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J. De Lepeleire ^a; A. W. Wind; S. Iliffe ^b; E. D. Moniz-Cook ^c; J. Wilcock ^b; V. M. González ^d; E. Derksen ^e; M. V. Gianelli ^f; M. Vernooij-Dassen and the Interdem Group ^g

^a Academisch Centrum Huisartsgeneeskunde, Katholieke Universiteit Leuven, Belgium ^b Centre for Ageing Population Studies, Department of Primary Care and Population Sciences, University College London, UK ^c Institute of Rehabilitation, University of Hull, UK ^d Sanidad Castilla y León (Sacyl), Primary Health Care Team of Villoria, Salamanca, Spain ^e Alzheimer Centre/Centre for Quality of Care Research, University Medical Centre St Radboud, Nijmegen, The Netherlands ^f Facoltà di Medicina e Chirurgia, University of Genova, Italy

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The primary care diagnosis of dementia in Europe: An analysis using multidisciplinary, multinational expert groups

J. De Lepeleire^{a*}, A.W. Wind^b, S. Iliffe^c, E.D. Moniz-Cook^d, J. Wilcock^c, V.M. González^e,
E. Derksen^f, M.V. Gianelli^g, M. Vernooij-Dassen^f and the Interdem Group

^aAcademisch Centrum Huisartsgeneeskunde, Katholieke Universiteit Leuven, Belgium; ^bHoorn, The Netherlands; ^cCentre for Ageing Population Studies, Department of Primary Care and Population Sciences, University College London, UK; ^dInstitute of Rehabilitation, University of Hull, UK; ^eSanidad Castilla y León (Sacyl), Primary Health Care Team of Villoria, Salamanca, Spain; ^fAlzheimer Centre/Centre for Quality of Care Research, University Medical Centre St Radboud, Nijmegen, The Netherlands; ^gFacoltà di Medicina e Chirurgia, University of Genova, Italy

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Objectives: To explore the extent of variation in the detection of dementia in primary care across Europe, and the potential for the development of European guidelines.

Method: A mixture of focus group and adapted nominal group methods involving 23 experts of different disciplines and from eight European countries.

Results: The diagnosis of dementia should be 'timely' rather than 'early'. Timeliness has an impact on the patient, on the caregiver, on healthcare professionals, and on society. Ethical and moral issues may interfere with the aim of timely diagnosis. Guidelines may be important for facilitating a timely diagnosis of dementia, but were infrequently used and not even available in three of the eight countries. Referral pathways often depended on health care system characteristics, differing throughout the eight European countries, whilst diagnostic strategies differed due to varied cultural influences. There was consensus that national variations can be reduced and timely diagnosis enhanced by combining simple tests using a systematic stepwise case-finding strategy, in conjunction with a strong infrastructure of multidisciplinary collaboration.

Conclusions: This study identified three key themes that should be considered in harmonizing European approaches to the diagnosis of dementia in primary care: (1) a focus on timely diagnosis, (2) the need for the development and implementation of guidelines, and (3) the identification of appropriate referral pathways and diagnostic strategies including multi-professional collaboration. The content of guidelines may be determined by the perspectives of the guideline developers.

Keywords: dementia; diagnosis; family medicine; European guidelines; primary care

Introduction

With the aging of Western society, dementia has become a growing health care concern (Hofman et al., 1991). Primary care teams and general practitioners (GPs) play an important role in the diagnosis and care of dementia patients and their families (Brodaty, Howarth, Mant, & Kurle, 1994; Downs, 1996; Downs et al., 2002, 2003; Howarth, Heath, & Snope, 1999; O'Connor, Fertig, & Grande, 1993). However, debate exists on whether or not family doctors miss the signs of dementia in patients (O'Connor, Pollitt, Hyde, Brook, & Roth, 1988; Waldorff, Rishoj, & Waldemar, 2005; Wind, Van Staveren, Schellevis, Jonker, & Van Eijk, 1994). Some physicians assert that dementia is often diagnosed in a late stage of the disease (Gifford et al., 1999; Van Hout, Vernooij-Dassen, Bakker, Blom, & Grol, 2000; Wind, 1997), whilst others argue that GPs have improved their diagnostic performance (De Lepeleire et al., 2004; Walstra, Teunisse, & Van Gool, 1997). Attitudinal factors can also play a role (McIntosh, Swanson, Power, & Rae, 1999; Olafsdottir, Foldevi, & Marcusson, 2001; Turner et al., 2004;

