Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma

Myrra J. F. J. Vernooij-Dassen[1]*, Esme D. Moniz-Cook[2], Robert T. Woods[3], Jan De Lepeleire[4], Antonio Leuschner[5], Orazio Zanetti[6], Joycelyn de Rotrou[7], Geraldine Kenny[8], Manuel Franco[9], Vincent Peters[10], Steve Iliffe[11] and the INTERDEM group

[1]*Alzheimer Centre/Centre for Quality of Care Research/Vocational training General Practitioners of University Medical Centre Nijmegen, The Netherlands*
[2]*Institute of Person Centred Research in Aging/Department of Clinical Psychology, Postgraduate Medical Institute with the Hull-York Medical School, University of Hull, UK*
[3]*Dementia Services Development Centre, University Bangor, Wales, UK*
[4]*Academisch Centrum huisartsgeneeskunde, KULeuven, Belgium*
[5]*Hospital de Magalhaes Lemos, Portugal*
[6]*Geriatrician, Alzheimer Research and Care Unit IRCCS Centro S. Giovanni di dio Fatebenetratelli. Brescia, Italy*
[7]*Hospital Broca, Service de Gerontologie Clinique, Paris, France*
[8]*Department of Psychology, northern Area Health Board, Dublin, Ireland*
[9]*Fundacion Intras, Zamora, Spain*
[10]*Business Administration, Radboud University, Nijmegen, The Netherlands*
[11]*Centre for Ageing Population Studies, Royal Free and UCL Medical School, London, UK*

SUMMARY

Background   Timely recognition and diagnosis of dementia is the pre-condition for improving dementia care, but diagnosis often occurs late in the disease process.
Objective   To compare facilitators and obstacles to the timely recognition of dementia across eight European Union states, in order to implement established policies for earlier diagnosis.
Methods   A modified focus group technique, including a pre and posterior procedure.
Results   Twenty-three participants from different disciplines, purposively sampled for professional expertise in dementia research and innovative practice, attended two focus groups. Stigma in ageing and dementia, accompanied by a sense that there is little to offer until later on in the disease, underpinned the widespread reluctance of GPs to recognise dementia at an early stage and were major obstacles to the timely diagnosis of dementia across all eight countries. Dementia care services varied widely across Europe. Countries with the greatest development of dementia health care services were characterised by national guidelines, GPs fulfilling a gatekeeper function, multi-disciplinary memory clinics and innovative programmes that stimulated practice and new services. Dementia-related stigma was perceived as being less prominent in these countries.
Conclusions   Overcome of delays in the timely diagnosis of dementia needs more than specialist services. They should address the processes associated with stigma, age and dementia, especially where these relate to physician practice and diagnostic disclosure. Stigma is perceived as variable across European States, with a promising finding that its impact is relatively small in countries with the widest range of dementia care services. Copyright © 2005 John Wiley & Sons, Ltd.

KEY WORDS — dementia; early diagnosis; focus group; stigma; health care services

*Correspondence to: Dr M. J. F. J. Vernooij-Dassen, Centre for Quality of Care Research, Alzheimer Centre, University Medical Centre Nijmegen, PO Box 9101, 6500HB Nijmegen, The Netherlands. Tel: 0031-(0)24-3615305. Fax: 0031-(0)24-3540166.
E-mail: m.vernooy-dassen@voha.umcn.nl

INTRODUCTION

Many governments stress the importance of early detection in their dementia strategies to help prepare families for the difficult road ahead (Moise *et al.*, 2004). However, it takes on average 30 months from the initial symptoms noticed by either patient or relative before a medical evaluation takes place (Haley *et al.*, 1992). In the absence of a diagnosis it remains hard to offer support to minimise the burdensome impact of the disease process. Consequently, patients who may be aware that something is wrong (Clare, 2003), remain isolated in their uncertainty, whilst family caregivers have episodes of depression, immune system disorders, altered capacity for wound healing, increased consumption of psychotropic drugs and increased mortality (Schulz and Beach, 1999). Timely diagnosis may prevent crises, facilitate adjustment and provide access to a range of treatments and support (Woods *et al.*, 2003). Timely recognition and diagnosis is defined as when the patient or 'caregiver' and the primary care physician recognise that there may be a developing disease. Timely detection can be enhanced by an understanding of the factors that delay early detection, consequent diagnosis and support of people with dementia and their caregivers.

