

## Article

# Optimising primary care for people with dementia

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## ABSTRACT

This review considers key areas in primary care regarding the diagnosis of dementia. Issues surrounding assessment, policy and incentives are considered. In addition, the relevance of non-medication approaches for dementia in primary care, which aim to enhance or maintain quality of life by maximising psychological and social function in the context of existing disabilities, is deliberated. Finally, key issues about primary care medication management are considered, and relevant therapeutic strategies with recommen-

dation for a collaborative approach that improve outcomes by linking primary and secondary healthcare services – including general practice and pharmacy – with social care needs are weighed up. A key aspect of such a collaborative approach is to support informal carers in optimising medication.

**Keywords:** dementia, diagnosis, medication, primary care, psychosocial

## Optimising primary care for people with dementia

The theme of World Mental Health Day 2013 is 'mental health and older adults'. Keeping with this theme, this paper reviews the current key issues

surrounding primary care for people with dementia (PWD).

## Dementia and primary care

Dementia is one of the leading causes of disability among older people and its prevalence doubles every 20 years with costs estimated at 1% of global gross domestic product. The needs of PWD are chronic and cumulative and require support from health and social care as well as from family caregivers or carers.

The societal impact of dementia is enormous<sup>1</sup> and the benefits of prioritising earlier recognition of patients have been well rehearsed.<sup>2</sup> These include an anticipation of the future needs of patients and families and access to early interventions. The role of psychosocial interventions and the use of medication in primary care for PWD offer significant benefits in improving care.

### Effective diagnosis

The diagnosis of dementia can be delayed by the insidiousness of the symptoms and the perceptions by both patients and general practitioners (GPs) that it may be just a sign of normal ageing.<sup>3</sup> General practice is usually the first point of contact for patients with memory problems or other symptoms of dementia; however, GPs appear reluctant to use brief cognitive tests and to refer patients for early assessment.<sup>3</sup> In UK practice, the early recognition and diagnosis of dementia by GPs is variable, with widespread underdetection reported.<sup>4,5</sup> About 30% of older people report concerns with their memory<sup>8</sup> with between 40% and 80% of dementia cases undiagnosed in primary care settings, which consequently go untreated.<sup>6,7</sup>

Primary care clinicians and caregivers often fail to recognise and respond to symptoms of memory problems,<sup>9</sup> but there is evidence that people want earlier diagnosis,<sup>10</sup> with younger professionals perceiving its worth<sup>11</sup> and the National Dementia Strategy emphasising the importance of early diagnosis.<sup>12</sup>

The barriers to the diagnosis of dementia can be considered to be the following.<sup>13</sup>

- 1 *Practitioner knowledge and attitudes*: a lack of confidence and associated risk averseness, therapeutic nihilism, negative attitudes towards the potential benefits of detecting and managing dementia, paternalistic attitudes and believing that people with dementia do not wish to know their diagnosis.<sup>14,15</sup>
- 2 *Organisation or system failures*: the failure of organisations providing clinical care to prioritise the diagnosis of PWD.

3 *Incentives* (Table 1): incentives are not sufficiently embedded in education<sup>16</sup> and there is a failure of targeting incentives in healthcare.<sup>17</sup>

4 *Access to ongoing care*: a lack of access to resources, for example social services and third sector services.

In primary care there is a need to develop training in assessment so that clinicians are more aware of dementia to deliver a timely diagnosis.<sup>18</sup> Focussing on practitioner knowledge has shown that primary care recognition can be enhanced; however, this does not always result in greater adherence to practice guidelines.<sup>19</sup> Education without a practitioner needs assessment, otherwise facilitation of system change does not improve performance or health outcomes<sup>20</sup> and it is suggested that small group education is important.<sup>21</sup> A 'whole system' approach has been advocated to improve self-management of long-term conditions, but interventions have limited impact on patient outcomes.<sup>22</sup>

### Screening versus case finding

The North of England Evidence Based Dementia Guideline Development Group states that 'population screening for dementia in the over 65s is not recommended; a case finding approach is recommended'. It makes the recommendation that 'general practitioners should consider using formal cognitive testing to enhance their clinical judgment'.<sup>23</sup> However, the development group fails to recommend which tests to use and how often to use them throughout the elderly population at risk. Although this group, despite its name, makes recommendations based on the clinical opinions of GPs, recommendations based on evidence are given more weight by most US organisations.<sup>24</sup>

