



## Commentary

### The assessment of dementia in primary care

#### Introduction

Dementia is an irreversible and progressive condition characterized by a global deterioration of a person's cognitive abilities. With an ageing population, the number of people diagnosed with dementia is expected to rise both in the UK and abroad. Consequently, government policies across the world have stressed the need to improve early diagnosis of dementia in the hope that this will facilitate adjustment to the illness and thus to prolong independence. Arguably, one way of achieving this aim is to strengthen the role of primary care in the assessment, diagnosis and subsequent support of people affected by dementia. The purpose of this commentary is to explore the role of mental health and memory nurses in this process drawing on examples from the UK and Australia. Although there are a number of risks about increasing the role of primary care, pressures from limited budgets and resources at a time when the numbers of people affected by dementia are set to increase, means that it is inevitable that primary care will have a more influential role in dementia care than before. Consequently, it is important that the implications of these policy changes for mental health and specialist memory nurses are clearly understood.

#### The health-care challenge of dementia

The initial signs of dementia typically involve deterioration in a person's short-term memory, with a range of other skills including those related to communication, organization and orientation also being affected as the illness develops. Dementia leads to a range of disabilities affecting the person's ability to perform activities that are fundamental to independent daily life (such as personal care) and reduces the person's ability to function in interper-

sonal and social relationships. Due to the progressive nature of the illness, people affected by dementia become increasingly dependent on their caregivers and require assistance with even the most basic of daily activities.

The syndrome of dementia is made up of a number of neurodegenerative illnesses. The most common of these is Alzheimer's disease which accounts for over 60% of dementia cases, with vascular dementia and mixed forms of these two illnesses comprising one-third (Knapp & Prince 2007). The less common types of dementia (e.g. Lewy body dementia and fronto-temporal dementia) account for between 5% and 8% of people with the syndrome (Alzheimer's Disease International 2013).

In the UK, recent estimates suggest there are between 670 000 and 800 000 people living with dementia (Matthews *et al.* 2013), a figure which is expected to rise towards 1.7 million by 2051 (Knapp & Prince 2007). In 2009, Alzheimer's Disease International (ADI) published global prevalence data on dementia. They estimated that across the world there would be 36 million people with dementia in 2010, and that this would almost double in size every 20 years to 66 million by 2030 and to 115 million by 2050. However, since population ageing is occurring at a much faster rate in low and middle-income countries, the bulk of the increase in numbers through to 2050 will occur in those regions. By 2050, 71% of those with dementia will be living in what are currently lower and middle-income countries. Although a number of recent trials of potential interventions have not been successful, nevertheless, many drug companies continue to make substantial investments in developing new products in the hope of bringing to market meaningful interventions that will be able to limit the impact of dementia. However, at best, these offer the prospect of change in the medium rather than the short term, and such treatments will indeed only be effective if diagnostic and care systems have already been established which can identify a large

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proportion of people affected by dementia. Unfortunately, the ADI estimated that currently less than half of those in high-income countries and fewer than 10% of those in lower and middle-income countries have received a dementia diagnosis (Alzheimer's Disease International 2013).

In anticipation of these major global demographic changes, many countries, and in particular those countries with major economies that are part of the G20, have begun to develop and enact plans to address Alzheimer's disease as a national priority (Rosow *et al.* 2011). For example, in the UK, governmental strategies have prioritized the development of robust assessment and diagnostic procedures [Department for Health, Social Services and Public Safety (DHSSPS 2011); Department of Health 2009; Scottish Government 2010; Welsh Government 2011]. These policy priorities in the UK have been further emphasized by the report of the All-Party Parliamentary Group on Dementia (2012) and the Prime Minister's Dementia Challenge (Department of Health 2012). One of the main advantages of diagnosing and treating dementia early that has been put forward is the expectation that this will facilitate adjustment to the illness, thereby enabling people affected by dementia to plan ahead and thus to prolong their independence and delay the need for care home or hospital admission (Banerjee & Wittenberg 2009, Guss 2014).

The shifting global focus within dementia care towards early recognition and detection presents challenges for both politicians and for health-care providers alike. For mental health nurses, meeting this challenge will involve developing new roles in working with family doctors and primary care teams rather than with specialist psychiatrists or geriatricians within a memory clinic. In particular, they will need to balance providing appropriate assessments and support to increasing numbers of people affected by dementia within a context of shrinking budgets and resources.

