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Patients' diagnosis decisions in Alzheimer's disease: The influence of family factors

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ABSTRACT

It is surprising to observe that the number of patients receiving a late diagnosis for Alzheimer's disease (AD) remains high even in countries promoting early diagnosis campaigns. We explore the impact of family history and family support on the risks of receiving a delayed diagnosis. We use French data of 1131 patients diagnosed between 1991 and 2005. We find that the presence of AD history in the family increased the risks of receiving a delayed diagnosis. This was true especially when AD history involved brothers, sisters and other relatives (uncles or cousins). The presence of an informal caregiver at the time of the first warning signs reduced the risks of receiving a late diagnosis, regardless of the informal caregiver concerned (spouse, son, daughter etc.). We identify several opportunities for early detection campaigns. Families with history of disease should be targeted. Campaigns should also target isolated patients, who do not benefit from informal care. Our results underline the importance of improving the diagnosis access for old patients and for men.

1. Introduction

The implementation of early detection campaigns in Alzheimer's disease (AD), which aim at minimizing the negative effects of the disease and preventing disease-related complications, is a global challenge. Indeed, the number of patients receiving a late diagnosis for AD remains high even in countries that promote early diagnosis campaigns. In France, it has been estimated that only 50% of AD patients are diagnosed, and that the average time from first warning signs to AD diagnosis is 2 years (Dartigues, 2011). Similar results have been observed even in countries that have developed integrated care systems, such as Canada (Carpentier et al., 2010).

Surprisingly, several surveys underline that people generally would prefer to learn their risks of having AD in the future. In the United-States, two surveys provided evidence that more than 70% of people would be willing to get a diagnosis test for AD if it was available, regardless of its accuracy (Neumann et al., 2012, 2001). Similarly, a French survey underlined that 90% of people declare willing to get a diagnosis test before the first warning signs for AD if such a test was available, 78% of them because the benefits associated with the news are expected to be greater than the costs (TNS-SOFRES, 2013). In other words, there is a disconnection between the willingness to get diagnosed for AD (as expressed in surveys), and the actual diagnosis rates observed when people actually face the first warning signs of the disease.

This difference underlines the complexity of the AD diagnosis decision. Indeed, several economic, social, psychological and disease-related factors can influence help-seeking behaviors, leading previous research to find a lot of heterogeneity in decisions (Neumann et al., 2012). Gender, education, income, family history, age and healthy behaviors were associated with differences in diagnosis decisions, and were found to influence the willingness to pay for a diagnosis test (Lin et al., 2013; Neumann et al., 2012, 2001). For many people, the associated social stigma and psychosocial consequences of the AD diagnosis make it not worth pursuing, and contribute to make the inclination to search for a diagnosis lower for AD than for other conditions such as arthritis or prostate cancer (Neumann et al., 2012). In consequence, diagnosis decisions must be further explored.

In the economic theory, the patient's attitude towards the risks and the uncertainty associated with her future health status, e.g. when she does not know with certainty the outcomes about her health state, can explain the diagnosis decisions. There is evidence that people would prefer risks over uncertainty (Ellsberg, 1961) and would present an aversion to ambiguous situation, e.g. when the

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probabilities of different outcomes are unknown or uncertain (Viscusi et al., 1991). Following these evidences, early AD diagnosis choices could be interpreted as choices made by people disliking the ambiguity coming with the first warning signs, and preferring negative news to an ambiguous situation (Neumann et al., 2012). Previous research showed that patients' disease risks awareness is a crucial variable to model the diagnosis-seeking process (Clare, 2003; Clare et al., 2008; Hutchinson et al., 1997). In addition, the demand for tertiary prevention strongly depends on the sick individuals' perception of its degree of efficiency: individuals will not make the diagnosis test if they are too pessimistic (Etner and Jeleva, 2013). Factors such as age, sex, and health status contribute to explain why people' perceptions of their risks of death or disease may differ from their objective risks (Andersson and Lundborg, 2007; Slovic, 2000). Beliefs about future health states may also contribute to reduce the willingness to get diagnosed. Specifically, anxiety (or aversion to information) can be an inhibiting factor that can lead patients avoiding a diagnosis in the presence of suspicious symptoms, when they anticipate that their health state undiagnosed and treated without a medical treatment is greater than their health state with the diagnosis and the associated treatment (Koszegi, 2003). Finally, previous research has explored the economic value of a diagnosis test, and provided evidence of the importance of the benefits and costs of potential treatments (Eeckhoudt et al., 1984). In AD, potential medical treatments have a low efficacy, which may reduce the incentive to get a diagnosis.

