

Access to diagnostic evaluation and treatment for dementia in Europe

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SUMMARY

This paper reviews and discusses existing barriers to diagnosis and treatment for patients with dementia in Europe as well as approaches to overcome these barriers. The barriers to care are manifold, being present at all levels in each society and between countries in Europe. Multilevel and multifaceted strategies are needed to improve diagnosis and treatments for all patients with cognitive complaints. A multidisciplinary approach based on close collaboration between GPs and specialised memory clinics may be the ideal model for early accurate diagnosis and subsequently early pharmacological and psychosocial interventions. For all healthcare professionals, there should be specialised training in dementia and frequently updated practice guidelines to provide the framework for standards of care. Culture-sensitive strategies to promote public knowledge and destigmatize dementia are essential. Policy makers and authorities should be made aware of the benefits of early access to diagnosis and treatment. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS—dementia; Alzheimer's disease; diagnosis; diagnostic evaluation; diagnostic assessment; early diagnosis; pharmacological treatment; early treatment

INTRODUCTION

Dementia is a significant public health problem for Europe both today and increasingly so in the future. Prevalence for dementia in 2002 was estimated as 7 million in Europe, of which 4.9 million were in

Western Europe (WHO, 2004). Age-specific prevalence of dementia increases from 1% in the 60–64 age group to up to 45% among those older than 85. Alzheimer's disease (AD), the major subtype accounting for 60–70% of all dementia cases, is the main contributor to this steep increase in prevalence with age (Jorm *et al.*, 1987; Corrada *et al.*, 1995; Lobo *et al.*, 2000). Based on the United Nation prognosis for the world population up to 2050 and the age-specific prevalence for dementia, the number of people living with dementia is predicted to increase by 161% by 2050 in developed countries (Wimo *et al.*, 2003).

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According to the disease burden estimates by WHO in 2000, dementia was listed as the second most burdensome of all brain diseases in Western Europe and as number five among the top ten diseases with the largest burden in Europe in terms of years of life lost and years living with disability (Olesen and Leonardi, 2003). The enormous economic costs of caring for patients with dementia have been documented across European countries (Jonsson, 2004).

Today, there is an international consensus favouring early diagnosis and treatment. Earlier and more accurate detection of AD is possible thanks to progress in neuropsychological, laboratorial and neuroimaging investigations (Nestor *et al.*, 2004). Although there is still a continuing debate about the efficacy of acetylcholinesterase inhibitors (AChEIs) (Kaduszkiewicz *et al.*, 2005), these drugs have been proven to be effective in delaying progression of symptoms in mild to moderate AD (Birks *et al.*, 2000; Birks and Harvey, 2006; Loy and Schneider, 2006). Early treatment aims to maintain the highest level of functioning when cognitive symptoms and impairment of activities of daily living are mild (Seltzer *et al.*, 2004) and may prove to be more effective in improving long-term treatment outcome if initiated at a stage when neuronal circuits have not been extensively damaged (Sorbi *et al.*, 2000). Moreover, early diagnosis facilitates full involvement of the patient and caregivers in planning medical, educational, and psychosocial interventions suited to their needs and expectations. However, dementia in general, and AD in particular, is probably under-diagnosed and under-treated in Europe. It has been estimated that 50 to 66% of primary-care patients older than 65 with dementia have not been diagnosed by their general practitioners (GPs) (Boustani *et al.*, 2003). This appears to be an international phenomenon (Valcour *et al.*, 2000; Dartigues *et al.*, 2002), with wide variations between nations.

The European Dementia Consensus Network (EDCON) was formed in 2002 by a group of leading European specialists from various disciplines with experience in diagnosing and caring for patients with dementia. The mission of EDCON is to identify controversial issues concerning the recognition and care of people with dementia and to build consensus statements around such issues to improve outcomes of care for patients, their caregivers, and society.

The increasing population of people with dementia and the associated burden inflicted upon the patients, their families, and society call for consensus on the important issue of access to diagnosis and care across Europe. In this review, the current barriers to diagnosis

and treatment for patients with dementia in Europe as well as approaches to overcome these barriers will be discussed. Due to lack of available information from Eastern European countries (Russia, Belarus, Ukraine, Moldova, etc.), this review concentrates mostly on European Union (EU) countries. Within this context, it will be pointed out how EDCON consensus regarding adequate access to diagnostic evaluation and treatment for patients with dementia in Europe has been reached.