### Diagnosis and treatment

While there is no cure for dementia, some symptoms can be managed with acetyl-cholinesterase inhibitors, such as Aricept or Donepezil (Eisai Ltd., European Knowledge Centre, Mosquito Way, Hatfield, Herts, AL10 9SN, United Kingdom), which can effectively reduce some symptoms of cognitive impairment in some people with Alzheimer's disease (Birks & Harvey 2006). However, in the

UK, the National Institute for Health and Care Excellence (NICE) practice guidelines (NICE/SCIE 2011) restrict prescription of these drugs to people with mild or moderate levels of cognitive impairment caused by Alzheimer's disease. In practice, then, prescribing acetyl-cholinesterase medication is a treatment option for less than half of all people with a diagnosis of dementia.

For the last 20 years or so, the diagnosis of dementia in the UK and elsewhere has mainly been the preserve of specialist clinical teams working within a memory clinic based within secondary care (Lindesay *et al.* 2002). Typically, the assessment process leading to diagnosis is provided by a team of professionals including a memory nurse, psychiatrist and psychologist and involves a number of procedures including: screening for other potential causes of memory loss through blood testing, neuropsychological assessment, clinical interviews with the patient and members of their family and neuro-imaging (NICE/SCIE 2011). However, the view of the memory clinic as the 'Gold Standard' for the assessment of people affected by dementia has been increasingly questioned, with some (e.g. Banerjee *et al.* 2007; Melis *et al.* 2009) pointing out that despite the widespread assumption in favour of diagnoses taking place within the memory clinic, there is, in fact, relatively little evidence to support their effectiveness. Moreover, despite recent efforts to increase the number of people diagnosed with dementia, the rate of diagnosis is often at low levels with patients and their families waiting many months for an assessment. Thus, there is concern that increasing the numbers of referrals to memory clinics may simply result in even longer waiting times for appointments (All-Party Parliamentary Group on Dementia 2012). The focus on assessment has also led to complaints that the assessment and diagnostic process has been prioritized at the expense of providing support to patients and families after a diagnosis (Foreman *et al.* 2004, Gardner *et al.* 2004, Watts *et al.* 2014).

### Potential benefits of primary care-led dementia diagnosis

One possible solution to these problems is for primary care practitioners to play a greater role in diagnosing dementia. Such a service change would have a number of potential clinical benefits. First, it might make dementia diagnosis more accessible for patients, and provide a more cost-effective use of

existing resources. Second, due to their familiarity and often long-established relationships with patients, many general practitioners (GPs)<sup>1</sup> will be in a unique position to provide close management of the post-diagnostic care for a person affected by dementia (Lee *et al.* 2010). As patients are seen by the primary care team for a range of long-term conditions and regular health checks, involving GPs more actively in dementia diagnosis may also make the assessment process more accessible and less stigmatizing. This would bring direct benefits to patients and their caregivers who could receive more timely diagnosis and appropriate post-diagnostic support in terms of making arrangements for future care, taking part in local peer support and tertiary services. Finally, improving GPs' awareness and skills in dementia care at the point of assessment and diagnosis may well increase their confidence in providing other areas of health care to patients with cognitive impairment who also have other complex comorbidities.

### Barriers to diagnosis in primary care

Increasing the role of GPs in dementia diagnosis is not, however, a straightforward task. There are a series of potential barriers to diagnosis that relate to patient, physician and system difficulties (Bradford *et al.* 2009, Aminzadeh *et al.* 2012). At the patient level, for instance, individuals may delay reporting symptoms of memory and cognitive decline due to the stigma associated with dementia and a lack of insight (Arlt *et al.* 2008). Physician-related barriers include pessimism around treatment, a lack of skills in dementia recognition, as well as lack of time and resources for management of dementia (Hansen *et al.* 2008, Koch & Iliffe 2010).

Among the service changes that have been trialled are attempts to improve GPs' knowledge and skills in recognition and management of dementia. For example, Wilcock *et al.* (2013) conducted an unblinded cluster randomized controlled trial of an educational intervention aimed at GPs, altogether involving 23 GP practices and a total of 1072 dementia patients. The authors developed and tested the effects of a training programme which involved assessment of GPs' educational needs

regarding dementia using eliciting questions within groups. This was followed by provision of a tailored training programme that consisted of group-based workshops and electronic information based on the NICE guidelines for management of dementia (Wilcock *et al.* 2013). Despite the direct tailoring of the intervention to GPs' educational needs, the authors reported no significant impact of the trial on the primary study outcomes (number of dementia patients' care reviews) and secondary outcomes (number of newly diagnosed cases). Consequently, while lack of skills and knowledge about dementia is a problem in primary care (van den Dungen *et al.* 2012; Aminzadeh *et al.* 2012), it appears that if we are really to improve the clinical service that people affected by dementia receive within primary care, then we will need to do more than just improve GPs' skills and knowledge about the condition. Thus, in each of the examples of service change that we will describe, specialist mental health nurses have played a crucial role in creating viable services.