### Case finding and diagnostic tools

A number of simple tools are available for use in the community to make an initial assessment of a patient's cognitive function.<sup>25</sup> The most commonly used cognitive assessment tool is the Mini-Mental State Examination (MMSE);<sup>26</sup> marked out of 30, a score of less than 25 is suggestive of dementia. However, this examination can take up to 20 minutes to complete and may not be practical for use within a primary care consultation, which is usually allocated just 10 minutes. Additionally, costs can be involved, which is a disincentive for using it. The General Practitioner Assessment of Cognition (GPCOG),<sup>27</sup> and two other cognitive screening tests, the Mini-Cog Assessment Instrument<sup>28</sup> and the

**Table 1** Primary care reimbursement systems<sup>17</sup>

Country	Predominant reimbursement mechanism	Pay-for-performance
Australia	Fee-for-service	Practice Incentives Program (PIP) Service Incentive Program (SIP)
Canada	Fee-for-service majority Some states mixed salary/capitation	
England	Capitation	Quality and Outcomes Framework (QOF)
Germany	Fee-for-service	
The Netherlands	Capitation	
New Zealand	Subsidised services: capitation Private services: fee-for-service	
Sweden	Salary	
USA: Medicare	Fee-for-service Some states considering capitation	Physician Group Practice Demonstration (PGPD)
USA: non-Medicare	Insurance-based system 60% of commercial health maintenance organisations (HMOs) pay-for-performance programme	

Memory Impairment Screen (MIS),<sup>29</sup> have been found to be as clinically and psychometrically robust and more appropriate for use in primary care than the MMSE. The GPCOG is estimated to take five to seven minutes to complete, with questions for both the patient and carer to answer, making it more relevant for primary care physicians.<sup>27</sup> An alternative, developed in primary care, is the Six Item Cognitive Impairment Test (6-CIT), which performs as well as the MMSE but is easier to use.<sup>30</sup> The addition of a clock-drawing test may also be a useful quick and simple test for the GP to use.<sup>31</sup> A recent systematic review<sup>32</sup> suggests that if length is not a major consideration, the MMSE may remain the best tool for primary care clinicians who want to make a diagnosis.

Technology platforms such as diagnostic support aids offer an important solution but need further research as there are accuracy and reliability issues with subsequent help-seeking behaviours reduced due to false-negative (and thus reassuring) results, or generating unnecessary distress with false-positive results.<sup>33</sup>

## Incentivising care

In the UK, the introduction of the Quality Outcome Framework (QOF) pay-for-performance system in 2004 should have led to a reduction in variations in diagnostic rates of dementia, but this has yet to be demonstrated because of differences in strategies to improve awareness and detection, and characteristics of secondary care systems.<sup>34</sup> The incentive may not be sufficient to support the time required and integration is key to manage resources to ensure a timely delivery.

From 2013, the Department of Health in England has directed the NHS Commissioning Board to develop a new directed enhanced service (DES) to improve diagnosis of at-risk patients for dementia. The purpose of the 'Dementia Case Finding Scheme' is to develop a proactive approach to the assessment of patients who may be showing early signs of dementia and to support improvements in the early diagnosis and care of such patients. The following groups of patients registered with a GP will be offered an opportunistic assessment to detect early dementia and refer for diagnosis and management (Box 1).

### Box 1 Case-finding of patients under the DES<sup>35</sup>

- Over the age of 60 with cardiovascular disease, stroke, peripheral vascular disease or diabetes
- Aged 40 and over with Down's syndrome
- Aged 50 and over with learning disabilities
- Those who have long-term neurological conditions with a neurodegenerative element such as people with Parkinson's Disease.

## Opposition to the DES

There has been significant opposition to the introduction of this new initiative including an open letter to the prime minister and chief medical officer for England, which was published in the *British Medical Journal* in 2012.<sup>36</sup> The letter cited a recent systematic review that found there was insufficient evidence to show that medical treatment aimed at modifying cardiovascular risk factors prevents cognitive decline or dementia in the elderly population.<sup>37</sup>

Other commentators describe the narrative around the 'epidemic of dementia'<sup>38</sup> and suggest that researchers, healthcare professionals and politicians are effectively competing for 'social capital'. Pierre Bourdieu's definition of 'capital' extends far beyond the notion of material assets to capital that may be social, cultural or symbolic.<sup>39</sup> In addition, opponents to a case-finding approach for dementia remind us that the diagnosis of dementia entangles a plethora of ethical issues, including overestimating the effects of current pharmaceutical treatment options and not balancing benefits and harms (side-effects), underestimating the relatives' experiences and capacity to care for the person with dementia and patient autonomy.

It is too early to draw conclusions from this new initiative yet, either for England or for other countries. If properly evaluated however, and depending on the outcome, implementation of the model with incentivising of case finding for dementia might be considered by other healthcare systems.

