



The Value of Knowing

Findings of Alzheimer Europe's five country survey on public perceptions of Alzheimer's disease and views on the value of diagnosis

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Foreword



This survey, carried out in four countries in Europe (France, Germany, Poland and Spain) and the US, examined public perceptions of Alzheimer's disease (AD) and views on the value of diagnosis. The survey demonstrated an overwhelming willingness of the public to confront AD despite their fear of developing it. The findings also showed that many people have first-hand experience of AD and that public awareness of the disease is high. However, public perception is that a reliable diagnostic test is available and that the treatment for people with AD is effective. There are some lessons for Alzheimer Europe and national Alzheimer's associations about the need to ensure that the public has reliable information on these topics.

AD is a major public health problem and it is essential that more is done to address the lack of effective treatments and the shortcomings in care before the 'epidemic' overwhelms healthcare funding. The majority of the public in the countries surveyed wish to see increased funding for finding new treatments and providing care for people with AD. This reinforces Alzheimer Europe's call for national dementia strategies and greater investment in research.

One important result for Alzheimer's associations is that while many people affected by AD have reached out to our organisations for information and support, there are still those who have not done so. We, as patient associations, need to continue our efforts to reach anyone affected by AD who might benefit from our support and services.

This survey provides an overview of the public perceptions of AD. It clearly adds to our existing knowledge and highlights areas where further research will be necessary. By increasing our understanding of the expectations of the public around AD, the survey will help us better target public health initiatives which are responsive to their needs.

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Executive Summary

This survey, carried out by the Harvard School of Public Health in association with Alzheimer Europe, was conducted in four countries in Europe (France, Germany, Poland and Spain) and the US. In total, 2,678 members of the public aged 18 years and older were interviewed by telephone during February 2011.

Most respondents stated that they would see a doctor if they or a family member were exhibiting symptoms such as confusion and memory loss to clarify whether these symptoms were due to AD. Respondents showed significant interest in obtaining a test prior to symptoms becoming apparent, if one were available. AD ranked as a major concern in many of the five countries surveyed, second only to cancer (except in Poland). Those aged 60 and over have the highest fear of AD. Most members of the public support greater government spending on research and care in AD.

The majority of the public surveyed have personal experience with AD, with the exception of Poland, and about one in three respondents had a family member with AD.

There was general agreement between countries on some symptoms of Alzheimer's disease. Confusion and disorientation, wandering and getting lost and difficulty remembering things from the day before were all identified by more than 90% of respondents. However, there was a lower level of awareness that AD is a fatal disease that reduces life expectancy.

Many members of the public believe that a treatment is currently available to reduce the existing symptoms and effectively slow the progression of the disease and a significant proportion believes that a reliable medical test to diagnose AD is currently available.

The majority of the public in all countries supported increased government funding for research into treatment and for providing care for people with AD.

Introduction

Early diagnosis of AD is important for a number of reasons: it allows the person affected and their family members to plan for the future and it allows early access to treatment. On the other hand, knowing early about a disease which cannot yet be cured may bring anxiety and distress to a family. In raising awareness of AD, associations need to ensure that they understand what members of the public feel and want in relation to early diagnosis so that they may effectively support them. This study aimed at ascertaining the public's knowledge of AD and their views on early diagnosis.

Alzheimer's disease (AD) is a progressive neurodegenerative disease which primarily affects older people, although diagnosis at a younger age occurs. It is classified as mild, moderate or severe. AD is associated with a decline in brain function over time and patients have an average life expectancy of 7-10 years after diagnosis.¹

AD is the most common form of dementia with between 50 and 70% of all people with dementia suffering from the disease.² It is estimated that 1 in 20 people aged over 65 years are living with the disease.³ Recent statistics indicate that 7.3 million people have dementia in the European Union and an estimated 5.4 million people in the United States have Alzheimer's disease.^{4,5} These numbers are expected to increase as the population ages and are predicted to double by 2040 in Western Europe and the United States and treble in Eastern Europe.⁶

Background to the survey

With the impact of the increasing incidence of AD on individuals and society becoming clearer, the early diagnosis and appropriate treatment of affected individuals is a public health priority. Reflecting this, many countries with a national dementia plan include an element covering early diagnosis. From an individual or family perspective, the benefits of early diagnosis are access to treatment at the earliest possible opportunity and the ability to make changes and plan for the future. This might include reducing working hours or stopping work altogether; clarifying what benefits and support services might be available; gaining information about the disease and its impact to ensure that everyone is prepared; and decreasing anxiety and uncertainty about why changes are occurring.

