Patient journey for people with Alzheimer's disease

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Background

Dementia is characterized by a decline in memory, thinking, behavior and the ability to perform everyday activities. Ultimately, dementia leads to a loss of independence and an increasing need for support by others. In Europe, currently an estimated 10.5 million people have dementia, and this number is expected to increase to 18.66 million in 2050 [1], which makes dementia one of the most challenging healthcare and socio-economic problems society currently faces. In 70% of the people with dementia, Alzheimer's disease (AD) is the underlying cause. In search of disease modifying treatments, research has increasingly focused on the pre-dementia stages of AD, which develop along a continuum from healthy asymptomatic, to the first symptoms such as memory complaints, to mild cognitive impairment (MCI) and subsequently to different stages of AD (mild, moderate, severe). It is yet unknown how an early diagnosis or such early treatments would affect patient and caregivers in clinical practice. We therefore aim to characterize the patient journey, by describing the patient and caregiver needs in the different AD disease stages and the potential effect of an hypothetical early intervention.

Methods

We used three different sources for the patient journey. First, Alzheimer Europe described care pathways to diagnosis and post-diagnostic care and support for people with dementia in 2014, which incorporated information from 30 European countries [2]. Whilst this work was specifically for people who have already symptoms of dementia, many of the conclusions from this work are also relevant to the pre-dementia stages. Second, as part of the VoT project, we performed interviews with people experiencing cognitive decline and their caregivers at the VUmc Alzheimer Center, Amsterdam, the Netherlands in 2016. Our target population for the interviews consisted of people in the early stages of AD, along the entire disease spectrum. We interviewed six participants, consisting of a person with subjective cognitive decline (SCD) and his caregiver, a person with MCI, a person with AD (young-onset) and his caregiver and a caregiver of a person with AD (late-onset). Third, the patient journey was further discussed in the VoT workgroup (April 22nd, 2016). Based on the available evidence, we identified two important treatment gaps: diagnosis and treatment.

Treatment gaps: diagnosis and treatment

Diagnosis is a critical stage for people with dementia and their families, as it may provide access to treatment and support. It has been estimated that around half of the people living with dementia in Europe have never been diagnosed and, for those diagnosed, it will most likely happen at a late moderate stage [3,4]. In most European countries the general practitioner (GP) is the gateway to diagnosis, but the diagnosis is mostly made by specialists including neurologists, psychiatrists and geriatricians. The most common barriers to the diagnosis of dementia include the lack of specialists, the long waiting lists, the variable provision of and access to diagnostic services in the country, the lack of guidelines and of clear pathways before and after diagnosis. GP's training and expertise in recognizing and managing dementia may be another relevant factor contributing to missed or delayed diagnosis [5,6]. Finally, lack of awareness about dementia (among the public and GPs) and the social stigma attached to the disease were perceived as important obstacles to diagnosis. This was also recognized in the patient journey interviews (see Box 1). Regarding **treatment,** care and support needs of the individual with dementia are not systematically monitored, with most countries reporting an "on demand" approach. Also, the type of information and the time at which people with dementia and their families receive information greatly varies among countries. It is often reported that information provided by GPs depends on their own knowledge and attitudes and may therefore not be consistent. Similarly, whilst social workers and community nurses are also relevant providers of information and may facilitate access to relevant services, these professionals are often consulted only when care needs arise. This suggests that, too often, care and support systems are crisis driven rather than preventive and proactive (see Box 2). The results are summarized in Figure 1.

Box 1 Diagnosis - patient journey interviews

"people distance themselves and are not very understanding when you experience cognitive problems. I became very lonely" (individual with MCI)

"not knowing what's wrong is very frustrating, a diagnosis should be made sooner" (individual with MCI)

"[the long trajectory of the diagnostic process was] a very difficult period of my life" (individual with AD)

'…receiving the diagnosis actually helped in a way; I now know it's not me […], it's the disease'. (individual with AD)

Box 2 Treatment - patient journey interviews

Both patients and caregivers mention knowledge gaps as an important limitation in receiving adequate care from the GP

'I had a separate conversation with the psychologist during the follow-up, which I thought was very worthwhile' (caregiver of individual with SCD)

"[By going to the University hospital] I can meet other people with dementia, I can participate in and contribute to scientific research. There is this whole community of people with dementia that attend lectures for laymen' (individual with AD)