Van Hout et al., 2000). To date, there are few determined efforts to remedy the situation across Europe (Warner, Furnish, Longley, & Lawlor, 2002). As a consequence, people with dementia and their caregivers often feel unsupported with their problems.

Family doctors are well placed to detect and diagnose dementia, but are often impeded by a lack of skills, suitable diagnostic instruments, training, infrastructure and basic conditions (De Lepeleire & Heyrman, 1999; Downs, 1996; Downs et al., 2002; Iliffe et al., 2002b; Iliffe, Manthorpe, & Eden, 2003; Iliffe et al., 2005; Wind et al., 1995). There appears to be a wide variation in diagnostic methodologies and responses across Europe, as well as in policies developed to overcome this variation (De Lepeleire, Baro, Buntinx, & Lasuy et al., 1994; O'Connor, Pollitt, & Brook, 1991; Waldorff & Moller, 2001). Some potential reasons for this may be differences in the health care systems, the role and skills of the GPs, the presence or absence of guidelines, and differences in the availability of specialist services that are often important for differential diagnosis in the earlier stages of the disease. The perspectives of those developing

*Corresponding author. Email: jan.delepeleire@med.kuleuven.be

guidelines may influence the recommendations given, and may not match the complexity of both dementia syndromes themselves and the organization of primary care.

Two recent papers concerning this project stressed the importance of the journey of the dementia patients and the problem of stigma (Iliffe et al., 2005; Vernooij-Dassen et al., 2005). This paper aims to explore the diagnostic processes in primary care and the potential for a pan-European guideline for the diagnosis of dementia. The participating experts were all members of Interdem (<http://interdem.alzheimer-europe.org>).

Methods

A focus group approach was taken, but was modified to incorporate useful themes of nominal group methods. The focus group approach was chosen because of its ability to elicit verbal and non-verbal information about a problem or task, to allow elaboration, criticism and defence of responses and propositions, and to produce ideas and priorities generated by the participants themselves and in their own vocabulary that may be missed in individual interviews (Kitzinger, 1999). In addition, the focus group approach has proved to be an effective technique for exploring the attitudes and needs of health care staff. Group work is more suitable than are individual interviews for examining how knowledge and ideas develop, operate and are expressed within a given cultural context (Kitzinger, 1999). For resource and pragmatic reasons, an adapted nominal group method was used to identify themes arising from the group discussion rather than taping and transcribing the groups' debates. Summaries of the debate were recorded on flip charts and presented to the group for clarification and modification, and to achieve consensus. Another aspect of nominal group methodology was also used: an expert panel briefed by prior distribution of relevant literature (Jones & Hunter, 1999). Following this all participants were asked to complete a questionnaire on new ways of supporting people with dementia and their families that were emerging in their country. The data from the questionnaires were collated and synthesized independently by two individuals and validated within a structured workshop two months later.

A purposive sampling approach was used by inviting 23 experts to join multidisciplinary focus groups that included individuals from eight European countries (Belgium, France, The Netherlands, Ireland, Italy, Portugal, Spain and the UK). The disciplines involved were clinical psychology, general practice, geriatric medicine, old age (geriatric) psychiatry, medical sociology, nursing and voluntary organization workers. All participants were actively involved in service provision for people with dementia, or research into dementia care in the community, or both.

They brought to the discussion their clinical experience and their knowledge of research findings.