Early diagnosis will also allow people with dementia to be involved in their own care decisions before their cognitive function is too impaired and to develop coping strategies and identify preferences about future care plans, including the possibility of drafting an advance directive or appointing someone to make decisions on their behalf when they become incapacitated.

Although research has demonstrated that patients want to be informed of their diagnosis and that non-disclosure or vagueness can be upsetting, early diagnosis continues to be the exception rather than the norm. The recent World Alzheimer's Report⁷ found that only between one third to half of people with Alzheimer's disease had actually been diagnosed. Carers also reported long delays ranging from ten months in Germany to 32 months in the United Kingdom between first noticing symptoms and the diagnosis. Finally, Alzheimer Europe found that disclosure of diagnosis was not universal and carers reported that only between 23% of patients in Spain and 80% in Scotland had been informed about their diagnosis. There are challenges with early diagnosis. There is, as yet, no single reliable medical test that can be used although considerable research is underway to find a method to make a definitive diagnosis. But, even if a reliable test is developed there remain questions about whether early treatment has a major impact on symptoms and disease progression.

As Alzheimer Europe, we have a clear remit to ensure that the debate around the best care of people with AD remains high on the public health agenda. This requires an understanding not only of what people with dementia and their carers believe is important, but also what those members of the public who may be affected in the future would wish to see in place. This survey was undertaken with the purpose of gaining the views of this latter group to contribute to the public health agenda.

Methodology

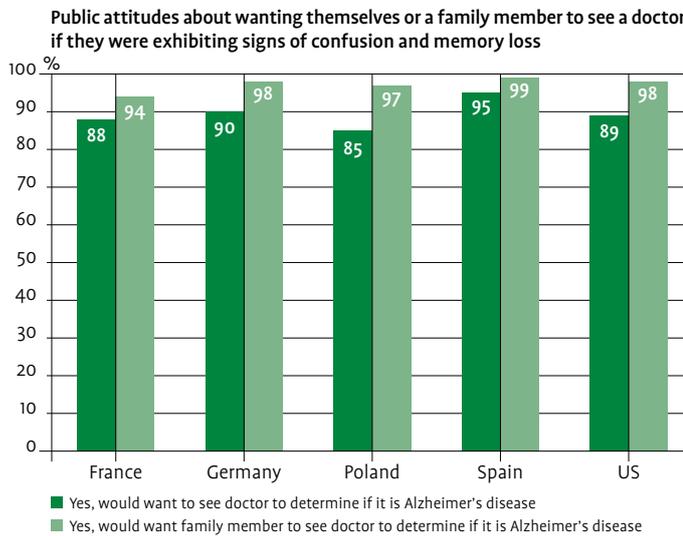
Participants were members of the public aged 18 and older from France, Germany, Poland, Spain and the US. They were interviewed in their own language using a structured questionnaire developed by the Harvard School of Public Health and Alzheimer Europe with the support of national Alzheimer associations in participating countries and external experts. The interviews were conducted by telephone by TNS, an independent research company.

Results

The number of people interviewed in each country was: France, 529; Germany, 499; Poland, 509; Spain, 502; US, 639. The respondents were representative samples of the respective populations with regard to gender, age, ethnicity and socio-economic background.

