Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey

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SUMMARY

The Facing Dementia Survey was undertaken to assess the awareness of and behaviours surrounding Alzheimer's disease (AD) and dementia among all key stakeholders in Europe. Interviews were conducted with more than 2500 persons, including caregivers, members of the general population, physicians, persons with AD and influencers of health care policy. Four key messages emerged from the results. First, AD often remains undiagnosed until symptoms become moderate or severe. This delay may be because of the difficulty of recognising the symptoms of early AD and the attribution of symptoms to so-called normal ageing, the fear of AD common among older people, inadequate screening tools for use by physicians and/or a delay in the confirmation of the diagnosis once suspicion is raised. Second, a majority of respondents perceive their governments as indifferent to the economic, social and treatment burdens associated with AD. Third, a substantial majority of caregivers, physicians and the general population appreciate the wide-ranging impact that AD can have on the quality of life of people who suffer from it and their informal caregivers. While most caregivers reported life-changing negative effects, a few also noted some positive aspects to their experience. Finally, survey results revealed that most caregivers and members of the general public do not have sufficient information about the benefits of treatment and care. The findings of the Facing Dementia Survey support the development of an agenda for change in dementia care across Europe.

Keywords: Alzheimer's disease; dementia; social survey; ageing; inequality

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INTRODUCTION

Alzheimer's disease (AD) and dementia evoke people's deepest fears about losing their memory, their identity and their independence. Although some effective treatments are available to preserve cognition and independence for mild-to-moderate disease, there is no cure. People with AD and their caregivers need extensive support to maintain functioning and dignity, but the diagnosis is frequently accompanied by stigmatisation that leads to increasing isolation and depression and a deteriorating quality of life.

The Facing Dementia Survey was undertaken to assess attitudes and behaviours towards AD in Europe. It was recognised that certain barriers to treatment and reimbursement in these countries may be rooted in an incomplete awareness on the part of institutions and citizens, in general, of the complexity inherent in the recognition, care and management of AD. Survey results will be used to identify barriers to optimal care and, ultimately, to develop a platform for an Agenda for Change – a programme to improve diagnosis and care across Europe. It is hoped that these results will also generate media interest in covering issues that affect ageing, help create a sense of urgency surrounding dementia and inspire a need to take action among the general population, third-party groups, health care providers and policy makers at every level.

METHODS

The Facing Dementia Survey is one of the largest research surveys done on dementia, involving more than 2500 persons from six countries (France, Germany, Italy, Poland, Spain and the UK). Interviews were conducted face to face or via telephone through Millward Brown, a global market research agency, in February and March 2004. The questionnaires were authored by Millward Brown in conjunction with Pfizer and Eisai, who provided financial support for the survey. One primary objective of the survey was to assess current attitudes about AD. For this, interviewers read a series of attitudinal statements about AD. For each statement, the respondents were asked whether they (i) strongly agreed; (ii) agreed; (iii) neither agreed nor disagreed; (iv) disagreed; or (v) strongly disagreed.

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Table 1 Overview of survey respondents interviewed in six countries*

Quantitative samples
Caregivers
618 spouses, children and other caregivers of someone with Alzheimer's disease (AD)
Approximately 100 each in six countries*
General population
1200 interviews with males and females ≥18 years of age
200 each in six countries*
Physicians
605 general practitioners, primary care physicians and specialists
100 each in six countries*
Qualitative samples
People with AD
96 persons with AD
15 persons each in six countries*
Influencers
60 health policy managers and decision makers
10 each in six countries*

*France, Germany, Italy, Poland, Spain and the UK.

In each country, quantitative samples were taken from at least 200 members of the general population, 100 caregivers and 100 physicians (Table 1). Qualitative samples were taken from approximately 15 persons with AD and 10 policy influencers in each country (Table 1). The general population respondents were men and women, 18 years or older, who neither had AD themselves nor were caregivers for persons with AD. These respondents were interviewed via telephone. Caregivers were spouses, children or others who were unpaid caregivers for someone diagnosed with AD. Caregivers were recruited from local AD associations, newspaper advertisements and referrals. In Germany, Italy, Poland and Spain, these interviews were administered face to face, and in France and the UK, they took place via telephone.