All participants were provided in advance with working papers that summarized knowledge of dementia epidemiology, research into primary care performance in dementia care, and differences in service provision in different countries. The 23 multi-professional experts participated in two groups over a two-day period at a first meeting. The groups concentrated on the related topics of obstacles to recognition of dementia, different national provision of services, lessons from innovations in early diagnosis and intervention, and methods of educating professionals. The groups considered the same topics, and individuals remained in the same group throughout.

Themes and sub-themes were recorded manually by two people independently, and presented to a plenary session for comments, qualifications and development. Themes identified in the group sessions were used in a grounded theory approach that allowed observations to be fitted to emerging theoretical concepts, and concepts to new observations (Glasser & Strauss, 1967; Murphy, Dingwall, Greatbach, Parker, & Watson, 1998). These themes were circulated to all participants and completed with factual information and discussed at a follow-up meeting 2 months later. The whole process is summarized in Figure 1.

Results

Twenty-three multi-professional experts participated in two groups over a 2 day period. The results of these sessions will be presented in four sections: the need for a timely diagnosis, the availability of guidelines, the referral pathways, and diagnostic strategies. The presented material is a result of a consensus within the plenary group.

The need for a timely diagnosis

The primary prerequisite for enhancing the diagnosis of dementia is that early diagnosis is accepted to be an important issue. First, the issue of 'timely diagnosis' was felt to be more relevant than that of 'early diagnosis.' Timely diagnosis is defined as the time when the patient or caregiver *and* the primary care physician recognize that a dementia syndrome may be developing. The preference for timely diagnosis implies that methodologies should concentrate not on population screening, but on a speedy response to the first reported signs of changed behaviour and functioning in the patient. There was no support for population-based screening. The groups were in favour of case-finding, but approaches and methods could not be defined due to a lack of consensus on that point.

Second, a definitional distinction must be made between 'detection' (i.e. becoming aware of a problem that could be caused by dementia), 'diagnosis' (i.e. confirming the diagnosis of a dementia syndrome) and

Figure 1. The project diagram.

finally the ‘etiological diagnosis’ (i.e. the diagnosis of sub-type).

Third, there are clear advantages, with no empirical evidence of disadvantages, for timely diagnosis, as shown in Table 1. It has to be noted that the evidence for each argument is not necessarily established.

Discussion arose about the moral and ethical problems that timely diagnoses can encounter. In most cases it is the caregiver, often a family member, rather than the patient, who approaches the family doctor for help. When doctors and other professionals act without the direct knowledge or permission of the patient, major problems can arise with informed consent, confidentiality, follow-up and use of or compliance with medication. In many countries, growing attention to the legal consequences of professional responsibility and the social consequences of diagnosis are additional concerns. There was consensus that the diagnosis should be clearly disclosed to both the patient and the family.

The availability of guidelines

Clinical practice guidelines can be a worthwhile tool in the management of complex problems like dementia, although some professionals do not see their importance. In three of the eight countries (Ireland, Portugal and Italy) represented at the workshop, no guidelines were available for GPs at the time of the meeting (ANAES, 2003; De Lepeleire & Heyrman, 1997a, b; De Lepeleire, Heyrman, Vanwelde, & Degryse, 1999; Eccles, Clarke, & Livingstone, 1998; Grupo de Trabajo Sobre Demencias, 1999; Gonzalez & Martin, 2002; Sociedad Española de Psiquiatría, 2000;

Table 1. Arguments for the timely diagnosis of dementia at four levels.