BARRIERS TO DIAGNOSIS AND TREATMENT

European countries and their health-care system

Costs of dementia care can be an important barrier to diagnosis and treatment. Costs increase exponentially with dementia severity and institutionalisation, being, for example, 6,300 and 53,000 Euros per patient per year for MMSE > 20 and MMSE < 10 respectively (France), and 5,350 Euros per home-dwelling patient vs 27,6200 Euros per institutionalised patient per year (Belgium) (Jonsson, 2004). This economic barrier is probably more important for European countries with transitional economy. In Europe, there are huge differences in per capita gross domestic product (GDP) between countries, ranging from 400 to 30,000 Euros per year (WHO, 2003). Within the given economic resources, patients with dementia should get their fair share of the health-care budget. However, there is still a double—if not triple—stigma against patients with dementia, i.e. older people with a mental illness, many of them are women (Watson, 2005). Although more efforts have been made in recent years, research and teaching/training in this field as well as specialised services for this group of patients are still underrepresented in Europe (Mendonca Lima *et al.*, 2003). Access to diagnosis and treatment is further limited by restricting rules and regulation. In many countries, the right to make a dementia diagnosis, to initiate diagnostic tests such as neuroimaging, and to start or renew cognition-enhancing medications, is reserved to certain specialists. Reimbursement for the costs of treatment is either lacking, partially available, or only available with strict criteria for reimbursement (Oude Voshaar *et al.*, 2006).

Based on data from International Marketing Services (www.imshealth.com) about sales of donepezil, galantamine, rivastigmine, and memantine, and data from Alzheimer Europe (www.alzheimer-europe.org) about dementia prevalence, treatment rates for AD for the year 2004 were calculated. The

number of patients treated was estimated based on the average number of sales during the 2nd quarter of 2004. This holiday-free quarter was chosen to avoid the increase in sales before and after the holiday period, which does not reflect actual drug use. Treatment days (a day of treatment for one patient) for each medication were calculated by dividing the number of tablets sold by the average daily dose. Treatment days were translated into number of patients treated during a given month. Patients' compliance was assumed to be 80% of the days or 24 days per month. Adjustment was made for co-prescription between AchEIs and memantine, which was estimated as 33% (average rate from three countries accounting for 80% of total memantine sales in Europe in 2004—Germany, France and Spain). Treatment rates were found to be very unevenly distributed between countries (Table 1) with an average of merely 30%. It was not possible to correct for wrong treatment indication, wrong diagnosis, and drugs sold in one country but consumed in another country.

The patients and their families

There are powerful emotional barriers to confirming the existence of dementia. Memory loss may still be dismissed as the result of normal aging. Fear of social stigma and lack of knowledge about the disease processes and available treatment are also obstacles to care. Different cultural beliefs could affect family members' perception and reporting of memory problems (Valcour *et al.*, 2000). Even when a memory problem is recognised, patients and family members in denial may delay physician consultation for more than one year after symptom onset (Wilkinson *et al.*, 2004), or not seek consultation at all.

Primary-care practitioners, specialists and specialised dementia clinics

GPs frequently overlooked the symptoms in their patients despite their regular contact and long-term knowledge of them. Many GPs feel that their

Table 1. Estimated number and percentage of AD patients treated with galantamine, rivastigmine, donepezil, and memantine in Europe in 2004

Country	Estimated number of patients with dementia according to Alzheimer Europe	Estimated number of AD patients (60% of all dementia cases)	Number of patients treated according to IMS 2nd quarter 2004	Estimated percentage of patients treated (%)
Austria	97,137	58,282	19,042	32
Belgium	129,389	77,633	23,274	30
Bulgaria	49,746	29,858	1,638	6
Cyprus	2,705	1,623		
Czech Republic	98,064	58,838	5,132	9
Denmark	65,959	39,575	11,003	28
Estonia				
Finland	58,797	35,278		
France	758,229	454,937	233,673	50
Germany	1,032,969	619,781	160,128	26
Greece	131,283	78,769	76,542	97
Hungary	90,614	54,368	1,493	3
Iceland	2,510	1,506		
Ireland	31,702	19,021	8,811	46
Italy	719,205	431,523	76,350	18
Latvia				
Lithuania	34,164	20,498		
Luxembourg	4,664	2798		
Malta				
Netherlands	164,910	98,946	7,917	8
Norway	57,758	34,655		
Poland	311,879	187,127	30,377	16
Portugal	103,690	62,214	20,405	33
Romania	139,787	83,872		
Slovenia				
Slovak Republic	42,197	25,318	2,542	10
Spain	488,956	293,374	118,133	40
Sweden	131,643	78,986	37,122	47
Switzerland	88,304	52,982	14,581	28
United Kingdom	741,042	444,637	78,816	18

