PATIENT ENGAGEMENT STRATEGIES TO MOVE TOWARDS EARLIER DIAGNOSIS OF ALZHEIMER’S DISEASE

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Summary: Alzheimer’s disease (AD) is an incurable disease that steals memories, identities, livelihoods and lives. We now know more about the pathophysiology of the disease and the scope of various preventative mechanisms; we also know that early intervention and treatment in AD can be both beneficial and cost-effective. Despite the importance of a timely diagnosis, many patients are not diagnosed at all. A cultural shift towards making the diagnosis of AD at a very early stage needs to be encouraged. The early recognition of AD is the first step towards providing patients with optimal opportunities for intervention.

Keywords: Alzheimer’s Disease, Diagnosis, Patient Engagement, Clinical Trials

Alzheimer’s disease remains a challenging disease

Alzheimer’s disease (AD) is the most common form of dementia (60%–80% of the cases). In 2018, it was estimated that 7% of the population over 60 years were affected by dementia in the European Union (EU). With age being a risk factor, this figure is expected to grow to 8% in 2040 due to the ageing of the population. Other risk factors include genetics, general unhealthy lifestyles and vascular, metabolic, and nutritional risk factors.

The financial impact of unhealthy ageing is projected to be a significant challenge to the sustainability of health care services in almost all EU Member States. Dementia is one of the major causes of disability and dependency among older people worldwide and consequently creates substantial costs for health and long-term care sectors and the wider economy. Moreover, it has an enormous physical, psychological, social and economic impact on carers, family and society at large. Understandably, AD is a critical public health concern in Europe.

Patients with mild cognitive impairment (prodromal AD) or early stage AD remain outside clinical settings and most patients are not diagnosed in a timely manner, or not diagnosed at all. Despite progress in identifying people with dementia, the diagnostic process is still poor and diagnosis rates are very low; more than half of the population in OECD (Organisation for Economic Co-operation
and Development) countries still do not receive a diagnosis and, if they do, it is at a late stage, when the symptoms are too severe to intervene.

Early AD diagnosis is a crucial step in accessing care and support for a person with dementia. With a proper diagnosis, patients and carers can have timely access to education, training and support programmes. Being aware of these different support opportunities can drive the decision to seek a diagnosis.

Unfortunately, there still is no treatment to cure dementia or to alter its progressive course. The numerous failures in clinical trials on AD drugs, and the need for modifying treatment to delay/cure the disease, call for further and significant research efforts in drug development.

The way ahead is to offer sustainable solutions for AD patients, their carers and health care systems to help people live better with AD, which relies on implementing better processes to support early diagnosis.

The underlying causes of late or under-diagnosis

There is evidence that early intervention and treatment of AD is beneficial for patients and their families, as well as cost effective for health care systems. However, there is still a significant proportion of undiagnosed or late diagnosis cases in Europe due to several factors:

A lack of awareness and understanding of the disease, results in stigmatisation and barriers to diagnosis and care. According to an Alzheimer’s Disease International (ADI) 2019 report: one in four people think nothing can be done to prevent dementia and just under 40% of the general population think that there are adequate community services for people living with dementia and for their carers.

Primary care is the entry point for people concerned about memory problems. However, medical school training on dementia is inadequate, and the number of general practitioners (GPs) has decreased in the EU in recent years. Primary care physicians are sometimes ill-prepared to take on the role of diagnosis, do not have the sufficient time slot needed to make a proper diagnosis of dementia, and lack motivation to develop their skills to fulfil the task. In OECD countries, GPs accurately identify dementia in only 50–75% of cases. This is also supported by the ADI 2019 World Report which states that 62% of health care providers worldwide assume that dementia is part of the natural ageing process. The report also reveals that around 40% of the general population are under the impression that doctors and nurses ignore people with dementia and 36% of all respondents say that they would seek help on the internet instead.

Insufficient referral and care pathways between primary and secondary health care settings in relation to both diagnosis and management of AD. Having access to a diagnosis and support is complex and varies across EU Member States. It is vital to monitor patients along the care process, and to provide them with appropriate facilities, services and tools. The monitoring process, which uses data from primary care physicians and professionals in other health settings, is still not standardised across Europe.