■	For the patient, a timely diagnosis:
●	Can answer concerns about early symptoms.
●	Can promote shared management between doctor and patient and carers.
●	Favours the establishment of plans for future care.
●	Enables initiation of early treatment for dementia (for example in Alzheimer’s disease).
●	Can improve the quality of life, social skills, and future security of people with dementia and their carers.
●	Enables the organization of timely counselling and social support.
■	For the family, a timely diagnosis:
●	Provides answers to concerns about cognitive and functional impairment of the relative.
●	Enables the search for solutions for the care and emotional burden of disease. Care plans can be initiated.
●	Opens up access to social support, resources and psycho-educational groups earlier, reducing caregiver strain.
●	Can improve the quality of life of the caregivers.
●	Enables the development of coping strategies to handle changes in functioning.
●	Allows anticipation and planning for future problems.
■	For the health workers, a timely diagnosis:
●	Enables physicians to design a specific and individual treatment and management plan.
●	Ensures that appropriate advice and information can be provided to the patient and the family.
●	Stimulates the liaison with colleagues in secondary and tertiary care regarding patient care and management.
●	Establishes a relationship with caregivers and family of patient.
■	For society, a timely diagnosis:
●	Could reduce the overall costs of dementia.
●	Could postpone the institutionalization in residences and nursing homes.
●	Could reduce dangerous and challenging behaviour (traffic accidents, gun use, etc.).
●	Enables the inclusion of patients in clinical trials for researching new treatments.

Sociedad Española de Geriatria y Gerontología, 2003; Sociedad Española De Neurlogía. Grupo de Estudio de Neurología de la Conducta y Demencias. Guías en Demencias, 2003; Wind, 1989; Wind et al., 2004).

The focus groups agreed that existing guidelines are not without problems. First, to be effective, guidelines have to be updated. Also problematic is that in some countries there is more than one set of guidelines available. For example, in Spain there are different versions for GPs and for specialists, so that responses for care provision and support even within a nation can vary significantly (Grupo de Trabajo Sobre Demencias, 1999; Gonzalez & Martin, 2002; Sociedad Española de Psiquiatria, 2000; Sociedad Española de Geriatria y Gerontología, 2003; Sociedad Española De Neurlogía. Grupo de Estudio de Neurología de la Conducta y Demencias. Guías en Demencias, 2002; Grol, 1992). Third, guidelines are often not utilized. For example, in France one-third of family doctors know of the existence of guidelines; but this knowledge did not guarantee use (Cantegreil-Kallen et al., 2004; Waldorff, Almind, Mäkelä, Moller, & Waldemar, 2003). Possible barriers to implementation include a lack of awareness of guidelines, an unwillingness to accept diagnosis and management as part of the role of primary care, and reticence to provide a 'heartsink' diagnosis in which treatment and support options are seen as limited. It is also possible that guidelines alone do not provide professionals with the range of skills necessary to manage the complex problems that clinical practice presents. Finally, guidelines are often produced by doctors for use by other doctors. This may limit the application of the guidelines to diagnose and treat dementia, which is not only a medical issue, but a social and cultural issue as well.

Referral pathways

The referral pathway to establish a diagnosis of dementia is influenced by the organization of health care and services for older people. Within this, the role of GPs as gatekeepers and the accessibility of specialists and facilities such as memory clinics are important factors (see Table 2). In countries such as Spain, Portugal, and Ireland this 'best practice' referral pattern is undermined by the lack of specialist services, while in France memory clinics are well organized and widespread. In Ireland, The Netherlands and Belgium, GPs can refer patients to different services (for example neurology, old age/geriatric psychiatry, geriatrics). Overall, the referral patterns in different countries are similar, depending on the major clinical problems. For example, patients are referred to a psychiatrist for behavioural problems and depression, to a neurologist for differential diagnosis and neurological signs, and to a geriatrician in the case of co-morbidity and social difficulties. Rules concerning the reimbursement of cholinesterase inhibitors are also important elements in referral patterns: in the Netherlands and the UK,

the specialist is the gatekeeper to cholinesterase inhibitors. This division of responsibility continues in the UK, and shared care protocols were made mandatory in 2001, as is also the case in Belgium. Different European health care systems have different structures. However, all health systems contain referral pathways, and all seem problematic for dementia care at the micro-, meso- and macro-levels.

Diagnostic strategies

What symptoms are important?