Timely recognition of dementia in primary care might have different expressions across Europe due to national variations in resources, service provision and professional cultures. Developing coherent European policies may therefore be problematic. One approach to enhance timely diagnosis is to consider national differences within a framework of a Quality Improvement Programme (QIP), as has been done in other chronic diseases such as diabetes (Grol, 2001). QIP methodology provides a systematic four stage approach to the process of implementation of new developments. We translated the four QIP steps as follows: first, given established policies for earlier diagnosis of dementia, a plan to improve dementia care through timely recognition in primary care was specified; second, examination of the facilitators and obstacles to recognition and timely diagnosis needs understanding; next change strategies for diagnostic practice can be developed; and finally, an intervention, using the identified facilitators to address the obstacles needs to be implemented and evaluated. To achieve our aim of improving knowledge and practice in the timely recognition of dementia in primary care, the second step of QIP methodology was used in a European Union (EU) funded study (DIADEM). The research explored the similarities and differences in facilitators and obstacles to the timely recognition and diagnosis of dementia within primary care, in eight EU states.

METHODS

Participants

A purposive sampling approach was used to derive multinational multidisciplinary focus groups. National experts in dementia and primary care in eight European countries (Belgium, France, The Netherlands, Ireland, Italy, Portugal, Spain and the United Kingdom) were invited. Experts were required to have national knowledge on dementia care and be actively involved in dementia service provision, or in dementia research in primary care, or both. Experts represented the following disciplines: general practice (GPs), geriatric medicine, old age psychiatry, nursing, social work, clinical psychology, neuropsychology, medical sociology and non-governmental organisations.

Modified focus group. The key technique used in this study was a modified focus group. Four topics were studied with this technique: facilitators and obstacles to timely recognition of dementia, methods to diagnose dementia, dementia-related national circumstances and management of dementia services. These topics were identified as important influences in timely diagnosis and covered medical, economic, psychosocial and cultural aspects related to dementia. The focus group interview is a qualitative method often used to address this type of research enquiry in health care. Its strengths are: eliciting verbal and non-verbal information about a problem; allowing elaboration, criticism and defence of responses and propositions; exploring attitudes (Fuat *et al.*, 2003); and generating ideas and priorities by participants, which may otherwise be missed during individual interviews (Kitzinger, 1995). In order to address the study aims adequately, national information was a pre-requisite and a pre and posterior procedure was therefore included as follows:

(1) Pre-procedure. Preparatory data for each participating country using standard data collection grids were circulated to all participants prior to the first interview. This allowed systematic data collection on epidemiology, research in primary care, practice and service provision in dementia care.

(2) Focus group sessions. Twenty-three participants were divided into two groups which remained the same throughout the four sessions. Each group

had representatives from the eight states and were matched for professional discipline. The sessions were facilitated by an expert methodologist (VP). Groups considered the same topics and chairpersons used a short topic guide. Each topic was considered in a focus group session lasting 1.5 h. Two scribes manually recorded themes and sub-themes independently. Summaries were presented to the group for clarification, modification and consensus. To derive themes from the groups a grounded theory approach was used. This allowed new observations to be examined against current knowledge and further refined to extend the knowledge base (Glaser and Strauss, 1967; Murphy *et al.*, 1998).

(3) Posterior procedure. The themes and sub-themes were then summarised in grids (Beaudin and Pelletier, 1996). These were circulated to all participants who convened two months later to integrate the findings in the light of theory, to develop concepts and thus extend knowledge. Member checks of these results were used as part of the error reduction process (Pope and Mays, 1995).

Thus an iterative research process, in which data collection, analysis, clarification and discussion were inter-related processes, was used (Corbin and Strauss, 1990; Wester and Peters, 1995).