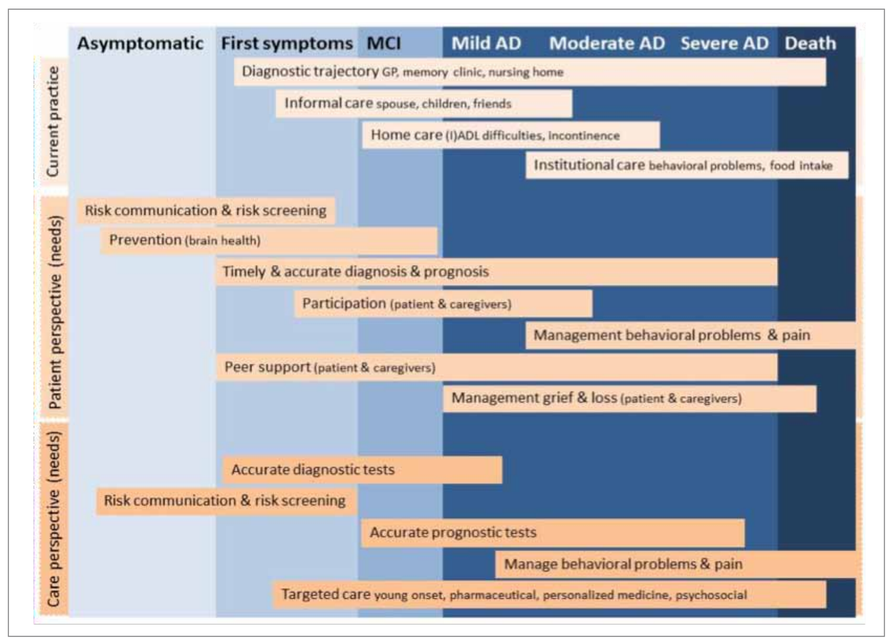

Figure 1: Patient journey treatment gaps and care needs along the continuum of AD

Recommendations

Based on our inventory we have the following six policy recommendations:

1. Increase awareness and understanding of early and at risk stages of AD. This would include a broad recognition of these stages as part of the disease spectrum, the burden of (early) AD, addressing stigma and fear of the disease.
2. Timely and accurate diagnosis. There is an urgency to ensure a rapid diagnosis to reduce long periods of uncertainty in patients and caregivers.
3. Improve access to diagnostic services and care. This would include training for GPs to address the diagnostic gap.
4. Ensure access to support for people with (early) AD following diagnosis. Navigating the care system is often perceived difficult, and should be improved.
5. Support the development of a comprehensive patient care pathway for the entire AD spectrum. This would need to include the patient and caregiver perspective.
6. Support and promote dementia research. This would lead to improved diagnostics and speed up the development of new promising therapies

Conclusions

The patient journey for people with or at risk for AD is characterized by a long diagnostic process, which can be improved by increasing awareness, understanding and access to diagnostic services and care. Care and treatment is not provided systematically, and navigating the care system is difficult. We provided recommendations for improving diagnosis and treatment, that will affect the entire continuum of AD.

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Potential health-economic impact of treating Alzheimer's Disease (AD)

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Background

In Europe, currently an estimated 10.5 million people have dementia, which is characterised by a decline in memory, thinking, behaviour and the ability to perform everyday activities. This not only affects persons' quality of life, it is also associated to large care-related costs. The largest costs are related to long-term care facilities and informal care. Developments in disease-modifying treatments have shifted towards early pre-dementia intervention in order to prevent a person from progression to dementia. Persons with subjective cognitive decline or mild cognitive impairment are among the target population potentially eligible for future treatment. Such treatments have the potential to reduce the dementia-related burden and associated care costs.

The aim of this study was to develop a health-economic model that assesses the potential value of disease-modifying treatment for people with amyloid pathology who have not yet developed AD dementia.

Methods

We constructed a Markov model to simulate the disease progression, costs and quality-adjusted life years (QALY) of a virtual cohort over a 25-year period. The baseline simulation cohort reflected persons who visited a memory clinic and had normal cognition or a diagnosis of MCI, and were tested positive on amyloid beta. Costs in the health care sector (medical, home care, institutionalized care and informal care) were included to reflect a societal perspective.

A strategy in which a hypothetical disease-modifying treatment (DMT) was initiated to a virtual cohort of 10,000 persons with subjective cognitive decline (SCD) or mild cognitive impairment (MCI) with positive amyloid beta was compared to the control strategy reflecting care as usual. Transition probabilities between the pre-dementia states were estimated based on data from the DESCRIPA, ADNI and ADC studies, and from a previously developed model by Green et al. [1]. Costs were obtained from the ICTUS study [2].

We assumed a 50% reduction of the progression to dementia due to the DMT, no treatment costs, no side effects, state-dependent mortality and a 3.5% discount rate.

Results

The results indicated that early identification and disease-modifying treatment of AD provides a window of opportunity to prevent progression to stages that affect activities of daily living when disease-modifying interventions are available in clinical practice.

