

## Dementia: issues in early recognition and intervention in primary care

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Changes in health policy in the UK are creating an experiment in dementia care which will be of importance to other societies and healthcare systems. A report from the Audit Commission, *Forget Me Not 2002*,<sup>1</sup> concludes that general practices should make greater efforts to diagnose dementia in its early stages. Likewise the National Service Framework (NSF) for Older People<sup>2</sup> emphasizes the need for early detection, with an enhanced role for primary care. A major challenge to implementation, however, is the observation that a substantial minority of general practitioners (GPs) are unconvinced of the benefits of early diagnosis. In the Audit Commission's survey of 8051 GPs in 73 areas of England, only 60% agreed that an early diagnosis of dementia was important—no change from the proportion in pilot data from 12 areas, collected in 1999.<sup>3</sup> Probably, however, GP opinion has become more favourable since the publication of National Institute for Clinical Excellence (NICE) guidance on use of acetylcholinesterase (AChE) inhibitors for the treatment of Alzheimer's disease<sup>4</sup>—advice that may have come too late to have much impact on the full survey. A common argument is that, in the absence of effective treatment, there is nothing to be gained from early diagnosis. *Forget Me Not 2002* notes that GPs who reported having received sufficient training in diagnosis and management were the ones most likely to favour early diagnosis; most GPs did not feel that they had received sufficient training. These findings may in part explain why nearly 75% of patients with

moderate to severe dementia are unrecognized by primary care clinicians as having cognitive impairment.<sup>5</sup> The Audit Commission<sup>1</sup> points out that, if the condition is not recognized early, the patient and family commonly experience a crisis, with specialist services called in too late to establish supportive care. More positively, the NSF suggests that early diagnosis provides access to treatment, allows planning of future care and helps individuals and their families come to terms with the prognosis.

### THE PATIENT'S JOURNEY

Models of both the care-giving career<sup>6</sup> and the experience of the person with dementia<sup>7</sup> emphasize how the diagnosis of dementia marks an important transition, from the uncertainty and ambiguity of the early cognitive and behavioural change to a phase in which the patient adjusts and learns to live with impairment and loss of function. Although such adjustments may be impossible if the diagnosis is late and arises from a crisis, a drive towards ever earlier diagnosis has drawbacks. Serious obstacles for the GP include diagnostic uncertainty in the early stages, their own feelings of embarrassment about conducting cognitive examinations and difficulty in communicating the diagnosis.<sup>8</sup>

Making the diagnosis in the early stages is not always straightforward. The use of specific tests such as the Mini-Mental State Examination (MMSE) is often recommended,<sup>9</sup> and *Forget Me Not 2002* notes that around 40% of GPs report using a specific test or protocol to detect dementia.<sup>1</sup> However, if a person in the late 80s is being assessed, the score on such a test may be depressed by factors such as poor physical health, sensory difficulties, anxiety, depression, educational level and English not being first language, as well as by the presence of a dementia. Specialist memory clinics, even with the benefits of detailed neuropsychological assessment and brain imaging, find themselves taking a watching brief in certain cases. The diagnosis of dementia may emerge over six months or a year, as changes in the person's performance are observed and monitored;<sup>10</sup> in

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some people with mild cognitive impairment,<sup>11</sup> dementia takes three years to develop.<sup>12</sup>

Secondly, the process of assessment may become confrontational. In the early stages of dementia, accommodation to or denial of changes in cognition, functional ability, mood or behaviour are common coping strategies. A cognitive test such as the MMSE, which may harshly expose the person's failures and the family's psychological defences, can be experienced as highly threatening by a person struggling to maintain a sense of competence. Family conflict can also arise—for example, when a person has been 'brought' to see the GP by a concerned family member and who then becomes angry for what seems like an act of betrayal. As the person's denial strengthens, the concerns of the family become more pressing, with the GP often caught in between and faced with apparently irreconcilable needs. On other occasions, both the family member (typically an elderly spouse) and the affected person seem oblivious to the cognitive impairment that is evident to the GP during a consultation on another medical matter. The couple have made an adjustment, often downplaying the importance of recent memory and orientation, with one partner acting as the memory for the other.<sup>13</sup>