RESULTS

Pre procedure data—epidemiology and mental health facilities in EU countries

Since there was no systematic registration of dementia cases in EU countries, we relied on epidemiological studies noting that dementia is primarily a disease of very old people, whose numbers will increase in the next two decades.

Table 1 summarises data collected prior to focus groups, set against national expenditure on mental health across each participating country. The available estimates of epidemiology are similar across the participating EU member states. However, these comparisons must be treated with caution as age groups and sources differed across countries. For example, whilst countries such as France rely on large epidemiological studies, others such as Ireland are based on contacts with psychiatric services which may reflect an underestimate of incidence, since many new cases are likely to be seen in geriatric medicine and may never come into contact with psychiatric services (Keogh and Roche, 1996).

We did not recruit new and emerging states to this study. Thus, based on World Bank 2000 criteria, all eight participating countries are within the high income group. Table 1 shows that although the proportion of the Gross Domestic Product devoted to the health budgets is highest in France (9.8%) and lowest in the UK (5.8%), the percentage expenditure on mental health is highest in the UK. The primary resource for dementia care in all eight countries is public funding combined with some private resources, except in France. These results do not seem to reflect differences in national prosperity. The rate of medical specialist involvement in diagnosing dementia appears to be a better reflection of national wealth. The relative number of psychiatrists and neurologists per 100.000 population is lowest in Spain, Portugal and Ireland. Notably no figures are available on geriatricians who are also involved in the diagnosis of dementia. This pre-procedure data provided support for the view that national dementia care resources varied between the participating countries and the potential differences and similarities were explored within focus groups.

Focus groups

Twenty-three experts participated in two focus groups conducted over a two-day period. This provided information on facilitators and obstacles to timely diagnosis of dementia in EU countries and strategies to improve timely recognition and diagnosis.

Facilitators. Four themes with related sub-themes were identified as follows: Methods for early diagnosis, GP education, Organisation of health care and Resources (see Table 2).

Methods for early diagnosis

Guidelines enhanced the diagnosis of dementia since they provided practitioners with a rationale for early recognition and methods on how to diagnose and treat dementia. In some countries such as Spain, guideline formation was mature with both a national guideline and several region-specific guidelines in place. Guidelines were absent in Portugal and Ireland.

GP education

All participant states had acted on the EU policy requirement of a three-year vocational training for GPs, which in theory should be a facilitator for timely

Table 1. National circumstances: epidemiology and mental health facilities.* (Source: www.who.int/mental_health)

EU country	Incidence	Prevalence	*Percentage of health budget to GDP	*Percentage of health budget on mental health expenditure	*Number of professionals per 100.000 population	
The Netherlands	Age 55 + 9.8/1000 (Ruitenberg et al., 2001) Males 10.5 Females 17.3 (Launer et al., 1999)	Total: Age 55 + 6.3% (Ott et al., 1995)	8.8	7	Psychiatrists Psychologists Neurologists	9 28 3.7
Belgium	Age 60+: 0.53 (Buntinx et al., 2002)	Age 65 + 6–9% (Ylief et al., 2002)	8	6	Psychiatrists Psychologists Neurologists	18 1
UK	Males 10.7 Females 18.5 (Launer et al., 1999)	Ages 65–70 1 in 50 Ages 70–80 1 in 20 Ages 80+ 1 in 5 (The Alzheimer's Society web)	5.8	10	Psychiatrists Psychologists Neurologists	11 9 1
Spain	No information available	Total Age 65 + 5 (Lobo et al., 1995)-16% (Vilalta-Franch et al., 2000)	8	No information available	Psychiatrists Psychologists Neurologists	3.6 1.9 2.5
Italy	150.000 new cases per year (Di Carlo et al., 2002)	Male Age 5.3% Age 65–84 Female Age 7.2% age 65–84 (Ilsa,1997)	9.3	No information available	Psychiatrists Psychologists Neurologists	9 3
Portugal	No information available	No information available	8.2	No information available	Psychiatrists Psychologists Neurologists	5 2.8 2.3
France	Males 11.5 Females 15.2 (Launer et al., 1999) 165.000 new cases per year (Ramaroson et al., 2003)	Age 65 + 5% (ANAES, 2000) 800.000 prevalent cases ≥ 75: 18% (Ramaroson et al., 2003)	9.8	5	Psychiatrists Psychologists Neurologists	20
Ireland	4000 new cases per year (Keogh and Roche, 1996)	Age 65 +: 5.5% (Keogh and Roche, 1996)	6.2	7.7	Psychiatrists Psychologists Neurologists	5 9.7 0.4