There was agreement that diagnostic strategies should start with symptoms or behaviours that are key potential triggers or with the first signs of cognitive deterioration and/or dementia. Within the population, forgetfulness is often considered to be part of the normal aging process and people will not consult a physician for further diagnosis. Informant histories from caregivers and medical and welfare professionals are important, but not always reliable due to under-reporting of memory problems. Behavioural and functional problems (Activities of daily living/ Instrumental activities of daily living) are important triggers for timely diagnosis of dementia and to differentiate normal from pathological.

Who does the assessment?

The importance of multidisciplinary evaluation was emphasized by the focus groups because of the complexities of making a diagnosis, particularly in the early stages and with regard to legal and ethical concerns (Van Den Hoven & Van Delden, 2002; Widdershoven & Widdershoven-Heerding, 2003). No professional should face complex problems of detection and diagnosis of dementia alone, since the assessment is at risk of being too narrow. In most countries, family doctors are involved in the diagnostic process, but there is great variation in the extent and content of the cooperation with specialists. In the Netherlands, referral to specialists is very important for care planning rather than diagnosis, while in Italy the diagnostic process is done largely at the specialist level. Across these two extremes, a variety of responses in Europe exists, influenced by the organization of health care, the availability of specialist care, local customs and culture, and the attitude of patients, caregivers and professionals.

What instruments are used?

There is no standardization in the use of cognitive function tests or other diagnostic tools across Europe. For example, in Spain, although no consensus exists, the most used and recommended test for dementia screening is the Mini Examen Cognoscitivo (MEC) (Lobo et al., 1999, 2000), while in France the MIS is popular. The Mini Mental State Examination remains widely popular, although the risks of its inappropriate

Table 2. Themes of the organization of health care contributing to the diagnosis of dementia.

EU member state	GP acts as a gatekeeper	Memory clinic or similar specialist diagnostic services	Professional involved in diagnosing dementia						Professionals having access to medicine			
			GP	Psychiatrist	Neurologist	Geriatrician	Psychologist	GP	Psychiatrist	Neurologist	Geriatrician	Psychologist
The Netherlands	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	
Belgium	no	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
UK	✓	✓	✓	✓	✓	✓	✓	✓ ^a	✓	✓	✓	
Spain	✓	–		✓	✓	✓	✓		✓	✓	✓	✓
Italy	✓	✓		✓	✓	✓		✓ ^b	✓	✓	✓	
Portugal	no	–		✓					✓			
France	no	✓		✓	✓	✓	✓		✓	✓	✓	
Ireland	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

^aMonitoring only; role under review. ^bOnly follow-up: prescription cholinesterase inhibitors.

use have been documented (Grigoletto, Zappala, & Anderson, 1999; Woods et al., 2003).

Despite the importance of neuropsychological testing, in-depth neuropsychological assessment such as the Camdex-R is not utilized in primary care in any European country. The focus groups agreed that the use of cognitive function instruments is necessary but not sufficient for diagnosis in primary care. As well as a disease-oriented diagnosis, a care-oriented diagnosis can take into account an assessment of the patient's functional ability or social circumstances.

Discussion

The output from this process could be useful if we want to improve the capacity of primary care professionals to diagnose dementia. Key themes for a coherent European approach to the development of dementia diagnosis guidelines can be derived from the results of the nominal group discussions. We emphasize the importance of a 'timely' diagnosis, the need for the development and implementation of guidelines, and the identification of appropriate referral pathways and diagnostic strategies.

The strengths of this study were in the recruitment of a wide-ranging group of inter-disciplinary professionals and researchers within dementia care from eight European nations. There are some inevitable limitations to our sampling process in that, apart from one social work participant, we did not recruit the broad range of social care providers that exist across Europe. Our procedure for participant checks and related thematic synthesis was strong, but there remains a potential problem of language and interpretation within group discussions. The majority of participants were thinking and speaking in their second or third language, which may have produced a bias in favour of the native English speakers; this may have compromised the richness and depth of themes. Finally, the content of diagnostic methods in dementia care within the 3 year GP vocational training that existed in all eight countries was not examined in detail. Dementia-specific training programs for primary care have been developed in some countries (The Netherlands, UK, Belgium), but these may require systematic policy-driven inclusion within national GP vocational training schemes and generalization across all countries.