Half the physicians interviewed in each country were primary care physicians (PCPs), general practitioners (GPs) or internists, and half were specialists (i.e. neurologists, neuropsychiatrists, geriatricians, psycho-geriatricians or psychiatrists). All were under the age of 70 years, had been in practice between 5 and 30 years and spent at least 50% of their time on direct patient care. In an average month, the GP respondents saw at least two patients with AD – whether or not the visit involved was specifically for AD treatment – and the specialists saw at least 10 patients with AD. In France, Spain and the UK, these physician interviews were conducted via telephone (and face to face in the remaining countries).

Qualitative samples were taken from approximately 15 persons with diagnosed AD and 10 policy influencers in each country. Respondents with AD ranged in age from 50 to 92 years and were referred by physicians, AD associations or pharmacists. Those making the referrals were specifically instructed to confirm wherever possible the diagnosed status of the patients. Health policy managers and decision makers were identified by Edelman (London, UK) from a previously existing database of experts on health care policy. These experts consisted of health economists, members of parliament, members of the European parliament, representatives of pan-European public health organisations, national health department officials and influential non-governmental organisation executive directors and board chairpersons.

RESULTS

Timing of Diagnosis

Survey respondents generally agreed that the symptoms of early AD or dementia are difficult to recognise (Figure 1). The vast majority of respondents among caregivers, physicians and the general population believed that most people would be unable to distinguish the difference between the signs and symptoms of early stages of AD and so-called normal ageing and also that most people would be unable to recognise the early signs of AD. Instead, respondents believed that

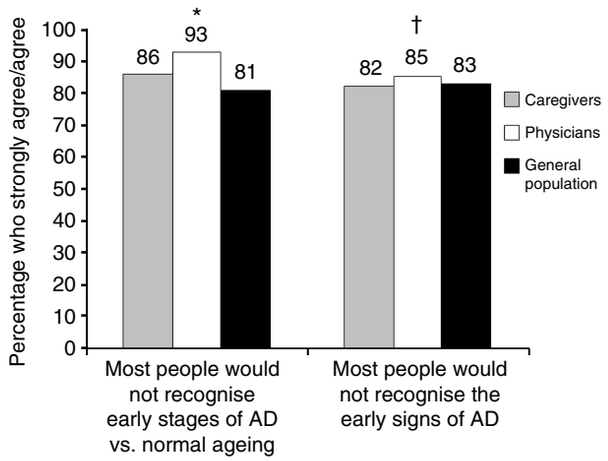

Figure 1 Survey respondents who reported difficulty in recognising early Alzheimer's disease (AD). *$p < 0.05$ vs. caregivers and general population; †$p < 0.05$ vs. general population.

symptoms would most often be interpreted either as normal behaviour in some context or as so-called normal ageing.

A majority of respondents (65% of caregivers, 70% of physicians and 50% of the general population) agreed or strongly agreed that many GPs and PCPs are unaware of the early symptoms of AD, hence do not recognise them and, consequently, fail to diagnose the disease (Figure 2). A possible implication of these findings is a widespread belief that AD is so complex that it cannot easily be recognised during a short consultation, especially if the physician is not looking for it. According to 42% of caregivers, 35% of physicians and 40% of the general population, even specialists have difficulty in making an early diagnosis (Figure 2).

Even when the symptoms are manifest, confirmation of the disease may be delayed. The average time from symptom recognition by carers to their consultation with a physician was 47 weeks across the six countries included in the survey. Caregivers offered several reasons for the delay. These included a lack of awareness that the signs they noticed were symptoms of AD (70%), a failure to recognise the severity of the symptoms (61%), a belief that the symptoms were those of other medical conditions (52%), denial that a loved one could have AD (64%) and a belief that the symptoms were part of so-called normal ageing (58%). At the same time, 52% of the public, 48% of caregivers and 53% of physicians agreed or strongly agreed that fear keeps people from speaking to their PCPs about AD.