Table 2.   Facilitators

EU state	NL	Be	UK	Sp	It	Po	Fr	Irl
Methods to diagnose dementia								
Guidelines	X	X	X	X	X		X	
GP education								
Educational programmes	X	X	X				X	
Three year vocational training	X	X	X	X	X	X	X	X
Organisation of health care								
GP gatekeepers	X		X	X	X			X
Memory clinics	X	X	X		X		X	X
Resources								
Evidence based innovative programmes	X		X	X			X	
Dementia expertise centres	X		X		X		X	

X = Facilitator present.

diagnosis and dementia care. However, specialist educational programmes in diagnosis and treatments of dementia were only evident in four countries (UK, BE, NL, FR).

Organisation of health care

The gatekeeper role of GPs appears to be an advantage in terms of timely diagnosis, since older people have easy, frequent, routine contact with them about other health complaints.

Gatekeeper GPs are well placed to recognise the early signs of dementia and enhance access to the necessary range of professionals and diagnostic tests that are often needed to address the complexities of diagnosing a dementia in the earlier stages, such as are found in memory clinics. Memory clinics are widespread across Europe, but there are huge within-nation regional variations in their availability and how they function. Where memory clinics do not exist, the concept of shared practice across primary and specialist services has been adapted to enhance timely diagnosis, for example between GPs and psychiatrists in one region in Portugal.

Resources

The variety and range of dementia care treatment and services within countries was associated with the presence of dementia research centres and government initiatives in dementia care. For example, in the UK and the Netherlands 'dementia centres' are associated with research departments that have broadened the variety of innovation, psychosocial practice and service development across regions, with some intervention targeting public awareness and stigma in

dementia. In Italy, the government-led national CHRONOS project (Raschetti *et al.*, 2003) standardised prescription of the cholineresterase inhibitors, within specialist centres.

Obstacles in use of services

Four service types were identified, relating to residential care, home care, respite care and service innovations. The availability of services was no guarantee of their satisfactory use. The extent to which services to support for both patient and family caregivers were used was influenced by the prevailing obstacle to their use (see Table 3).

Residential care

The percentage of people with dementia living in an institution ranged from 15% in Italy to 38.5% in France. The availability of residential care was limited in Spain, Ireland and Portugal. In some countries access to residential care was prohibited by costs. For example, in Spain only low-income families received governmental financial support and costs were therefore prohibitive for those of mid-income status. In all countries residential care was seen as a last resort for the person and the carer. Furthermore, there were variable standards for residential care.

Home care organisation

Home care organisations were available in all participating countries, but obstacles to access included uneven geographical distribution, bureaucracy and waiting lists. Complex financing was a major problem in France and Italy.

Respite care

This was provided in a variety of ways such as day-care centres and in-home volunteer visiting schemes. Both waiting lists and under-use of specialised services prevented effective service usage. Under-use was related to a poor understanding of the real benefits of the particular service.

Innovative projects

These were present in most EU states but common obstacles were lack of funding for systematic evaluation or short-term funding which usually did not allow for implementation of effective results into mainstream services.