knowledge and skills in diagnosing and treating dementia are inadequate, and that there is a need for clear diagnostic guidelines and reliable, user-friendly screening tools (Olafsdottir *et al.*, 2001; Waldorff and Moller, 2001; Turner *et al.*, 2004). Other barriers include lack of time, lack of financial reward, lack of resources such as access to neuropsychological consultations and neuroimaging investigations, and lack of prescription right for AchEIs (Olafsdottir *et al.*, 2001; Errebo-Knudsen *et al.*, 2003). GPs may be sceptical about the efficacy of cognition-enhancing medications (Woods *et al.*, 2003), or may not believe that the benefits of intervention outweigh the hazards of early recognition of dementia (Iliffe and Manthorpe, 2004).

The problem of under-recognition also exists for other healthcare providers. Twenty-two percent of nursing staff who cared for elderly who lived in assisted-living or skilled-nursing facilities failed to recognise dementia symptoms in subjects with clinically diagnosed dementia (Greiner and Snowdon, 1997). Primary-care nurses and community-based nurses in the UK expressed uncertainty about their diagnostic skills concerning dementia (Bryans *et al.*, 2003; Manthorpe *et al.*, 2003b).

Once the patients are referred to specialists, their diagnosis and treatment are further delayed by waiting lists, which can be weeks to months. Poor coordination and communication between the primary and secondary health sectors can lead to inefficient use of resources and unsatisfactory results in diagnosis and treatment (Vernooij-Dassen *et al.*, 2005), with evidence from the UK that dementia care is seen as someone else's role (Manthorpe *et al.*, 2003a).

OVERCOMING THE BARRIERS

Redistribution of health-care resources

The high costs associated with dementia are largely due to non-medical care such as institutionalisation, special accommodation, home care, caregivers' time etc., which directly correlated with disease severity. In comparison, costs associated with diagnostic investigations and cognition-enhancing medications are relatively modest (Jonsson, 2004). Cost-effectiveness of treatment with AchEIs is still a controversial issue, but there is no evidence that treatment with AchEIs is not cost-effective (Birks, 2006). Early diagnosis and treatment, if implemented on a larger scale, can potentially reduce the total costs by maintaining the patients' functional level, reducing comorbidities and related hospital admissions, and alleviating care-

givers' burden. Thus, adequate healthcare resources should be channelled to improve access to diagnosis and treatment. Within this context, a balance has to be found between the beneficial effects of early diagnosis and disadvantages such as the social and emotional burden of being labelled with dementia, and the risk for both false-positive and false-negative diagnoses, as it is difficult to make a specific diagnosis when the symptoms are subtle.

Many patients still present to the health-care system in late stages of AD, usually characterised by behavioural disturbances and more severe medical co-morbidities, and thus are in greater need of medical and psychosocial interventions. Memantine is nowadays available as symptomatic treatment for severe AD (Sastre *et al.*, 2005). Resources should also be directed to ensure these patients the care they need and change the nihilistic attitude among caregivers and healthcare professionals.

Low clinical threshold: the first step towards early detection of cognitive problems

The benefits of routine screening for dementia in older adults have not been proven (Boustani *et al.*, 2003). Nonetheless, GPs should maintain a high index of suspicion to improve detection of dementia in primary care. Diagnostic evaluation should be initiated in all patients with impaired daily activities due to persisting or worsening memory complaints. As impaired insight and awareness can be associated with dementia (Vogel *et al.*, 2004), patients without subjective complaints but observed by relatives to have cognitive problems should also be evaluated. Diagnostic evaluation should be considered even when symptoms are not severe enough to meet diagnostic criteria for dementia. People with mild cognitive impairment (MCI), defined as those who are memory-impaired, but function well otherwise and do not fulfil diagnostic criteria for dementia, are at increased risk for developing dementia or AD when compared with age-matched individuals in the general population (Petersen *et al.*, 2001). Patients with MCI should therefore be identified and followed closely to detect the onset of dementia and subsequently initiate early interventions.