The average delay from the point when symptoms were first noticed by carers to diagnosis of AD was 20 months (Figure 3). There were inter-country variations in the time to diagnosis after the caregiver retrospectively first noticed symptoms. The interval was greatest in the UK (32 months), whereas Germany was reported to have the shortest interval (10 months) ($p < 0.05$).

AD as a Health Care Priority

A majority of caregivers and physicians agreed or strongly agreed that their governments do not view AD as a health care priority, as reflected by inadequate investment of money into treatment or providing adequate resources to help the affected people (Figure 4A). The general public was somewhat less concerned than physicians and caregivers about government's indifference. In addition, caregivers, physicians and the general population agreed or strongly agreed that government was unaware of the threat of AD (70, 52 and 54%, respectively), acted as a barrier to receiving medication

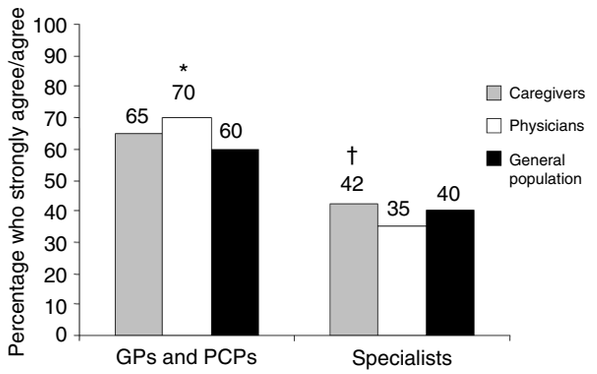

Figure 2 Ability of generalists and specialists to identify early symptoms of Alzheimer's disease. GP, general practitioner; PCP, primary care physician. *$p < 0.05$ vs. general population; †$p < 0.05$ vs. physicians.

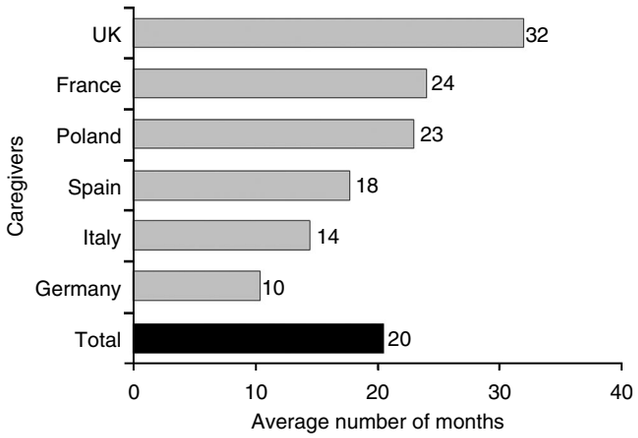

Figure 3 Time taken to diagnosis of Alzheimer's disease after symptoms were first noticed.