Patients' attitude towards risks and uncertainty is likely to be influenced by two family factors: disease history in the family and the presence of informal caregiver when the patients experience the first warning signs. First, there is evidence that individuals' attitudes towards a disease change when a close a relative was previously affected by this disease. For instance, previous research underlined that smoking intensity was complementary to newly diagnosed non-smoking-related family cancers (Ganz, 2001). In New-Zealand, the presence of family disease history was associated with delayed physicians visits among a breast cancer population (Meechan et al., 2002). Moreover, there is evidence that when past experience is composed by the decision relevant events, it directly influences insurance decisions (Cohen et al., 2008). Following these evidences, it can be assumed that AD history in patients' close family is likely to influence the behavior of the person experiencing the first warning signs. For instance, it is likely that individuals with a family history of AD do not feel the need for diagnosis since they have observed that AD treatments remain minimally efficacious. Moreover, it can be assumed that patients with AD history in the family have worked out familial strategies from prior dealings with the condition, which could increase the odds of a delayed diagnosis.

Second, diagnosis choices can be explained by interactions between individuals. In particular, previous research underlined the central role of informal caregivers (in general, spouses or partners) in the management of AD (Wimo et al., 2002). It is likely that the siblings of someone experiencing AD signs play a role in the diagnosis seeking decision. In France, 38% of people would ask advice to a close family member before deciding to get a diagnosis (TNS-SOFRES, 2013). Focusing on the initial phases of AD patients' care trajectory, previous research also provided strong evidence that family members, friends and neighbors play a central role in the recognition of the disease, which is crucial to implement interventions for early detection (Carpentier et al., 2010). Finally, there has been evidence that family members often were the first to express concerns about the patient's health, and played a key role in the initiation of the diagnosis (Hansen et al., 2008). Following these evidences, it is expected that the presence of informal caregivers would impact the diagnosis decision.

In this paper, we explore AD diagnosis decisions from an empirical perspective. Using data from a population of community-dwelling French patients diagnosed between 1991 and 2005, we explore to what extend family factors influence the AD diagnosis delays. Specifically, we have two objectives. First, we explore whether the presence of AD history in the family is associated with risks of a late diagnosis. Second, we explore to what extend the presence of informal caregivers at the date of first signs is associated with risks of a late diagnosis. Providing empirical evidence that family factors are influencing the diagnoses would be very important from a health policy perspective, as AD detection campaigns usually involve informal caregivers.

2. Research design

2.1. The PLASA study

Our sample was drawn from the PLASA study, which design, inclusion/exclusion criteria, demographics, and methodology are detailed in previous publications (Nourhashemi et al., 2010, 2008). It is a French sample of 1131 community-dwelling patients recruited between 2003 and 2005 nationwide. The study was funded by a public grant from the French government. In the overall study, patients were randomized in two arms, one receiving the intervention and the other usual care. Ethical procedures were followed in the study through an internal review board agreement. Consent processes following the French Law were used. The Institutional Review Boards of the University of Toulouse approved methods in May 2003. The aim of the PLASA study was to explore the impact of a multicomponent intervention designed to decrease the rate of functional decline in patients with mild to moderate AD compared with usual care in memory clinics. Note that the intervention design is not relevant in our article, since we used data collected prior to the intervention. We used historical data collected from the PLASA participants, and our analyses focus on events that occurred prior to inclusion or at inclusion when the diagnosis was provided when the patient entered the study.

Patients were recruited if they had a diagnosis for mild to moderate AD. The diagnosis was given by a doctor using the criteria of the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer, Disease and Related Disorders Association or probable or possible Alzheimer's disease (McKhann et al., 1984), with a Mini Mental Status Examination (MMSE) score between 12 and 26. Patients were recruited with age 60+, but there were no age limits. Patients were recruited if they had a primary informal caregiver: patients were asked if a relative, co-resident or not, was providing assistance for performing activities of daily living. The primary informal caregiver was asked to participate in the study. Informal caregivers were family members or close relatives in charge of providing the general support to the patient. Specifically, the primary informal caregiver was defined as the person mainly in charge of helping the patient with her activities of daily living, instrumental activities of daily living, and involved in her supervision.

Patients and caregivers were recruited directly from memory clinics. Note that in France, access to healthcare is subject to a minimal out-of-pocket contribution. The memory clinics were sampled regardless of convenience sample considerations, but were chosen to have sufficient expertise in both diagnosis and management of AD. Written informed consent from both the patients and their caregivers were obtained at inclusion, and the study was reported "*according to the consolidated standards of reporting trials statement and its extensions to cluster randomized trials and to non-drug interventions*" (Nourhashemi et al., 2010).