Multidisciplinary approach

Today, dementia is considered as a family of diseases with a variety of overlapping clinical and neuropathological characteristics (Armstrong *et al.*, 2005). Consequently, management of dementia is moving

towards a tailored programme for each individual patient, taking into consideration the heterogeneity in aetiology and symptomatology (Vernooij-Dassen and Olde Rikkert, 2004). The differential diagnoses of dementia are extensive, covering a wide range of neurological, psychiatric, and internal medicine conditions. Clearly, diagnosis and management of patients with cognitive complaints is a multidisciplinary task.

Within this framework, a functional and efficient model of cooperation between the primary and secondary health sectors is necessary. A two-step diagnostic evaluation is hereby proposed. The first step is to determine whether the patient is cognitively impaired (dementia syndrome). This can be carried out by GPs, preferably assisted by a specialised nurse or physician assistant. The second step involves determining the pathological processes underlying dementia and identifying potentially reversible conditions (e.g. depression, normal pressure hydrocephalus, metabolic derangement) and indication for secondary prophylaxis (e.g. vascular dementia). This step should always include assessment of the patients' comorbidities, functional performance, and level of care needed; and the burden for caregivers. A thorough assessment is the key to adequate guidance and care, which will be more likely to make a difference in outcome. It is best carried out in a multidisciplinary memory clinic that is embedded in and has full access to advanced hospital facilities. GPs' diagnosis of dementia syndrome was shown to be reasonably accurate (van Hout *et al.*, 2000; van Hout *et al.*, 2002). However, when diagnosing specific dementia subtypes, family physicians performed considerably poorer compared to a multidisciplinary memory clinic (van Hout *et al.*, 2000). Compared to multidisciplinary diagnostic assessments, monodisciplinary assessment either by a GP or a specialist (psychiatrist, neurologist, geriatrist, or internist) only reached a sensitivity of 61% and a specificity of 93% in diagnosing dementia syndrome, and a sensitivity of 23% and specificity of 96% in diagnosing AD (Verhey *et al.*, 1993).

Based on multidisciplinary diagnostic assessment, an individualised programme consisting of medical management and multi-component support for the patients and caregivers can be made. Multi-component psychosocial interventions were found to be most effective for patients with dementia and caregivers in reducing the caregivers' burden and patients' symptoms while improving caregivers' sense of well-being, knowledge and competence (Acton and Kang, 2001; Belmin, 2003). Programmes allowing the possibility

of choice between interventions were most effective in strengthening caregivers' sense of competence and delaying patients' institutionalisation (Vernooij-Dassen *et al.*, 2000).

Multidisciplinary cooperation can also take place through other models depending on the clinical context. For example, dementia can be detected during admission caused by an acute somatic illness or during an ambulatory course in a specialist clinic. In such settings, guidelines for detection of cognitive impairment and referral to a dementia clinic once the patients are discharged, directly or via their GPs, should be established.

The decision concerning the level of diagnostic evaluation has to be made by GPs together with the patients and their caregivers based on considerations such as the patients' comorbidities, functional performance, life expectancy, and prognosis. For example, intensive investigations for patients with severe medical comorbidities may not be appropriate.

The standard of care

GPs work at the frontline of the healthcare system, detecting patients with dementia, initiating diagnostic evaluation, and making referrals. Training programmes for GPs in diagnosing and managing dementia are essential, and both practice-based education workshops and computer decision support systems have been shown to improve diagnostic skills in general practice (Downs *et al.*, 2006). Training should also be available to community-based and primary care nurses who are in regular contact with older patients (Manthorpe *et al.*, 2003b). Similarly, the multidisciplinary approach calls for formal trainings across many disciplines.