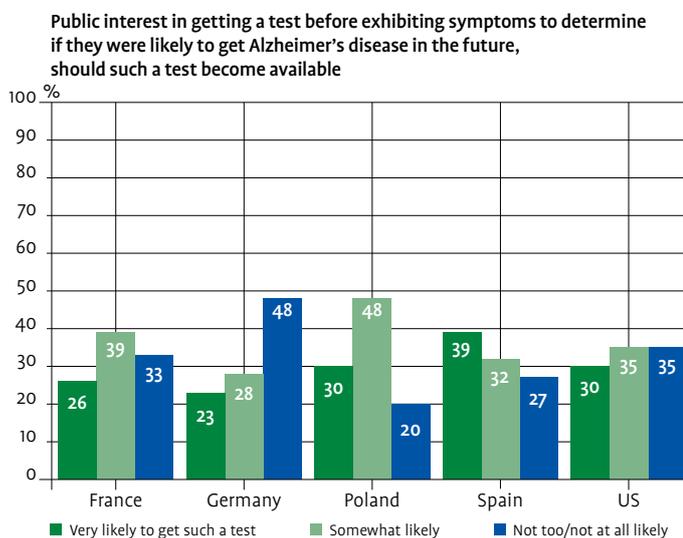
The purpose of the study was to gain a better understanding of how members of the public viewed AD, how well they understood the disease, and their expectations around diagnosis and treatment. There was remarkable alignment between countries on many of the questions. Significant differences are outlined in the detailed results below.

Most people with symptoms would see a doctor for diagnosis



More than eight out of ten adults (range: 85% in Poland to 95% in Spain) would go to a doctor if they were exhibiting confusion and memory loss to determine whether the cause of the symptoms was AD. Similarly, nearly all respondents would want a family member who was displaying signs of AD to see a doctor for a diagnosis. Most respondents (range: 94% in Spain to 98% in Germany; not asked in US) would wish to be told about a diagnosis of AD and most (in Europe, not asked in US) would want their relatives to be informed of the diagnosis.

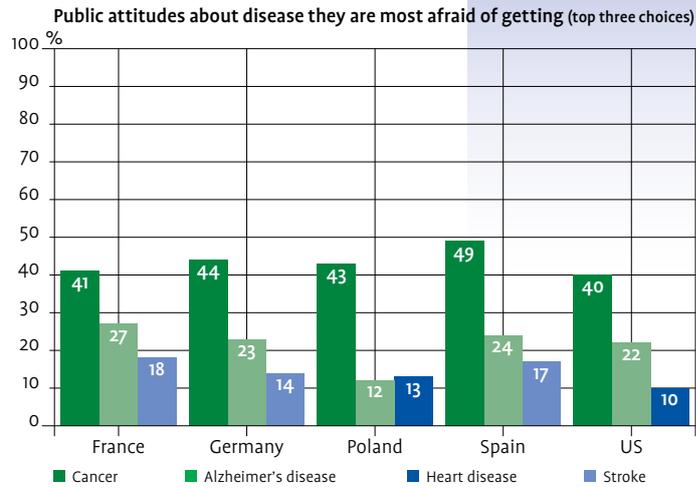
There is significant public interest in pre-symptomatic diagnostic testing



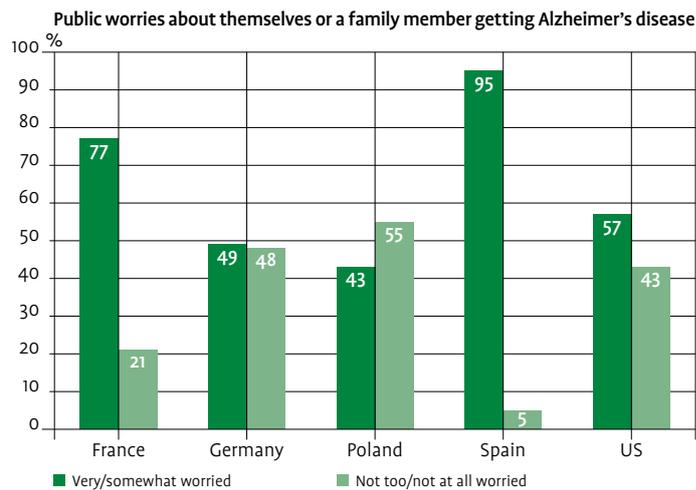
Respondents were asked whether they would want to take a medical test, if one became available in the future, which would tell them before they had symptoms whether they would develop AD. There was public interest in such a test, with roughly three in ten (range: 23% in Germany to 39% in Spain) indicating that they would be very likely to get a test for early diagnosis.