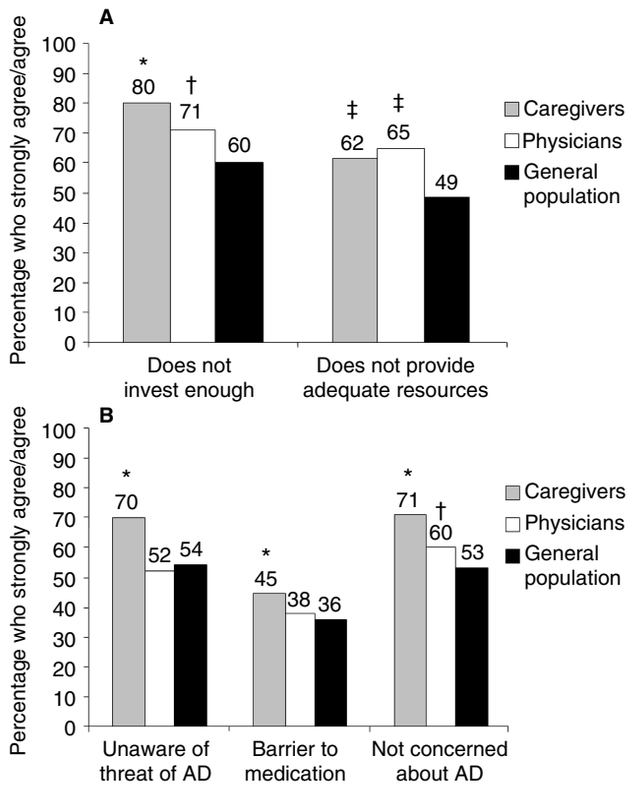

Figure 4 Perceptions about government's indifference towards Alzheimer's disease (AD). A) *$p < 0.05$ vs. physicians and general population; †$p < 0.05$ vs. general population; ‡$p < 0.05$ vs. general population. B) *$p < 0.05$ vs. physicians and general population; †$p < 0.05$ vs. general population.

(45, 38 and 36%, respectively) or was not concerned about AD (71, 60 and 53%, respectively) (Figure 4B). They believed that government emphasises diseases such as diabetes or breast cancer more than AD and other dementia.

A theme from the qualitative interviews with people with AD is a feeling of dissatisfaction with the government and an expectation of little help from that quarter. An AD interviewee from the UK said, 'The government should support the clinical trials to find solutions'. Another, from Germany, noted, 'The doctors should get more money and more time for every patient – employ more people in the hospitals. Health is the most important thing in our lives!'

This theme also emerged from the qualitative interviews with key policy makers and health care providers from all six countries. Government's indifference to the needs of AD patients and caregivers was perceived as a serious obstacle to improved care. One influencer from the UK noted that the health budget for AD, particularly with regard to research spending, was not proportional to the impact of the disease. Another, from Spain, termed AD 'the plague of 21st century', because it cannot be cured and its origin is not 100% known. From an Italian influencer came the telling point that the frailest sectors of the population, children and the elderly, especially when ill, are penalised, because they do not have any contractual power or the ability to argue for their rights.

Impact of AD

The devastating effects of AD on caregivers and families were recognised by a substantial majority of caregivers (91%), physicians (97%) and the general population (93%). Caregivers often reported significant changes in terms of their lifestyle (75%), loss of freedom (48%), emotional impact (39%) and imposition of a physical burden (11%). The impact on paid work (7%) and the financial impact (7%) of caregiving were mentioned by only a minority of caregivers. A caregiver from Italy said, 'It had a devastating impact on our tranquil life. Before the illness, my wife was very active and alert. My life now is very difficult, because we are alone and I am also ill and old'. Patients themselves realised the strain their disease placed on loved ones. One person from Poland summed up the impact of AD by saying, 'My daughter is enslaved to my disease'. Another said, 'I guess my wife's life has changed a lot. She needs to be with me all the time, and she cries often because I am sad and low'.

Although most caregivers expressed negative feelings about their role (difficult, 91%; exhausting, 89%; depressing, 69%), some were able to recognise the positive aspect of their situation (Figure 5). Surprising and heartening, approximately one-third found the caregiving experience rewarding (27%) or fulfilling (30%), and these figures may even underestimate the positive aspects, given people's tendency to talk about the difficulties they encounter.

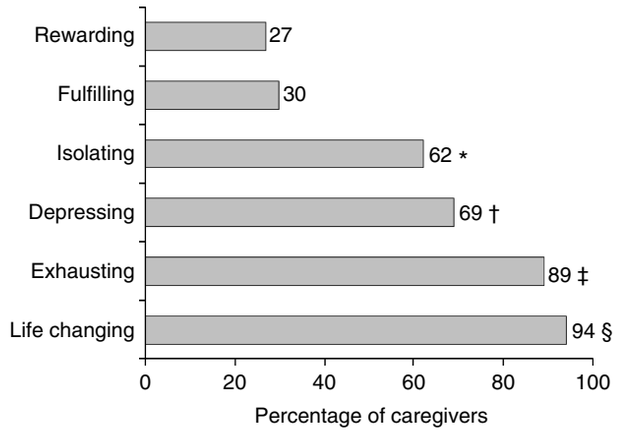

Figure 5 Range of emotions reported by caregivers. *$p < 0.05$ vs. rewarding and fulfilling; †$p < 0.05$ vs. isolating, rewarding and fulfilling; ‡$p < 0.05$ vs. depressing, isolating, rewarding and fulfilling; §$p < 0.05$ vs. all others.