The main findings of this international group differs somewhat from other perspectives, for example the Edcon paper (Waldemar et al., 2007) Because seen from a primary care perspective, 'timely' diagnosis of dementia appears to be more appropriate than 'early diagnosis', the benefits of timely diagnosis were perceived at four levels: patient, caregivers, health care professionals and society. For patients and caregivers an early diagnosis may not correspond to their understanding of the problems that are emerging, whereas timeliness implies a common agreement

between professionals, patients and carers about the problematic nature of cognitive and functional impairment. Primary care professionals are particularly anxious about potential adverse effects of labeling and stigmatizing patients with early dementia (Cahill, Clark, Walsh, O'Connell, & Lawlor, 2006; Iliffe et al., 2003). Our earlier reports from Interdem underline this widespread perception of the significance of 'timely' diagnosis (Iliffe et al., 2005; Vernooij-Dassen et al., 2005). For these reasons our consensus group favoured case-finding over population screening in line with other reviews (Boustani, Peterson, Hanson, Harris, & Lohr, 2003; De Lepeleire & Heyrman, 1999; Eccles et al., 1998; U.S. Preventive Task Force, 2003).

The development and implementation of guidelines can be an important tool for the purpose of timely diagnosis of dementia. However, in developing guidelines we have to be aware of the effects on recommendations at risk of different interests and scopes and of the divergent results that can reflect different balances in professional interests. Although there is case for developing guidelines for diagnosis and management in primary care (Waldemar et al., 2007), there is little evidence that guidelines improve patient outcomes. Further research is necessary to determine whether the more recent evidence-based guidelines have more of an effect on patient outcomes (Worrall, Chaulk, & Freake, 1997), identification of barriers to implementation in clinical practice (Wilcock et al., 2003) and physician learning and change (Davis, 1998).

Referral pathways and the way GPs and specialists work together in the diagnosis of dementia often depend substantially on health care system characteristics such as the presence or absence of memory clinics and waiting lists. (Iliffe et al., 2005). The referral pathways seem, problematic in all countries at all levels. Evidence exists that a lack of social service support and a gap in the service provision are obstacles for a timely diagnosis (Bisset & MacPherson, 1996; Turner et al., 2004).

As to the diagnostic process, uncertainty exists about the importance of symptoms and signs and the interpretation of symptoms influenced by cultural themes, e.g. the belief that dementia is part of the normal aging process. It is, however, clear that the assessment of cognitive impairment needs the input of practice nurses and neuropsychologists, and has to be done in a multidisciplinary professional group. Furthermore, combining simple tests in a stepwise procedure with proper use of adequate instruments in a case-finding procedure is recommended. This combination should include cognitive and non-cognitive tests (including functional and behavioural elements), using a psychosocial focus as well as longitudinal scope.

Finally, multi-professional educational efforts must become mandatory if positive results in the timely diagnosis of dementia in primary care are to be achieved. Published recommendations underline the importance of appropriate education and continuing medical education for primary care practitioners

(Cheok, Cohen, & Zuccherro, 1999; McIntosh et al., 1999; Turner et al., 2004; Pucci et al., 2004; Robinson, Barry, Renick, Bergen, & Stratos, 2001).

This study adds to the consensus on timely diagnosis and of attention for cultural and ethical aspects. These themes can be used in guideline development. In education, not only these key themes should be considered but also the stigma attached to dementia by professionals (Vernooij-Dassen et al., 2005).

Conclusions

These findings and recommendations make possible an empirically driven, well-designed pan-European multi-centre research program on the timely diagnosis and management of dementia in primary care (Vernooij-Dassen et al., 2003), because they explore the complexities of recognizing and responding to dementia syndromes. They can also be used as a frame for the evaluation of the efforts, plans and changes in each European country in order to promote better management of patients with dementia and their caregivers.

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