagnosed according to consensus criteria based on standardized assessments.* **Measurement:** *The use of formal care as registered by the municipalities' registration systems. Costs were estimated by applying unit costs, including municipal expenses and out-of-pocket contributions. Clinical data were collected at baseline to identify cost-predicting factors.* **Results:** *Costs for formal care were increasing from € 535 per month of survival (MOS) at baseline to € 3,611 per MOS during the third year, with a mean of € 2,420 during the whole observation period. The major cost driver (74%) was institutional care. The costs for people with dementia with Lewy bodies (€ 3,247 per MOS) were significantly higher than for people with Alzheimer disease (€ 1,855 per MOS). The most important cost-predicting factors we identified were the living situation, a diagnosis of non-Alzheimer disease, comorbidity, and daily living functioning. The use of cholinesterase inhibitors was related to lower costs.* **Conclusion:** *Formal care costs increased significantly over time with institutional care being the heaviest cost driver. Studies with longer observation periods will be necessary to evaluate the complete socioeconomic impact of the course of dementia.* (Am J Geriatr Psychiatry 2014; 22:381−388)

Key Words: Dementia, DLB, AD, formal care, costs, cost-predicting factors

Like all developed countries Norway faces the challenge of an aging population and an increasing demand for formal and informal care. To preserve the personal control, dignity, and quality of life of these vulnerable individuals as long as possible is an important goal and authorities struggle to

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prepare for this predicted increase. There are scarce data on which to base the projections of future needs, however.

Dementia is one of the most common causes of morbidity in the elderly,[1] with Alzheimer disease (AD) as the most common form of degenerative dementia, followed by dementia with Lewy bodies (DLB) and vascular dementia (VaD), whereas other forms like dementia in Parkinson disease (PDD), frontotemporal dementia (FTD), or alcohol dementia are diagnosed more rarely.[2,3]

Previous studies have shown that dementia causes high costs to the society, mainly due to high costs for care.[4,5] Disease severity, behavioral disorders, and type of dementia have been described as cost-driving factors.[6,7] Dementia is the most common reason for institutionalization,[8,9] and a 20% shortage of registered nurses is forecasted towards the year 2030.[10] There are few studies, however, observing the development of costs over a longer period than 1 year,[11,12] covering point of diagnosis as well as the gradual decline until admission to a nursing facility. In addition, there are few studies focusing on costs in patients with DLB, and none with a longitudinal design.

The aim of this study was to evaluate the use of formal care in a cohort of patients with mild dementia during the first 3 years after diagnosis. We further estimated cost for formal care in this patient group and evaluated cost-predicting factors.

METHODS

Patients

Patients were drawn from a longitudinal incidence study of dementia in western Norway, the Norwegian DemWest study. From March 2005 to March 2007 a total of 196 patients with mild dementia (defined as Mini-Mental State Examination MMSE][13] score $\geq$20) and a first-time diagnosis were included. A thorough description of the case finding, diagnostic criteria, and diagnostic procedures is given in Aarsland.[2] All patients were examined at baseline where demographic and clinical data including present medication were taken. The diagnosis was re-evaluated during the clinical follow-up and the final diagnosis was made as a consensus between two experts in geriatric psychiatry. To date seven patients have had a postmortem examination, and the clinical diagnosis has been confirmed in all cases.

We used a subset of this study cohort by including only those 131 patients who lived in one of the four biggest municipalities of the study area (Bergen, Stavanger, Haugesund, or Sandnes). In order to retrieve data from the municipal files we obtained separate consent from all surviving patients. The patients were asked for consent by letter, with one reminder, in May and June 2010, respectively, with a response rate of 80%. There were no significant differences regarding age, years of education, or the living situation between responders and non-responders. Thus, 109 patients were included in the study. For each patient we collected data about the use of formal care from the date of baseline examination and during the following 3 years. In order to evaluate cost-predicting factors, baseline data were collected by the following instruments: MMSE for the cognitive state, Neuropsychiatric inventory (NPI)[14,15] for psychiatric symptoms, Greene Relative Stress Scale for relatives' perceived stress,[16] the Unified Parkinson Disease Rating Scale motor subscore (UPDRS III)[17] for parkinsonism and the Rapid Disability Rating Scale-2 (RDRS-2)[18] for activities of daily living (ADL). In patients where one or two items of the RDRS-2 were missing we substituted them by the mean score for this item. As we used both the version with 19 and with 21 questions of the RDRS-2 questionnaire, we transformed the values into z-scores to get coherent data, based on means and standard deviations (SD) from all patients included in the DemWest study. The total burden of medical illness was described by the Cumulative Illness Rating Scale (CIRS),[19] which scores 14 body domains, including neurological and psychiatric disorders excluding dementia. We also registered the use of cholinesterase inhibitors (ChEI). As the prescription of ChEI is usually linked to the diagnosis of dementia, we chose not to register the use of ChEI at baseline but at the first follow-up assessment after 1 year. The prescription of memantine is restricted to moderate to severe dementia by the Norwegian health authorities. Still, some of the participants of this study about mild dementia used memantine during the first year after diagnosis, probably due to psychiatric symptoms. As case numbers were low, however, the use of memantine was not included into the analysis.