Thirdly, once the diagnosis of dementia has been made, the patient and family will have questions regarding the future that are by no means easy to answer. Even an apparently obvious prediction—such as that a further decline in cognitive abilities is likely—may be inaccurate since a substantial proportion of patients show little or no decline for a period.<sup>14</sup> To communicate a prognosis that is uncertain and likely to be influenced by numerous factors other than progression of the brain disorder is difficult, when the aim is to aid planning. Some patients and families will already have drawn prognostic conclusions on receiving the diagnosis; the very word Alzheimer's will conjure up a picture of severe impairment.

#### FROM EARLY TO TIMELY RECOGNITION

What then is the way forward? We would argue that there is indeed a need for timely detection and diagnosis that will prevent crises, facilitate adjustment and provide access to treatments and support. Clearly, when over half of a large sample of GPs who responded to a survey believed themselves insufficiently trained to diagnose and manage dementia adequately, it is tempting to focus on GP training as a priority. However, the disease process is complex and simple approaches such as training in use of brief screening instruments have lacked impact in general practice.<sup>15</sup> Multiprofessional training, amongst practitioners from different primary care disciplines, has been received positively.<sup>16</sup> Obstacles to recognizing and responding to

dementia in general practice are understood.<sup>17,18</sup> An evidence-based curriculum designed on learning principles has been prepared in various formats<sup>18</sup> decision support software has been developed and tested<sup>19,20</sup> and a randomized trial of different educational interventions is now underway.<sup>21</sup>

An educational programme of this kind needs to be coupled with ready access to specialist services (only 60% of GPs surveyed by the Audit Commission in 2002 reported that they had such access) if the dilemmas of early diagnosis are to be well handled and if AChE inhibitors are to be prescribed according to the NICE guidelines. Given that dementia is only a small part of a GP's caseload (perhaps 2 new cases per year in a list size of 2000), training may be as much about the benefits of diagnosis and indications for referral as about the mechanics of diagnosis itself. The essential requirement is for clear arrangements between primary care teams and specialist services regarding diagnosis, care and treatment, and this is an NSF requirement to be achieved by April 2004.

The NSF also requires specialist mental health services to work with primary care trainers to develop training in, *inter alia*, 'at least one screen for cognitive impairment'. The prominence given by the NICE guidelines to the MMSE in defining suitability for the prescription of the AChE inhibitors might reinforce a temptation to recommend this much used but much criticized measure. The influences of age, educational level and social class on MMSE scores have been well-documented,<sup>22</sup> and in community samples this instrument gives a high false-positive rate.<sup>23</sup> It mixes a wide variety of items, and two patients may achieve identical scores with completely different cognitive profiles and with quite different implications. Several studies have demonstrated that much briefer tests have equivalent or better levels of validity. These typically include a new learning test (e.g. recalling a name and address), orientation items and a simple concentration task. The 6-item Cognitive Impairment Test (6CIT) is a good example of a brief test likely to be more acceptable in the primary care context than the MMSE.<sup>24</sup> However, the utility of cognitive screening will be much enhanced if it is combined with other assessments such as history of cognitive and behavioural change from a third party.<sup>25,26</sup> DSM-IV criteria for dementia specify that cognitive changes have to be sufficient to affect day-to-day behaviour; thus it is important to explore whether there have been changes in abilities such as managing money and planning activities.<sup>27</sup>

A broader procedure for the recognition, early detection and diagnosis of dementia takes into account the history of consultations with the GP,<sup>8</sup> perhaps over a considerable period.<sup>10</sup>