## Summary

A correct early diagnosis of dementia may be appreciated by patients even without disease-modifying treatment, and a diagnosis could be valuable since it allows informed planning for the future.

At worst, the diagnosis could lead to stigmatisation and result in feelings of hopelessness and despair. The role of the clinician and the patient's support structure, such as family members, relatives, friends and other members of the 'dementia-friendly' community, will be to mitigate against this. Certainly, the ethical consequences in a false-positive diagnosis should be considered. The label may cause unnecessary worry and this could be perceived as infringing on the basic medical ethical principle of non-maleficence, accurately summarised in the Latin phrase *primum non nocere* (first, do not harm).

## Psychosocial interventions in primary care

Psychosocial interventions in dementia are non-pharmacological approaches involving interactions between people to support cognition, emotion, meaningful activity, interpersonal relationships and a sense of control. They aim to enhance or maintain quality of life by maximising psychological and social function in the context of existing disabilities.<sup>40</sup>

For people living at home, the best effects are seen when interventions are combined to meet the needs of both the person with dementia and their family carer,<sup>41</sup> although many interventions have a strong bias towards supporting the family carer.<sup>42,43</sup> This may be due to the huge influence that families have in the management of a relative with dementia, as is seen even in the arena of the 'potential for inappropriate medication usage', where family carers can strongly influence the inappropriate use of drugs for both their relative and themselves.<sup>44</sup> Studies in primary care suggest that supporting the patient without due consideration of the family can result in increased carer distress and poorer overall outcomes for both patient and carer.<sup>45</sup>

Effective psychosocial interventions are usually multi-component, individualised and targeted to the context and personal needs of both the patient and the family.<sup>43</sup> In care homes they can involve wide-ranging components such as the environment and leadership in the home as well as interventions that are individualised to meet the particular needs of the person with dementia.<sup>46</sup> A range of individually tailored approaches have been developed,<sup>47</sup> including cognitive stimulation, cognitive rehabilitation, reminiscence therapy, emotion-based care and adaptations from standard psychological therapies such as cognitive behaviour therapy (CBT) which can be used with the person and/or the carer<sup>48,49</sup> to reframe experiences of dementia and

thus improve quality of life and coping with the condition. Other approaches include involving pets, music, dance, exercise and art therapies, although the evidence for these has yet to be established. Group-based support in dementia care is an intuitively popular approach that does not come with a strong evidence base.<sup>47</sup> An exception is Cognitive Stimulation Therapy (CST), an activity and discussion group therapy that aims to improve quality of life by enhancing cognitive and social functioning.<sup>50-52</sup> Originally developed in care homes and day centres it has now been translated into wide-ranging community settings with an ongoing large-scale evaluation.<sup>53</sup> In the UK it has been recommended 'for all people with mild to moderate dementia' (see the NICE Guideline for Dementia<sup>2</sup>), although not all PWD want to engage in group therapy. Psychosocial interventions to help PWD and families adjust to changing roles and relationships and learn ways to minimise the impact of dementia are an important focus for those in dementia care.<sup>54</sup> Individualised interventions such as cognitive rehabilitation<sup>55</sup> and occupational therapy,<sup>56</sup> usually involving family or friends helping the person with dementia achieve their goals in life, remain an important avenue for the future of psychosocial interventions in dementia care. These approaches can also have components to meet the needs of the family carer(s).<sup>56</sup>

The application of psychosocial interventions in primary care often focus on educational interventions for practitioners,<sup>57</sup> although studies of the quality of care in primary care suggest more psychosocial approaches can be undertaken,<sup>57,58</sup> even though carefully developed quality indicators for the delivery of dementia care currently exist.<sup>59</sup> This may be due to the paucity of understanding of psychosocial interventions in community settings.<sup>60</sup> Information provision is seen as key to dementia care support<sup>48</sup> but this does not appear to be timely or tailored to the continuing needs of patients and their families.<sup>61</sup> This may be because of the application of a medical management model,<sup>60</sup> where a social disability framework for delivering support in primary care is more relevant in guiding dementia care practice.<sup>48,60</sup>

Collaborative primary care-based interventions supported by specialist practitioners and personalised to the individual and/or the family carer show huge promise. In some parts of the world improvements have been demonstrated in the quality of care and management of behavioural problems associated with dementia<sup>62</sup> and in carer distress.<sup>63</sup> These interventions can also prevent depression in PWD.<sup>64</sup> However, translating such evidence for psychosocial interventions into routine practice in both primary and specialist community care is a key

challenge because landmark interventions developed in one setting do not necessarily translate successfully in other settings.<sup>65</sup> This does not mean that there is no hope for the wide-spread delivery of psychosocial interventions in primary care. Encouraging examples of specialist support practitioners, such as health visitors to manage patients and families in primary care exist.<sup>66</sup> Furthermore, communication with the GP is valued by older patients; this influences their quality of life<sup>67</sup> and may also enhance the timely uptake of available psychosocial interventions by PWD.<sup>68</sup>

