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Original article

Factors influencing time between onset of signs/symptoms and referral for dementia in elderly outpatients

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ABSTRACT

Background. – The few studies that have focused on Time between Onset of Signs and Symptoms and Referral (TOSR) for dementia to a memory center suggest a substantial delay of 1–3 years. This delay has a negative impact on both patients' and their caregivers' quality of life.

Objective. – This study aimed to evaluate this delay and the factors associated with it in a cohort of community-dwelling elderly people attending a memory clinic, as well as assess the impact of the Third French National Alzheimer Plan (2008–2012).

Methods. – All patients referred to the Bretonneau Memory Clinic for the first time between January 2006 (the clinic has maintained a specific database since then) and March 2016 were included in the study.

Results. – Of the 8543 patients attending our Memory Clinic during the study period, 3353 attending for the first time and with complete data were included. Briefly, their ages were 82 ± 7 years, and 67.2% were female; MMSE score was 21.2 ± 6.6 , IADL was 4.06 ± 0.78 and the social-needs category of the Groupes Iso Ressources (GIR); Iso-Resource Group (IRG) scale was 4.04 ± 0.37 . The TOSR was, on average, 35.4 ± 30.24 months, and increased after implementation of the Third French National Alzheimer Plan, from 26.68 ± 26.28 months before 2009 to 40.08 ± 31.2 months after 2009. Age and MMSE were associated with TOSR, but not the type of dementia, household composition and social characteristics. Also, there was a shorter TOSR for mild cognitive impairment than for dementia patients.

Conclusion. – Our results emphasize the need for more education and information among the general public about the early signs of cognitive impairment, especially in elderly people.

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1. Introduction

Alzheimer's disease and other kinds of dementia are a major health problem for people aged 65 and older [1]. The presence of a long prodementia stage is now generally acknowledged, and an expert opinion consensus recommends early diagnosis [2], and proposes more accurate criteria to refine the etiology of dementia and to eliminate the possible causes that can be specifically treated (such as hydrocephalus, hematoma and depression) [2]. The capability of making an early diagnosis has profound implications for patients as well as their caregivers, as providing early intervention can help families avoid financial losses and expenses associated with cognitive disorders [3], and also prevent exhaustion [4]. In contrast, later diagnosis reduces the ability to manage the illness effectively, affects the quality of life of both patients and caregivers, and leads to increased resource utilization [5]. Cognitive disorders and dementia also need nursing care and constant supervision, which is usually undertaken by family caregivers [6], often with negative health consequences [7]. Moreover, announcement of the diagnosis is often delayed, whereas earlier announcement would allow the patient and family to better understand the disease, recognize the patient's behavior and organize their daily life activities [8,9]. An expert consensus has proposed a protocol for making the diagnostic announcement, given the importance of a clear explanation of the disease and sufficient time to allow a dialogue to take place [10]. Physicians should also change their attitudes towards patients after they have been diagnosed with dementia [11]. Various dementia plans [12] have been implemented in Europe over the past decade. The Third French Alzheimer Plan (2008–2012) [13] focused on improving the quality of life for patients and their families, and on reducing the time to diagnosis by increasing the number of memory clinics. Although there is currently no drug treatment for dementia, current research focuses on the preclinical and early stages of the disease [14].

To our knowledge, only a few studies have focused on the Time between the Onset of Signs/Symptoms and first Referral (TOSR) for dementia to a memory center, and the factors associated with it. Their results suggest a substantial delay [15,16] of 1–3 years [8,11]. In a study [8] focused on caregivers in 11 European countries, the TOSR was about 1 year, but the authors emphasized that, after a semi-structured interview, it appeared that the first signs had been ignored. Less than half the patients had their diagnosis clearly established in primary care [17], while about 50% of people with dementia, including patients with mild but also moderate dementia, had never received such a diagnosis [18]. When Cattell et al. [11] assessed all patients referred to a memory clinic during an 18-month period, and collected their sociodemographic and medical data, they found a time to diagnosis (defined as the difference between the date of the visit and time of onset of initial signs) of 13.8 ± 10.8 months.

Our objective was to evaluate the TOSR and its associated factors in a cohort of community-dwelling elderly people attending a memory clinic for the first time. Our second objective was to evaluate the impact of the Third French Alzheimer Plan (2008–2012) on this delay.

2. Methods

2.1. Population

This retrospective single-center study took place at the Memory Clinic of Bretonneau Hospital in Paris (Assistance Publique Hôpitaux de Paris). This clinic is primarily for people aged ≥ 65 years. It was set up in 2003, with an increase in staff during the French Alzheimer Plan (2008–2012).

The Memory Clinic has maintained a specific database since 2006 (under Commission Nationale de l'Informatique et des Libertés authorization No. 1858079). This database was created locally by all the professionals at the hospital to facilitate patient follow-up and allow memory consultations to be categorized. It operates independently of the National Alzheimer databank [19], which was created later at the national level. All practitioners must complete the database for each patient, which they have been trained to do. It should be emphasized that all practitioners are encouraged to complete the database because funding for the Memory Clinic depends on the data transmitted, anonymously, to the French social security insurance services.

In particular, the diagnostic criteria for the different forms of dementia, cognitive disorders and psychological symptoms are recorded, and there is a weekly multidisciplinary meeting to decide on complex cases. Our present study covers a period of 10 years, during which time the criteria for different forms of dementia changed. In 2006, the professional consensus of the Memory Center was based on Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) [20] criteria, the Hachinski Ischemic Score [21], the National Institute of Neurological Disorders and Stroke (NINDS)-Association Internationale pour la Recherche et l'Enseignement en Neurosciences (AIREN) criteria [22], the first McKeith diagnostic criteria [23], the Lund-Manchester criteria [24] and the first Petersen criteria [25]. These then evolved with, among others, the McKhann criteria [2], and criteria for vascular dementia [26] and frontotemporal dementia [27].

The present study used the diagnoses indicated in the database at the second or third visits, that is, after a full evaluation. However, when no firm diagnosis could be made, practitioners recorded 'diagnosis not established'. Also, our study analysis retained the date of first referral to the Memory Center, and all patients referred to the Bretonneau Memory Clinic for the first time between January 2006 and March 2016 were included in our study.

2.2. Patient characteristics from the Bretonneau database

Patients attended with their primary caregivers (typically, family members), if they had any. Practitioners collected information on the patients' sociodemographic characteristics, including age, gender, marital status, household composition and years of formal education (seven levels: 1 = no school, 2 = 10 years, 3 = 14 years, 4 = 17 years, 5 = 18 years, 6 = 20 years and 7 = > 20 years of education). The presence of multiple illnesses (polypathology) was indicated by a binary answer (yes or no).

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