Understanding of Treatment Information

Most caregivers and members of the general public expressed the belief that they did not have sufficient information about the benefits of treatment and care (Figure 6). However, although 30% of caregivers and 24% of the general population did not believe that there were effective treatments, about two-thirds to three-quarters of the general population, caregivers and physicians agreed that delaying treatment has negative effects, that early treatment can delay the disease's progression and that medication exists to slow the pace of AD, despite society's current inability to catch and diagnose it in its early stages.

Few respondents with AD were aware of their national or local Alzheimer's associations. Those who were in contact with such groups, however, found them valuable for providing general help, a venue for exchanging views and tips or a list of consulting psychologists and other professionals, as well as a source of companionship and entertainment. As one person with AD in Germany said, 'It also helps when you

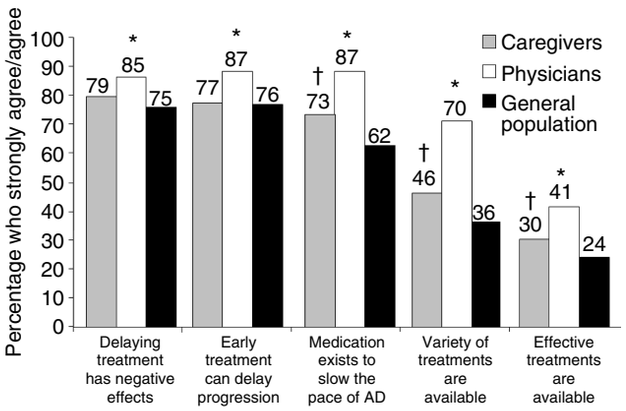

Figure 6 Perceptions about current treatment options among the general public, caregivers and physicians. *$p < 0.05$ vs. caregivers and general population; †$p < 0.05$ vs. general population.

realise that you are almost alone with your problem and other people had the same problem'.

Physicians were more cognisant of the need for early treatment (87%) and the fact that medication exists (87%). Less than half, however, recognised that effective treatments are available (41%). The survey results regarding physicians' perceptions about the timing of treatment revealed some interesting differences among countries. Most physicians in France (84%), Germany (83%), Italy (86%), Poland (96%) and Spain (86%) accepted that there is a critical window of opportunity for instituting treatment of AD (Figure 7). Perception of a critical window was significantly higher ($p < 0.05$) in these five countries than in the UK. When asked about the length of the critical therapeutic window, a majority of physicians from these countries replied that treatment should begin immediately. In the UK, however, only about half of physicians (55%) felt there was a critical window for initiating treatment, a minority considered that immediate therapy was important and a majority believed that initiating treatment in 2 months or more was acceptable.

DISCUSSION

Four key areas in the Facing Dementia Survey findings illuminated current barriers to care for persons with AD: (i) timing of diagnosis; (ii) AD as a health care priority; (iii) the impact of AD on the lives of patients, caregivers and their families; and (iv) understanding of available information about AD and its treatment.

The first key message from the Facing Dementia Survey is that AD is difficult to recognise. The opinions of the survey respondents reflect the views of health professionals from a number of countries (1–3). Respondents to the survey widely recognised that people with AD and their families often ignore or dismiss early symptoms of the disease as the so called normal effects of ageing rather than recognising them as indicators of the disease process. As a result, the family and the person with AD delay seeking advice from

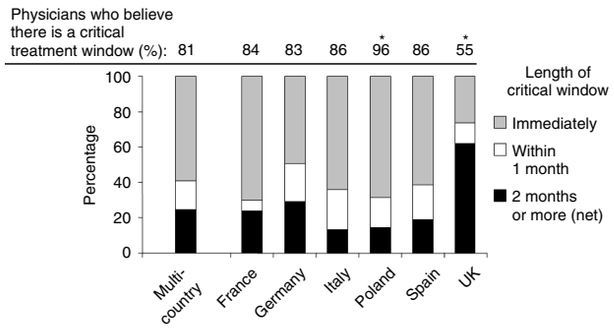

Figure 7 Physicians who believe there is a critical window during which treatment for AD should be initiated and perceptions about the length of the critical window. *$p < 0.05$ vs. any other country.

their health care providers. These opinions reflect studies showing that older people fear dementia (4–7) and that they attribute a range of treatable conditions to so-called normal ageing. This attitude was exemplified by a participant in an earlier study who commented, 'Everybody has got to grow old, and you're bound to lose your faculties as you get older – you can't help it, really' (8,9).