Apart from being a source of updated evidence in clinical practice, guidelines help to set the standard of health care. The following national guidelines in English regarding diagnosis and management of dementia have been released or updated in Europe within the last 5 years (Table 2). The Dutch College of General Practitioners and the Italian Neurological Association published their revised dementia guidelines in 2004 (Boomsma *et al.*, 2004; Musicco *et al.*, 2004). There are many other national guidelines, which are not available as publications in English. A more complete review of recent European guidelines as well as international guidelines has been published in Germany (Muller *et al.*, 2003). Within the last five years dementia guidelines have also been published in the US, Canada, and Singapore (Knopman *et al.*, 2000; Doody *et al.*, 2001; Hsian *et al.*, 2001; Patterson *et al.*,

Table 2. European national and international guidelines in English published or updated from 2000–2005

Published by	European Federation of Neurological Societies (Waldemar <i>et al.</i> , 2000, 2006)	Societa Italiana di Neurologia (Sorbi <i>et al.</i> , 2000; Musico <i>et al.</i> , 2004)	National Institute for Health and Clinical Excellence, NICE (HTA) NICE, 2001)*	Royal College of Psychiatrists (Jones <i>et al.</i> , 2005)
Publication date (1st/update)	2000/2006	2000/2004	2001/2005	2005
Access	Journal/Online	Journal	Online	Online
Target group	Multidisciplinary	Multidisciplinary	Multidisciplinary	Multidisciplinary
Level of evidence based on predefined protocol	Yes	Yes	No	Yes
Diagnosis guidelines	Yes	Yes	No	Yes
Management guidelines	Yes	No	Yes	Yes
Pharmacological treatment for AD	Yes	No	Yes	Yes

*Revision in progress.

2001; Petersen *et al.*, 2001; Rabins *et al.*, 2002; Cummings *et al.*, 2002a; Cummings *et al.*, 2002b; Bridges-Webb *et al.*, 2003). These guidelines are quite diverse in terms of target groups and specific topics for recommendations. Although there is a general agreement about multidisciplinary approach, the roles of GPs and specialists are not clearly defined in most guidelines.

Thus, at the regional and national levels multidisciplinary dementia guidelines with specific instructions and clear division of responsibilities as well as quality indicators for the primary and secondary health sectors are needed. In order to harmonise these guidelines, an international cooperation is called for to outline the minimal European standard for diagnosis and treatment. Strategies concerning implementation and dissemination of guidelines should be made in order to improve physicians' adaptation of practice guidelines.

Increased awareness

As important barriers come from the patients and their families, culture-sensitive strategies to promote public knowledge and awareness about dementia are needed. This and all other measures discussed in this paper require resources, which are regulated by health-care policies. Therefore, authorities should be made aware of the fact that patients with dementia should have better access to medical care.

CONCLUSION

Many barriers to diagnosis and treatment for dementia in Europe exist in all societies and in all countries. A multidisciplinary approach based on clear-cut division of responsibilities between the

primary and secondary healthcare sectors and clearly defined standard of care may be the best model for early accurate diagnosis and subsequently early pharmacological and psychosocial interventions. Memory clinics should be made available to a larger proportion of the rapidly growing population of patients with cognitive problems in Europe. For all health care professionals, there should be specialised training in dementia and up-to-date clinical guidelines to provide the framework for standard of care. The public and the government should be made aware of the benefits of early access to diagnosis and treatment.

The European Dementia Consensus Network (EDCON)

- Convinced that early access to diagnosis and treatment is beneficial for patients with dementia, for their families, and for society,
- aware of the fact that access to facilities for diagnosis and treatment is at present insufficient in most European countries,
- concerned with the low rate of recognition of dementia and the lack of clear guidelines about the treatment and care for people with dementia in most countries of Europe.

Recommends the adoption of the following consensus statement:

1. Policy makers, health authorities and health professionals as well as the general public should be made aware of the magnitude of problems related to dementia and of the benefits of its early recognition and treatment.

KEY POINTS

- Access to facilities for diagnosis and treatment of dementia is insufficient in most European countries.
- Treatment rates for Alzheimer's disease varies considerably across Europe.
- The European Dementia Consensus Network (EDCON) recommends appropriate legal, educational, administrative, and economic measures to improve the access to diagnosis and treatment.

2. Access to diagnosis and treatment for patients with dementia should be facilitated by appropriate legal, educational, administrative and economic measures.
3. Specific training programmes about various aspects of dementia management should be developed and introduced into the undergraduate and postgraduate education of health-care staff.
4. Health-care professionals, in collaboration with non-professional caregivers and relevant authorities should develop guidelines concerning the recognition and management of dementia, monitor their implementation, and ensure that they are updated when necessary.

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