Stigma and dementia

Synthesis of the data highlighted the prominence of cultural norms in dealing with dementia, coloured by the stigma associated with dementia. Stigma reflects a process of disqualification whereby a normal person is reduced to a person with whom something is wrong (Goffman, 1963). Stigma emerged as an important influence on delays in recognition and diagnosis in primary care through the processes of concealment, minimisation or ignoring of early signs and symptoms. A striking similarity across all states was dementia-related stigma by professionals and in most, but not all cases, this was regardless of financial resources. There was the belief that there was little to offer since dementia was a deteriorative disease. This was associated with reluctance toward an early diagnosis and pessimism about prognosis, which in turn enhanced therapeutic nihilism in early stages of dementia. The nature and processes through which stigma is manifested remains complex, since stigma attached to dementia in the general population is a variably distributed phenomenon both within and amongst countries (Iliffe *et al.*, 2005). For example, physicians were particularly resistant to providing a diagnosis in Spain and Portugal. In some countries, such as Portugal, avoidance of the dementia label is related to resources, since it may preclude access to nursing home care (lliffe *et al.*, 2005). In Belgium there is a national debate on dementia and euthanasia, with one view that suffering from dementia reflects an undignified existence and another, predominantly from the Alzheimer societies, that preserving the dignity of people with dementia is an important endeavour. In the Netherlands, UK and France, where there are strong Alzheimer Societies, the role of stigma appears to be declining in the general population. Shame associated with having a family member with dementia may also be declining in these countries (Table 3).

Table 3. Obstacles in use of services

EU state	NL	Be	UK	Sp	It	Po	Fr	Irl
Residential care								
Available on large scale but waiting list	X	X	X		X			
Limited availability				X		X		X
Too expense for mid- or low incomes		X						
Home care organisation								
Available on large scale but bureaucracy and waiting lists	X	X	X					
Uneven geographical distribution				X	X	X		X
Complex financing							X	
Limited availability						X		
Respite care								
Underuse of particular services	X							
Available, but waiting lists daycentres	X		X					
Too expensive for mid or low income groups		X		X				
Limited availability					X	X		X
Innovative projects								
Short time funding	X		X					
No or very limited resources		X		X		X		X
Implementation	X	X	X	X				
Cultural norm: stigma								
Professionals: incurable and untreatable 'Feeling of having nothing to offer'	X	X	X	X	X	X	X	X
Population: disease to be hidden for friends		X		X	X	X		X

X = Obstacle present.

Suggestions to improve timely diagnosis of dementia

- Explore and address the role of stigma perceived by physicians
- Pay special attention to early symptoms of dementia
- Adopt a stepwise diagnostic process: affirmation of signs by using a short instrument (Hopman-Rock et al., 2001) followed by assessment of memory complaints, cognitive functioning and (I)ADL functioning.
- Promote multidisciplinary collaboration both in making the diagnosis as well as in early intervention. The need for structural collaboration, co-ordination and continuity of care is stressed.
- Organise early intervention for carers focussed on their individual needs, facilitated by an instrument to diagnose care giving competence and suggestions to meet needs for care.
- Develop early psychosocial intervention support programmes, to maintain the patient's unique identity and minimise their anxiety and depression.

Can timely diagnosis be improved?

Using the QIP framework, we translated the findings into suggestions to promote timely diagnosis (Figure 1). First, special attention should be paid to stigma. Education initiatives that directly address the role of stigma and its impact on patients' awareness, carers' problems and effective interventions might help to alter physician practice. Reluctance surrounding diagnostic disclosure may then be addressed through step-wise diagnostics and multidisciplinary collaboration, which actively includes the GP in the whole process (Wind et al., 2003). This may assist GPs to balance their perceived lack of time and the sense that they have nothing to offer.

DISCUSSION

This study is a first attempt to achieve a coherent EU approach to a timely recognition and diagnosis of dementia in primary care, by exploring the facilitators and obstacles to this. There was wide variation in the obstacles to timely diagnosis of dementia in primary care across EU countries, apart from a prevailing hesitation surrounding early recognition by the GP, associated with stigma related to dementia in older people. Guidelines and the availability of health care services such as memory clinics to assist early diagnosis were seen as necessary, but not sufficient, to overcome the delay in diagnosis. This study suggests that stigma associated with dementia by professionals is the over-riding factor in delaying timely diagnosis, regardless of available resources. Other studies also note the presence of stigma associated with dementia in the health care sector (de Mendonça Lima et al., 2003: De Lepeleire et al., 2004). Stigma was often cited as a reason for not disclosing a dementia diag-

nosis (Bamford et al., 2004). Our results on the relationship of stigma and the reluctance to provide a dementia diagnosis are supported by the findings of Milne et al. (2000) who note that specific beliefs underpin GP attitude to early diagnosis and that there is a strong link between GP attitude and subsequent action and practice.