The survey results showed broad agreement that fear makes people hesitate to consult doctors about AD. Although not directly addressed in this research, it is possible that such fear, combined with poor awareness of early symptoms and their ambiguous nature, creates a high level of uncertainty forestalling any action until the disease process has advanced so far that no one can any longer deny there is something wrong.

There is a perception among members of the general public– and caregivers as well – that physicians themselves have difficulties in identifying the early symptoms of AD. However, early recognition remains important for making a timely diagnosis, and the Facing Dementia Survey underscores the need to broaden the understanding of health care professionals – particularly those who are not psychiatrists, such as cardiologists, internal medicine practitioners and GPs. The result of all these factors, as the survey results indicate, is a potentially critical delay in making the diagnosis.

The observations concerning the indifference of government send a powerful message about age discrimination in health care, which is consistent with the findings of other studies (10). Society values children and working-age adults rather than older people. Dementia primarily affects older people, and discrimination against this population is the greatest. For people with dementia, who are too frail to stand up for their rights, discrimination is even greater.

A third message from this survey is that AD is recognised as having a devastating impact on the lives of the affected person and family. The key costs for caregivers are the physical burden – particularly among older caregivers – emotional stress, social isolation and, in some cases, loss of income. It may seem somewhat surprising that so few respondents noted the impact of AD on paid work and the financial impact of caregiving. Other studies, particularly in the United States, have suggested that the loss of income is an important consequence of caregiving. This may be the effect of the European Social Protection Systems, which are more generous than those in North America.

At the same time, about one-third of caregivers found a positive aspect of their situation. These findings are supported by a range of international studies that identified the physical (11–17) and psychological (12,14,18–24) burden of caregiving. The survey also highlights the need to see the caregiving experience in positive terms. As other studies have shown, there are benefits for caregivers mixed with the better-understood burdens of caregiving (25,26).

Finally, the lack of understanding concerning the benefit of treatment and care strongly reinforces the need to provide all populations with comprehensive information. The public and caregivers' views of treatment did demonstrate some awareness of treatment options. It is worth noting that there was agreement across all groups surveyed that a delay in treatment has negative effects and that early treatment can delay progression. A majority also know that medications exist to slow the pace of AD. At the same time, many fewer believe these treatments are effective. This apparent discrepancy may be attributable to different understandings of the meaning of *effective* among survey respondents, but there are insufficient data to draw any conclusions on this point. It is possible to suppose that effective treatment implies a cure in the minds of some; this, however, would be pure speculation. Health care professionals were somewhat more likely than caregivers and the general public to be aware of the availability as well as the efficacy of treatments for AD.

The primary limitations of this study are the use of a convenience sample rather than a scientifically drawn, fully representative sample and the limited size of the samples, which affects sampling error. Despite these limitations, however, the results of this survey provide a comprehensive story that is generally consistent across countries and in accordance with the observations made in a range of other studies.

CONCLUSIONS

Overall, the results of the Facing Dementia Survey indicate that there are four key public barriers to increasing the availability and development of treatments and support organisations for people with AD in Europe. The first and most important barrier is the fact that AD and dementia provoke a great deal of anxiety. Second, the disease results in the sufferer's isolation from his or her world. Because of confusion and the inability to carry out everyday tasks, people with AD come to feel less competent, are embarrassed by their inabilities and gradually withdraw from others. They need to remain socially and intellectually engaged as thoroughly and for as long as possible. A third barrier is a lack of awareness and knowledge of symptoms, and a fourth is a lack of information about treatments and supportive care options.

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