### Primary care-led dementia service: model examples

In response to the need for improving recognition of dementia, new models of dementia services embedded in primary care have been developed and trialled. Their aims are to provide easier access to dementia care and to reduce waiting times for assessment and diagnosis. Given the global impact of dementia, the need to develop resources within primary care settings has led to initiatives being trialled across the world, including Canada (Lee *et al.* 2010), the USA (Valcour *et al.* 2000, Boustani *et al.* 2005), Thailand (Boongird *et al.* 2011), Norway (Engedal *et al.* 2013) and the Netherlands (Meeuwssen *et al.* 2012). Common to all of these models is the changing, and central, role for nurses.

The Dementia Collaborative Research Centre in New South Wales, Australia, carried out a feasibility study into a nurse led intervention to assist and support GPs in identifying and managing dementia in primary care (Convery *et al.* 2013). This study used a participatory action research approach as an aid to the development of the service change. Initially, the main role of the specialist memory nurses was to conduct a comprehensive assessment on behalf of the primary care team. However, the research methodology identified the fact that GPs benefited greatly from nurses having an enhanced role in which their expertise in dementia allowed

<sup>1</sup>A local family practice physician providing ongoing care covering a range of medical problems in patients of all ages. General practitioners will refer patients to a hospital specialist when needs cannot be addressed locally.

them to provide guidance on a range of care management issues. The authors suggest that this role of the specialist mental health or memory nurse should be expanded to enable them to liaise more effectively with the multidisciplinary team in primary care practice.

In the UK, the Gnosall model of primary care memory clinics was launched in 2006. Within this model, specialist services, families and primary care providers worked together to screen patients for cognitive decline, focussing in particular on patients with a vascular history (Greaves & Greaves 2011). 'Eldercare facilitators' including nurses organized assessment, provided further support and linked with specialist services which were provided at a monthly memory clinic in every GP practice provided by a psychiatrist (Greaves *et al.* 2013). This primary care dementia service reduced the waiting time for a diagnosis of dementia to just 4 weeks, and reported significant savings to the National Health Service<sup>2</sup> while also showing high levels of service users and professionals satisfaction (Greening *et al.* 2009, Jolley *et al.* 2010, Clark *et al.* 2013).

A similar model of primary care led assessment service was trialled in Croydon. This model involves a low-cost, high-throughput, multi-agency service which aims to enable early identification and intervention in dementia. All of the members of the team including nurses, regardless of whether they had a health or social care background, were trained to provide early recognition, carry out assessments and to provide support to people with suspected dementia. Responsibility for making and sharing a diagnosis was shared within the team, with the option to refer patients for a specialist assessment. A mixed qualitative and quantitative methodology evaluation was used with a 6-month follow-up of a cohort of 290 consecutive referrals. The service showed high levels of acceptability, with over twice as many referrals from minority ethnic groups compared with that expected from general population. Overall, there was almost a two-third increase in the number of new cases of people affected by dementia seen in Croydon. At 6-month follow-up, patients referred to the service had decreased behavioural disturbance and increased

quality of life compared with baseline (Banerjee *et al.* 2007).

In contrast, the Bristol model of primary care-led dementia services differs from those in Gnosall and Croydon as the main diagnostic processes were led directly by GPs. The Bristol model involved a series of changes to the way in which services were delivered with assessment and diagnosis being provided by GPs. Similar to the study carried out in Australia (Convery *et al.* 2013), GPs were provided with the assistance of memory nurses who were attached to practices to provide expert support to GPs and to liaise with patients, carers and the memory clinic. General practitioners were able to prescribe Donepezil (an acetylcholinesterase inhibitor) where appropriate and referral to secondary care memory clinics for complex cases or where an early onset dementia was suspected was still possible. The Bristol model was first piloted between August 2012 and December 2013, before being rolled out so that all GP practices in Bristol are now working under the new guidelines.

An evaluation of the Bristol model identified two main issues (Dodd *et al.* 2014). First, memory nurses attached to the practices involved in the pilot project played a crucial role in helping GPs to arrive at a diagnosis and without their support, GPs would not have been able to take on this increased role. Second, both secondary and primary care-led dementia care services were perceived positively by patients and their families. The findings also showed that health-care practitioners identified positive outcomes in terms of reduced delays and better awareness about dementia among GPs, although some also reported a rather relaxed approach to diagnosing people with dementia.

Around the same time as changes in Bristol, neighbouring South Gloucestershire looked at reconfiguring some dementia diagnosis into primary care. This model also involved GPs liaising with a specialist mental health nurse both to assess patients where there were concerns about their memory, and then to discuss the most appropriate treatment options. However, the large numbers of GP practices signing up to this service change meant that there were not enough memory nurses to be individually attached to practices in South Gloucestershire. Consequently, centrally located mental health nurses were instead made accessible to GPs for advice and support. Those people who were aged 75 or under or who presented with atypical symptoms or 'red flag' symptoms such as

<sup>2</sup>The health-care system in the UK: the core principle that good health care should be available to all, regardless of wealth – free at the point of use for anyone who is a UK resident.

behavioural changes and expressive language problems continued to be referred into the secondary care memory service for a specialist assessment.