AD is a major healthcare concern for many people

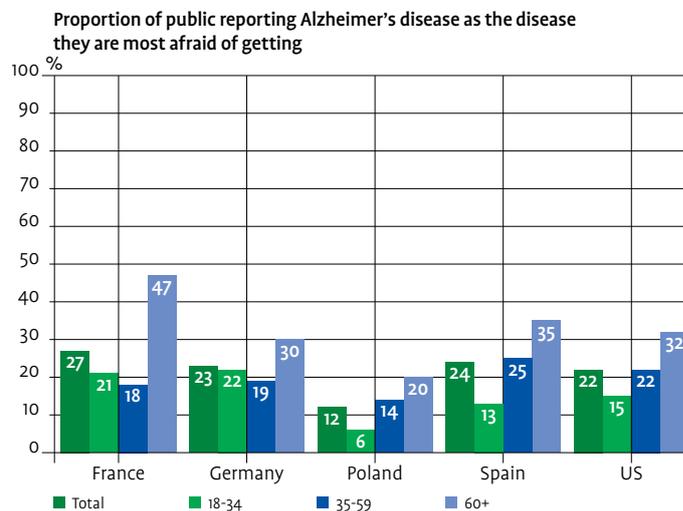
Respondents were asked to choose, from a list of seven diseases, the one they were most afraid of getting. The most frequently identified disease was cancer, quoted by around 40% of respondents. The second most feared illness was AD, identified by about one quarter of adults in four of the five countries. The exception was Poland, where the proportion citing AD was about half of that in the other countries surveyed.



Respondents were asked whether they were very worried, somewhat worried, not too worried or not at all worried that they or a family member would get AD. In Spain, nearly all respondents were very or somewhat worried about themselves or a family member getting AD. The figures were lower for the other countries (range: France 77% to Poland 43%) and in Poland a majority of respondents were not worried about themselves or a family member developing the disease.

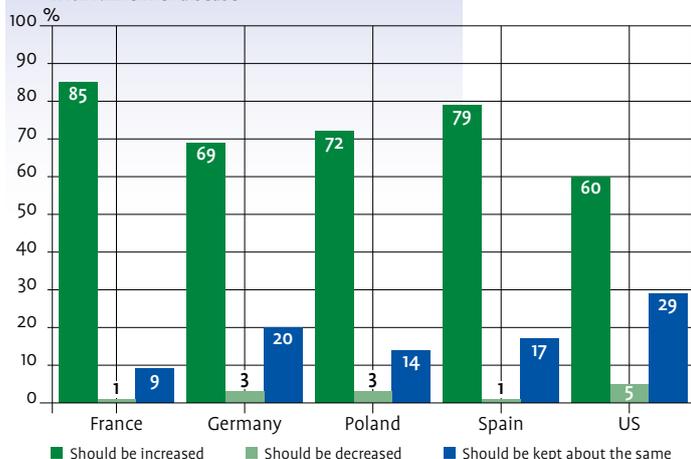


Fear of getting AD is highest in all countries among those aged 60 and over (range: 20% to 47%) and lowest in three out of five countries among 18-34 year-olds (range: 6% to 22%).

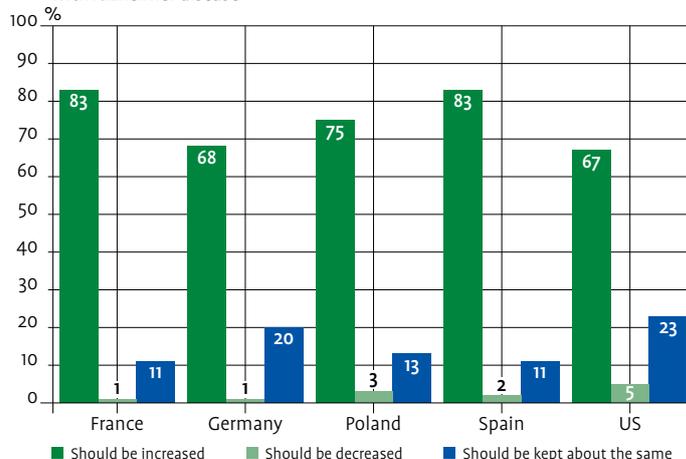


The majority of respondents in all countries wish to see government spending increased both on research into treatment for AD and caring for people with the illness.