A number of national EU dementia strategies focus on referral systems that require improvement, both in relation to diagnosis and management of the condition. Nevertheless, some examples of more efficient coordinated care in dementia strategies in EU Member States exist. Italy, for example, makes reference to a multidisciplinary team approach covering both diagnosis and coordination of interventions for dementia. The French strategy prioritises access to shared assessments and guarantees access to personalised care. In Spain, the system uses a shared medical history system, where a multidisciplinary team covers both diagnosis and coordination, with interventions involving the patients’ relatives.

Looking at innovative ways to address the diagnosis gap in AD

In this challenging policy context, while research into AD causes and treatments remains a major priority in Europe, it is crucial to also identify approaches to help overcome the obstacles to more efficient, early and appropriate diagnosis. One example of such research can be found in the EU funded MOPEAD (Models Of Patient Engagement for AD, https://www.mopead.eu) project, which is designed to assess different Patient Engagement models across Europe, to identify efficient approaches of earlier identification of mild AD dementia and prodromal AD patients.

MOPEAD is an Innovative Medicines Initiative (IMI) multi-regional project performed in Germany, the Netherlands, Slovenia, Spain and Sweden. It was established to test four different strategies for efficient identification of early stage AD and mild AD in the general population. MOPEAD tested two pro-active strategies whereby citizens voluntarily perform a cognitive test: 1) Citizen Science – an online pre-screening tool; 2) Open House – pre-screening tests performed in a memory clinic without a physician’s referral. MOPEAD also studied two passive strategies for patients at risk, in which their cognition was tested in two settings: 1) Primary Care setting – patients were identified and tested by the primary care physician; 2) Tertiary Care setting – the identification and tests were performed by endocrinologists specialised in treating Type-2 Diabetes, a risk factor for AD. The persons considered of being at risk were then offered a full diagnostic assessment in a memory clinic that they were free to accept or refuse.

MOPEAD assessed key tools, mechanisms and processes for community engagement, patient identification and evaluated resource utilisation. The project aims to ultimately provide value to patients, their carers and to health care systems. MOPEAD’s findings will be used to raise
awareness about prevention, the value of early diagnosis, engagement in clinical trials and social research.

Taking stock of EU research and policy recommendations

There is a political will to combat AD and other forms of dementia: dementia has been recognised as a European, national and international health and societal challenge. At EU level, two European Joint Actions have investigated and confirmed the importance of improving the diagnosis of AD. ALCOVE (ALZheimer’s COoperative Valuation in Europe) (2011–13) and ‘Act On Dementia’ (2016–19).

The 2009 European Commission Communication, European Initiative on Alzheimer’s disease and other dementias, recommended early action to diagnose the disease. Under its ‘Health, demographic change and wellbeing’ priority, Horizon 2020, the current EU research programme, funds projects that address unmet medical needs such as dementia. In the next programme, Horizon Europe, the ‘Global challenges and European industrial competitiveness’ pillar includes a health cluster. Dementia is an area where Horizon Europe could make a significant impact on society and policymaking and, as such, be considered as one of Horizon Europe’s future missions.

At national level, several countries have committed to improve dementia care systems by establishing national dementia plans. At international level, the World Health Organization has declared dementia control a global health priority.

The European Alzheimer’s community, including people living with the disease, their carers, researchers and policymakers, must build upon this momentum to promote early intervention. Early intervention would give people the opportunity to have more time to take serious decisions that would affect their present and future lifestyle. Without a proper diagnosis, family members and carers do not have access to training and support programmes available to help them cope with the disease. There are great expectations that the new European Commission and the new European Parliament will take stock of the past recommendations and new initiatives to improve the diagnosis of AD.

In this context, MOPEAD serves as an innovative strategy to make the “hidden” population with cognitive impairment visible and to encourage health care systems to implement diagnostic and support strategies that will respond to the challenge. An AD diagnosis without a supportive environment minimises the value of early diagnosis.

References


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