### Post-diagnostic support

As we have outlined above, one of the main drivers towards the development of primary care-led dementia services has been the recognition that secondary care-based services were unable to manage the volume of referrals being presented to them. At the same time, proponents of this shift in service provision have also expressed the hope that by placing primary care services at the heart of the assessment process, then this would also empower family doctors and the primary care health team to play a greater role within post-diagnostic support. If this were to be the case, then this would go some way to counter concerns that people affected by dementia and their families typically raise about a post-diagnostic cliff in which the energy expended on achieving a diagnosis contrasts sharply with the lack of adequate support services (Dodd *et al.* 2014, Watts *et al.* 2014). As Innes, Szymczynska and Stark (2014) comment, 'Without post-diagnostic provision Government targets for diagnosis are just that, quota targets, rather than a means to improve service experiences'.

However, if nurses and others working within primary care are to play a greater role in post-diagnostic support, then they themselves need further support and training. One way to do this is for memory clinic nurses to provide therapeutic support groups – a possibility that was trialled within the Living Well with Dementia group therapy project. The results of this pilot study suggested that nurses with little or no experience of previously acting as group facilitators could, following a 2-day training course, provide a therapeutic group intervention which showed a strong trend towards improving self-esteem and quality of life (Marshall *et al.* 2014).

### Discussion

Ultimately, commissioners face a delicate balance between delivering the right level of assessment to enable an accurate diagnosis, while not placing carers and patients under an undue stress, and at the same time not diverting scarce resources from post-diagnostic care. However, the increasing role

of primary care services, including specialist nurses, offers the potential for both improvements in service provision and a more cost-effective service. Ideally, primary care led dementia services would become an important part of dementia-friendly communities in which patients become experts in their own condition, being able to have both more choice in what happens to them and increased power to make decisions about their condition.

A number of important questions remain unanswered, however. For instance, while primary care led services may lead to more diagnoses being made, it is not clear whether diagnoses made by non-specialist health professionals are as accurate as those made in a specialist memory clinic. The diffusion of dementia assessment across primary care may have advantages, but inevitably any one primary care surgery will see far fewer patients with a possible dementia than would a specialist memory clinic. As GPs will not be regularly exposed to presentations of possible dementias, then invariably, their lack of practical experience will present clinical challenges – for instance, it may make it harder to identify when a complex presentation warrants referral on to specialist services. In addition, this lack of experience is likely to lead to greater variations in the quality of services which are available. This may impact upon the way in which a diagnosis is disclosed, the access that patients and carers have to post-diagnostic support or advice and opportunities for involvement in research. It is thus unsurprising that all of the dementia assessment services that we have outlined here either provided specialists operating within primary care (in the case of Croydon and Gnosall), or provided a specialist memory nurse to support GPs in making the diagnosis with complex cases being referred into a specialist memory clinic (in the case of New South Wales, Bristol and South Gloucestershire). Whether carried out in primary, secondary or tertiary care, the assessment, diagnosis and support of people affected by dementia is carried out most effectively using a multi-method approach by a team rather than by an individual practitioner. The role of the specialist mental health or memory nurse in facilitating the assessment process and in supporting patients and their families after diagnosis is crucial. They are, perhaps, uniquely placed to assist in reducing the barriers to primary care assessment, diagnosis and treatment of dementia.



Thus, nurses will increasingly need to work at a variety of levels: with the person who is directly affected by dementia; with their family and carers; and with the system of health and social care professionals who come into contact with the person, so that they can be supported where necessary to take account of the person's particular needs. In Australia, Duane *et al.* (2013) evaluated a clinical nurse consultant role providing person-centred pre-diagnosis support in the community. They found that this work was not only highly regarded by clients but also by other health professionals. In the UK, Admiral Nurses are specialist dementia nurses who give much-needed practical and emotional support to family carers, as well as the person with dementia. They offer support to families throughout their experience of dementia that is tailored to their individual needs and challenges. In addition to providing families with the knowledge to understand the condition and its effects, Admiral Nurses also work collaboratively with other professionals

in order to improve the quality of life for people with dementia and their carers. Similarly, given the often low level of awareness and training of GPs in assessment and diagnosis of dementia, specialist mental health/memory nurses will play a vital role within primary care led dementia services in facilitating not only assessment but also providing support after diagnosis (Dodd *et al.* 2014, 2015).

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