### Effective medication management

PWD are commonly prescribed complex regimens, containing both psychotropic and physical medication and effective medication management is a key element of providing optimal primary care for PWD.<sup>69</sup> The current focus has been on the use of antipsychotics to treat behaviour that challenges – also called behavioural and psychological symptoms in dementia (BPSD) – and the National Dementia Strategy targeted a reduction in such usage by two-thirds.<sup>70</sup> However, focussing solely on a single medication may be counter-productive and could simply transfer prescribing to other equally inappropriate treatments, including benzodiazepines.<sup>71</sup> If treatment for BPSD is required because there is a risk of harm to the person with dementia or others, guidelines from the Alzheimer's Society should be followed.<sup>72</sup> These guidelines recommend a short course of the only licensed product, the antipsychotic risperidone, commenced at a low dosage, continuously reviewed and prescribed for up to six weeks. More generally, effective medication management in dementia is much broader than just the appropriate treatment of BPSD and support for carers and wider aspects of iatrogenic disease in dementia is considered below.

Family members and other informal carers of older people have a key role in ensuring safe medication management.<sup>73</sup> PWD may rely upon informal carers to manage their medication and these carers may conduct various medication management activities including noticing and managing side-effects and deciding whether to administer medication.<sup>73</sup> The role of informal carers increases as dementia in the patient progresses and places significant strain on such carers.<sup>74</sup> Furthermore, the greater the number of medication management activities, the worse the mental health and social functioning of the informal carer.<sup>73</sup> This burden appears to be mostly hidden from health and social care professionals and clinical support mechanisms,

possibly involving community pharmacists, need development.<sup>69,71</sup>

Primary care clinicians should be aware that dementia increases the likelihood that key risk factors – including inappropriate prescribing, old age, adherence issues, drug interactions, comorbidity and polypharmacy – for medication-related adverse events are present.<sup>75</sup> Despite this, there has been little research on the causes, prevalence and clinical consequences of both medication errors and adverse drug reactions in PWD.<sup>76</sup> Medication errors may be more common in PWD because of the involvement of multiple health and social care professionals; the primary–secondary care interface may be particularly risky.<sup>76,77</sup> Cognitive impairment may make PWD less likely to query a change in medication, be less aware of potential side-effects and of whether monitoring is required, therefore making them less likely to identify a potential medication error.<sup>76,78</sup> This cognitive impairment and resultant lack of capacity places a greater burden on clinicians and carers to ensure safe medication management.<sup>79</sup>

Specific factors including frailty and multimorbidity may increase the risk of adverse reactions.<sup>75</sup> Falls are a major cause of injury in older people and 14 000 people die annually from osteoporotic hip fractures.<sup>80</sup> Psychotropics including antidepressants, antipsychotics and benzodiazepines fall into one of the main groups of medicines associated with falls. NICE guidance found that psychotropics increased the risk of falls by an odds ratio of 1.66 (1.40–1.97).<sup>81</sup> Polypharmacy is also a risk factor for falls and older people should have regular medication reviews. If possible, psychotropics and other unnecessary medicines should be discontinued to reduce the risk of a fall. There is also increasing evidence that treatments specifically administered for the symptoms of dementia cause falls. Acetyl cholinesterase inhibitors cause bradycardia, increasing the risk of syncope and hip fracture.<sup>82</sup> If family carers are not aware of the potential link, they may continue to administer acetyl cholinesterase inhibitors despite a recent history of falling in the patient.

To summarise, safe and effective medication management in dementia is complex and difficult to achieve. A collaborative approach that improves outcomes by linking primary and secondary health-care services – including general practice and pharmacy – with social care needs to be developed. A key outcome of such a collaborative approach would be to support informal carers to optimise the management of medication.

## Conclusion

Primary care is pivotal to the delivery of good quality assessment and care for PWD. There is a need for greater dementia-specific awareness through education and the organisation of systems both within practices and across interfaces between organisations. There are specific areas that need addressing to improve care of PWD in primary care.

- 1 Standardising assessment tools and the use of technology to facilitate early diagnosis.
- 2 Better awareness of the benefits of psychosocial interventions in primary care for PWD.
- 3 Improved understanding of the use of medication by PWD and an enhancement of supportive strategies for patients and carers.

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#### CONFLICTS OF INTEREST

None.

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