Public attitudes on government spending on caring for people with Alzheimer disease

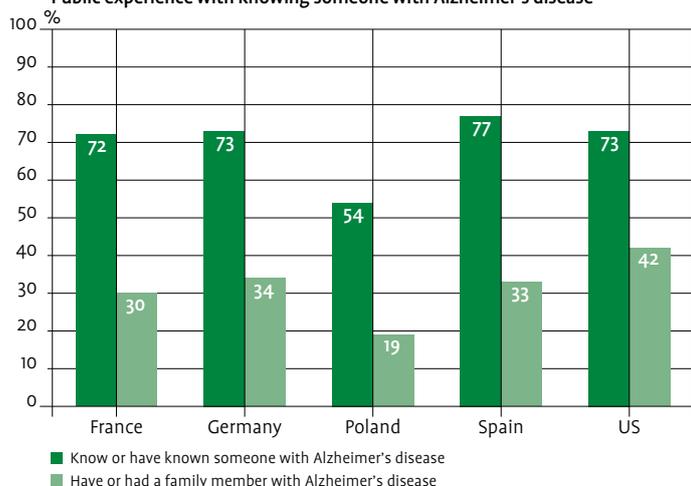


Public attitudes on government spending on research for people with Alzheimer disease



Personal experience with AD is very common

Public experience with knowing someone with Alzheimer's disease



A large proportion of respondents indicated that they had some experience with AD, with the majority in all five countries reporting that they know or have known someone with AD. The results for France (72%), Germany (73%), Spain (77%), and the US (73%) were consistent; Poland was noticeable for having the fewest members of the public with personal experience of AD (54%).

Around three in ten respondents know or have known a family member with Alzheimer's disease (range: 19% of respondents in Poland to 42% in the US).

In addition, about one in ten members of the public has had significant life experience by being one of the people involved in the day-to-day support of the person living with the illness. One in seven has had a role in relation to financial support, decision making or day-to-day support (range: 13% Poland and 27% Spain).

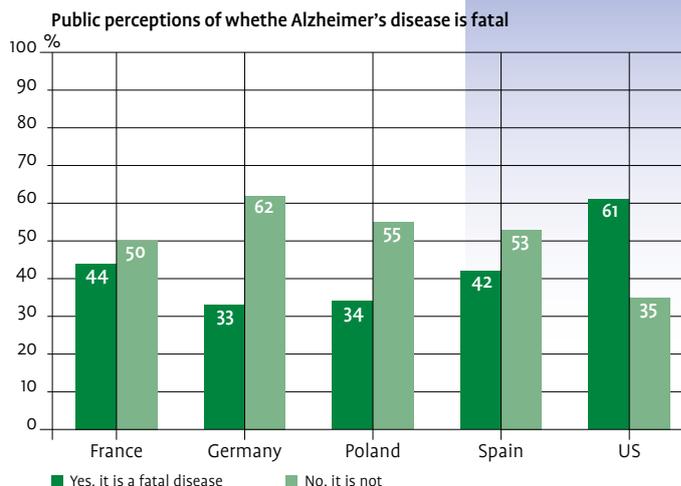
Awareness of some symptoms of AD was good but few know that it can be a fatal disease

Respondents were asked to identify, from a given a range of symptoms, those that were associated with AD. Certain symptoms are widely believed to be characteristic of the disease. In each country a large majority of respondents correctly identified each of the following as being a common sign of AD:

- confusion and disorientation
- wandering and getting lost
- difficulty remembering things in their life from the day before
- difficulty managing daily tasks
- difficulty managing and paying bills.