Reducing AD progression in pre-dementia by 50% was estimated to maintain persons longer with NC and MCI. This resulted in a smaller proportion of persons living with mild, moderate or severe dementia. Because mortality was lower in pre-dementia states, people were estimated to live longer (see figure 1 for the number of persons in states over time in usual care).

Reducing AD progression was estimated to increase the total of quality-adjusted life years (QALYs), both due the higher quality of life of living with less severe disease states as well as increased life years (see figure 2).

Slower progression in the treated cohort resulted in reduced care-related costs. The average total costs over the 25-year time horizon varied across European countries (Netherlands highest, Greece lowest), although the majority of the costs were attributed to home/day care, long-term institutional care and informal care (see figure 3).

However, results were dependent to our assumptions regarding mortality. Sensitivity analysis showed the outcomes were sensitive for assumptions on treatment effectiveness, mortality and treatment duration (see table 1). Assuming a flat mortality rate of 10% resulted in a larger cost savings of € 20,351 per person over lifetime versus 12,406 under the assumption of state-dependent mortality.

This study showed the importance of considering a societal perspective with regard to the possibility to finance treatment from savings in other care sectors as the savings in the medical sector reflected only a proportion of the total savings. However, a large reduction of the savings originated from the value that was placed on informal care, which might not fully reflect transferable resources to finance treatment.

Conclusions

The simulation study showed the potential of early intervention with pharmacological treatment in persons with SCD and MCI with regard to improving QALYs and reducing care costs. The results were, however, sensitive to assumptions among which a state-specific or flat mortality rate.

Fig.1: Number of persons in states over time (control group)

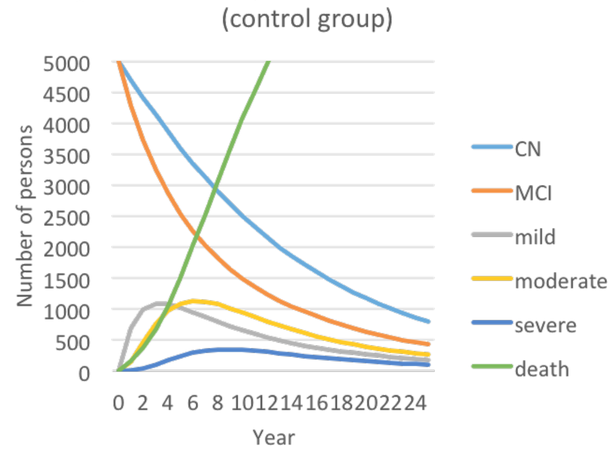


Fig.2: Quality-adjusted life years over time

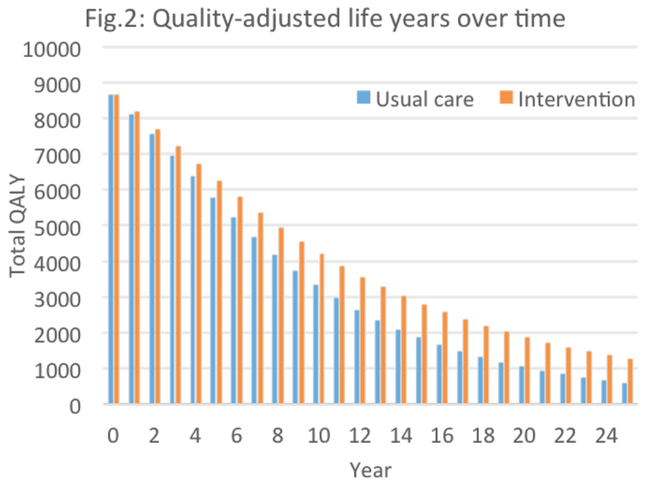
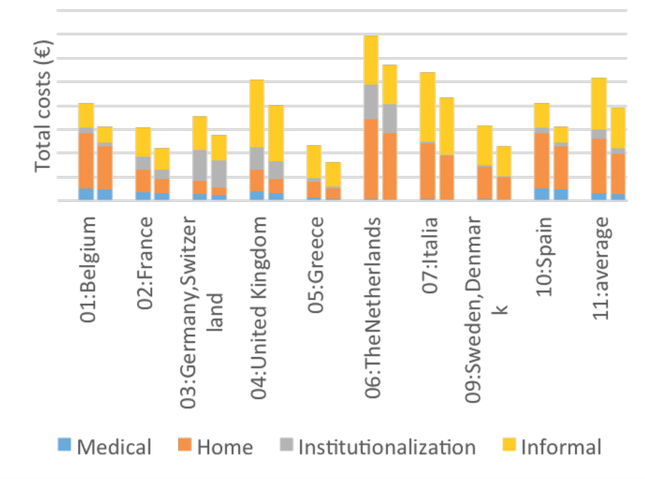


Fig.3: Total costs per country for usual care (left bar) and treatment (right bar)



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