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Featured Articles

Survival and early recourse to care for dementia: A population based study

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Abstract

Background: A large proportion of dementia cases are still undiagnosed. Although early dementia care has been hypothesized to benefit both patients and families, evidence-based benefits are lacking. Thus, investigating the benefits for newly demented persons according to their recourse to care in the "real life" appears critical.

Methods: We examined the relation between initial care recourse care and demented individuals' survival in a large cohort of incident dementia cases screened in a prospective population-based cohort, the Three-City Study. We assessed recourse to care for cognitive complaint at the early beginning of dementia when incident cases were screened. We classified patients in three categories: no care recourse, general practitioner consultation or specialist consultation. We used proportional hazard regression models to test the association between recourse to care and mortality, adjusting on socio-demographical and clinical characteristics.

Results: Two hundred and fifty-three incident dementia participants were screened at the 2 year or 4 year follow-up. One third of the incident demented individuals had not consulted a physician for cognitive problems. Eighty-six (34.0%) individuals had reported a cognitive problem only to their general practitioner (GP) and 80 (31.6%) had consulted a specialist. Mean duration of follow-up after incident dementia was 5.1 years, during which 146 participants died. After adjustment on potential confounders, participants who had consulted a specialist early in the disease course presented a poorer survival than those who did not consult any physician (hazard ratio = 1.64, 95% confidence interval 1.03–2.62). There was a trend but no significant differential survival profile between participants who complained to their GP and those without any care recourse.

Conclusion: Neither recourse to a specialist nor recourse to GP improve survival of new dementia cases. Those who had consulted a specialist early in the disease course even reported a worse life expectancy than those who did not.

Keywords: Early recourse to care; Dementia; Survival; Population-based study

1. Introduction

In Europe, the number of dementia cases could reach more than 14 million in 2050 [1]. Because of the wide range of

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adverse consequences (functional limitations, complication of other medical conditions, financial abuse…), optimizing dementia care is a public health priority. Nevertheless, many obstacles have to be overcome. A major problem is the large number of people for who the dementia diagnosis is delayed or never made. As a consequence there is a high proportion of undiagnosed cases in the population even at severe stages [2–4]. Many barriers to diagnosis have already been reported, including sociodemographic, educational, cultural, clinical factors [5,6], and the controversial benefit of systematic active screening of cognitive impairment in primary care [7]. Indeed, there is some evidence that memory clinics may be no more effective than standard care provided by general practioners [8]. Furthermore, while an early access to dementia care has been hypothesized to benefit both patients and families [9], a recent study of psychosocial intervention including counseling, education, and support in very mild Alzheimer's disease has not shown any benefit over 1 year [10]. Implementing such trials assessing the influence of early dementia care represents still a major challenge in particular concerning their acceptance in primary care settings [11–15]. Thus, until an evidence-based approach of its benefits is possible, investigating the prognosis of incident demented persons according to their initial recourse to care in the "real life" appears critical. These benefits must be assessed by universal health outcomes such as survival, which is affected by the numerous health, safety, and care issues in dementia [16]. Prospective population-based studies that actively screen for incident dementia cases can estimate differential survival in elders who receive or not care. In this perspective, factors affecting both recourse to care and survival have to be investigated and considered in the analyses. One such factor could be the preclinical evolution before diagnosis because the slope of cognitive decline in this time frame could influence the timing of physicians' consultations, and also seems to be a major prognostic factor for survival [17,18]. Analyzing the survival of demented individuals who do or do not consult a GP or specialist early in the disease course could bring arguments about the issue of early dementia care. The objective of our study was to examine the relation between initial recourse to care and demented individuals' survival in a large population-based cohort, taking into account potential confounders.

2. Methods

2.1. Study population

This study was part of the Three-City (3C) Study, a collaborative research program based on a longitudinal cohort of 9294 subjects aged 65 years or more. Its main objective is to estimate the risk of dementia and cognitive impairment attributable to vascular factors and to define target groups for future preventive strategies. The participants were recruited between March 1999 and March 2001 in three French cities: Bordeaux (2104 participants), Dijon (4931), and Montpellier (2259). Trained staff administered standardized questionnaires and performed clinical examinations at baseline and 2, 4, 7, and 10 years after. Details of the 3C Study have been reported elsewhere [19]. The study protocol was approved by the ethics committee of the Kremlin-Bicetre University Hospital and all participants provided informed consent.

2.2. Diagnosis of dementia

At baseline and at each follow-up visit, trained psychologists assessed cognitive function and dementia was actively screened. After the neuropsychological examination, participants suspected of having dementia, based on their neuropsychological performances or decline relative to a previous examination, were examined by a neurologist or geriatrician, in the presence of an informant for nearly half of the interviews (47%). The same clinical protocol was applied for dementia diagnosis and classification in each center. For each subject with suspected dementia, the physician who examined the participant documented the evolution and severity of the cognitive disorders and any prior consultation for cognitive problem. After this examination, the final diagnosis of dementia was made by a panel of five highly qualified neurologists, independent of the 3C Study investigators, who reviewed all available ancillary information. The diagnosis of dementia was established on the basis of *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)* criteria (American Psychiatric Association) [20]. Alzheimer's disease was diagnosed according to the National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria [21].

2.3. Indicators of care consultation for cognitive problem

Recourse to care was assessed at the follow-up when the dementia diagnosis was posed by the neurologist or geriatrician of the study; it was made by both self-reported information given by the subject and/or the informant and by the inventory of all medications. The data were collected during a face-to-face interview conducted by the neurologist or geriatrician. Individuals were classified into three categories: (1) no recourse to care for those who did not express cognitive problems during any care consultation; (2) recourse to general practitioner (GP) for those who had declared that they had consulted their GP for their cognitive problems but had not consulted a specialist; (3) recourse to specialist for those having consulted a specialist (neurologist, geriatrician or psychiatrist) for their cognitive problems and/or were treated with antidementia drugs (cholinesterase inhibitors or memantine). This latter category included participants with or without previous recourse to GP. Indeed in France, the whole population is covered by public health insurance and everyone has their own general practitioner who plays the gatekeeper's role for patients' care pathway. The GP refers his patient to a specialist in case of doubts or to