## DISCLOSING THE DIAGNOSIS

There has been a large change in attitudes to communicating the diagnosis of dementia. Whilst family caregivers are nearly always told the diagnosis,<sup>28</sup> the affected person is often not, even if the dementia is mild.<sup>29,30</sup> Furthermore, when people with dementia are told what is wrong, it is more often expressed in terms such as 'memory problems' or 'confusion' than in medical terms such as Alzheimer's disease.<sup>31</sup> The NSF (para. 7.39) asserts 'treatment of dementia always involves explaining the diagnosis to the older person and any carers'. This is clearly an area where all the professionals involved, including those in specialist services, will benefit from skill development. Information must be geared to the individual, taking into account his or her perception of the difficulties. In many instances, disclosure of the diagnosis will be a process rather than an event,<sup>32</sup> enabling the person to absorb and assimilate the information at a suitable pace. A dialogue that allows the person and family to plan ahead for potential eventualities, whilst function, competence and self-esteem are maintained in the present, contributes importantly to adjustment. Even the person who copes by living one day at a time can be encouraged into contingency planning by the knowledge that the outcome is uncertain rather than inevitable.

## PSYCHOSOCIAL INTERVENTIONS

Although the AChE inhibitors represent a step forward in treatment and management of dementia, they are only part of the available options. Indeed, many people with dementia do not fall within the NICE guideline definitions (not having Alzheimer's or being too impaired), or do not respond (the number needed to treat for one person to benefit is typically between 3 and 7).<sup>33</sup> A range of psychosocial approaches can be offered, primarily targeted at the family. Although the evidence on interventions to support families is mixed,<sup>34</sup> the conclusion from major studies is that a combination of family meetings and peer support is effective in reducing care-giver strain and delaying institutionalization,<sup>35–37</sup> and that the best outcomes are achieved by multidimensional interventions individually tailored to carer needs.<sup>38,39</sup> Cognitive rehabilitation—using for example memory aids and training—has been applied with promising results in mild/moderate dementia.<sup>40</sup> There is evidence that cognitive stimulation improves cognitive function,<sup>41</sup> and reports of a randomized controlled trial indicate that memory rehabilitation adds to the efficacy of AChE inhibitors.

The emotional adjustment of the person with dementia is probably no less important than cognitive function itself. Cognitive and behavioural therapies can aid adjustment to the diagnosis and improve depressed mood.<sup>43–45</sup> Increased

awareness of these psychosocial interventions will encourage their further commissioning and development. Memory clinics provide an excellent setting for their implementation.<sup>46</sup>

## MEMORY CLINICS AND PRIMARY CARE

There are already suggestions that carers benefit when a memory clinic provides feedback on the assessment, when family conferences are offered,<sup>47</sup> or when sharing of the diagnosis is followed by a home-based psychoeducative and skills training intervention.<sup>44</sup> Memory clinics that offer only access to pharmacological treatments are missing an opportunity to offer individual support that can prevent future distress for both patient and family.<sup>32,44</sup> Memory clinics at the interface of primary care could also allow research in people with minimal cognitive impairment,<sup>11</sup> which affects 50% of older people<sup>48</sup> and has been associated with excess mortality.<sup>49,50</sup> There remains scope for memory clinics to develop liaison intervention within primary care,<sup>32,44</sup> and this has already occurred with the AChE inhibitors, where some services have established shared-care protocols with GPs. Establishment of liaison memory clinic services in primary care might encourage the timely detection of dementia by GPs, especially if the services embraced the full range of rehabilitative and support packages outlined above.

## CONCLUSIONS

Meeting the expectations about dementia care raised by the NSF will be difficult for general practice, and memory clinics may help GPs to achieve timely recognition and intervention. Memory clinics are most effective when they have close working relationships with primary care.

*Note* Other members of the INTERDEM group are Dr Linda Clare (UK); Professor Frans Verhey (The Netherlands); Geraldine Kenny (Ireland); Professor Jan De Lepeleire (Belgium); Inge Cantegeil-Kallen (France); Dr Barbara Romero (Germany); Dr Ramiro Verissimo (Portugal). This paper was drafted at an INTERDEM meeting co-funded by the European Commission.

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