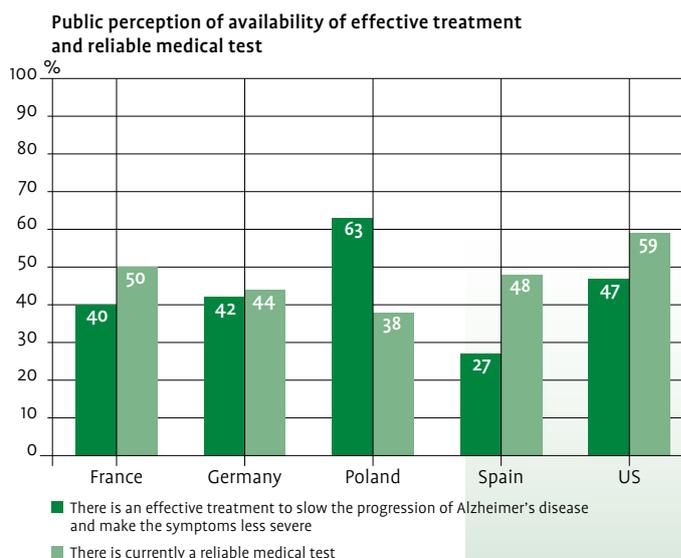
Fewer people thought other possible symptoms were associated with AD and the range of responses was wider. These symptoms included difficulty remembering things from years before (range: 44% to 76%); anger and violence (range: 35% to 53%); loss of appetite (range: 21% to 52%); hallucinations and hearing voices (range: 24% to 40%). There was a consistent response from 50 to 68% of respondents that pain was not a common symptom.

The question of whether AD is potentially fatal produced noticeably different responses with 61% of US respondents stating that it is a fatal disease whereas respondents in Germany and Poland were least likely to believe people could die as a result of their AD (33 & 34% respectively).



Public expectations of the available treatments is high in some countries, low in others

Respondents were asked about the availability of effective treatment for AD. There was a noticeable difference between the answers obtained in Spain and Poland: in Spain, only 27% believed that an effective treatment is available whereas 63% believed this in Poland. France, Germany and the US were similar in their responses, falling between Spain and Poland (range: 40 – 47%). Asked whether there would be an effective treatment in the next five years, respondents were more positive with more than half of respondents in all countries believing that there would.



Respondents were asked about the availability of a reliable medical test to diagnose AD, clearly important if a treatment is available to slow the disease progression and make the symptoms less severe. The responses were varied, with 38% of respondents in Poland to 59% of US respondents mistakenly believing that there is currently a reliable medical test to determine whether a person suffering from some confusion and memory loss is in the early stages of AD.

Conclusion

There were marked differences across countries with respect to the public's experience with AD, with respondents in Poland representing a much smaller percentage of those with family experience. There was remarkable consistency across countries, except Poland, with regard to how they ranked AD among diseases they fear the most and respondents in Poland also provided the lowest percentage of respondents who feared AD. There were significant differences between countries as to the public's concerns or worries about getting AD.

However, the survey found no significant differences in the willingness of respondents to see a doctor, if they displayed relevant symptoms, to know whether they had developed AD. We found no marked differences between this willingness to confront the disease between men and women, between people with or without first-hand experience of AD or between people believing that an effective treatment will become available in the next five years and those who did not.

This survey highlights a glaring gap between public expectations and reality, as recent research highlighted that only between a third and half of people with Alzheimer's disease actually received a diagnosis. Additional research is therefore necessary to identify the existing barriers and how best to overcome them.

The clear interest in early diagnosis and in confronting the disease confirms Alzheimer Europe's position of promoting better access to diagnostic services in order to ensure that early diagnosis becomes a reality for the majority of people with Alzheimer's disease. However, the survey also highlights that a significant proportion of people seeking a diagnosis will have the expectation that a reliable test and effective treatments are available, when the reality is that diagnosis is not always straightforward and there is no cure for AD.

The results of the study indicate that there is a need to educate members of the public about some of the realities of AD but there is overwhelming interest in obtaining a diagnosis if symptoms exist and, if and when a test becomes available, in knowing before the signs of the disease are obvious. In addition, Alzheimer Europe believes that early diagnosis should not be made in isolation as no diagnosis should be made without adequate post-diagnostic support. Newly diagnosed people should be given the contact details of their national or local Alzheimer's association, have access to advice on how to make advance directives or appoint a person of their choice to make decisions on their behalf when it becomes necessary, as well as access to peer support, psycho-social interventions and medical treatment.

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