This present study reflects the second step within a QIP where the focus was on the facilitators and obstacles to timely diagnosis. The next step in the QIP is to develop change strategies for diagnostic practice that address the role of stigma attached to dementia by GPs. Both educational programmes and guidelines may alter this belief. Educational programmes may focus on personal beliefs and images of stigma in dementia, such as the double negative labelling of being old and having a psychiatric disorder (Benbow and Reynolds, 2000; Sartorius, 2003, Iliffe et al., 2005), the association of dementia with its last phase (Iliffe et al., 2005) and the perception that people with dementia have no capacity for pleasure (Graham et al., 2003) or that they lack awareness (Clare, 2003). Strategies to dispel myths and change perceptions associated with dementia can include information that only 14% of institutionalised patients may in fact reach the end phase of dementia (Koopmans et al., 2003) and that there is individual variation in awareness amongst people with dementia (Clare, 2003). Person centred approaches to intervention aimed at maintaining quality of life (Brodaty et al., 2003; Vernooij-Dassen and Olde Rikkert, 2004) may be used to address the perceived lack of treatment (van Hout et al., 2000; Bamford et al., 2004). Since all eight states now have a three-year vocational GP training programme, there is scope for integrating the primary care dementia care educational initiatives that have been developed in some countries, to facilitate timely

recognition and diagnosis (Iliffe *et al*., 2000). Developing guidelines where they do not exist and updating these to address the obstacles to timely diagnosis, as has been recently achieved in the Netherlands using the present study findings (Wind *et al*., 2003), are further change strategies that can be considered. The relatively minor role of stigma in the general population in countries with stronger Alzheimers societies and the widest range of dementia care services is a promising observed outcome, but the processes by which de-stigmatisation can occur at the personal, organisational and societal levels have yet to be properly understood. In this paper we have addressed the first three stages of a QIP in dementia care, i.e. specified the aim, understood the facilitators and obstacles and suggested strategies for change based on these findings. The fourth QIP step which requires an intervention study to implement the proposed change strategies will, we suggest, provide the evaluative arena for further clarity on the complex processes associated with stigma, ageing and dementia across the participant countries.

The strength of this study on primary care and dementia was its eight nation sampling of multi-professional experts who were at the forefront of research and innovative practice. Limitations include the obvious problem of sampling experts who may not reflect the experience of their non-expert professional peers. Another potential confounder was that focus groups occurred in English whilst the majority of participants were thinking and speaking in their second language, which may have reduced the range and quality of emergent themes. To overcome this problem we strengthened the focus group technique with a pre and posterior procedure which enhanced reliability within an iterative review process.

This study underlines the urgency for an active and systematic approach to improve dementia care across Europe that can begin to combat stigma. Our results suggest that GPs have a pivotal position in engaging with older people, but this needs to be followed by interventions that address the pan-European need for them to have higher expectations, better training and multi-professional support. The process of diagnostic disclosure is a powerful early intervention for the person and the family (Moniz-Cook and Woods, 1997), where communication strategies to facilitate the practical meaning of dementia can be addressed (De Lepeleire and Heyrman, 1999). Timely recognition of dementia in primary care should allow people with dementia and families, with the support of specialist services, the communities that they live in, and the wider society, to maintain pleasure and a sense of

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KEY POINTS

- There is wide variation across EU member states in facilitators of timely diagnosis, such as the availability of guidelines and memory clinics.
- There is cultural variation in the role of stigma in dementia, across countries. This is associated with attitudes about early intervention and prognosis as well as the range of dementia care services available.
- The hesitancy and delay surrounding timely recognition, is prominent in all EU states and specialist services in themselves are not enough to overcome this. Stigma associated with dementia by professionals seems to be the most powerful influential factor.
- Both pan-European guidelines and educational programmes addressing general obstacles and national guidelines addressing nation-specific obstacles by using nation-specific facilitators are required.

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well being, despite their disability. Whilst cure is not possible, current underused interventions can be maximised to improve the life of patients and carers and to combat fear, shame and stigma.

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