RCGP Policy Position Statement on the role of general practice in the identification and treatment of people with dementia

Introduction

There is a growing public debate involving patients, carers clinicians and politicians about whether people with dementia in the UK are receiving the best possible diagnosis and treatment. A number of voices within this debate have argued that there is a need to improve diagnosis and management of dementia in general practice. As well as receiving significant media attention, the issue has also risen up the political agenda and is considered a priority by both the Prime Minister and the Secretary of State for Health. The debate has not been confined to England and is relevant to health services across the UK.

With an ageing population, the number of people with dementia is projected to rise exponentially, which will place an increasingly heavy burden on families, carers and health and social care systems. There are around 800,000 people with dementia in the UK, and the disease costs the economy £23 billion a year. By 2040, the number of people affected is expected to double - and the costs are likely to treble. Dementia is also a global health problem and public health measures to reduce contributing factors such as cerebrovascular disease and diabetes are of paramount importance. The RCGP has already taken action to respond to this growing clinical challenge posed by dementia by creating a clinical priority in this area and appointing two Clinical Champions for Dementia from 2012-15.

This paper aims to establish the basis for an agreed RCGP policy position – informed by and closely linked to the College’s clinical work in this area – a policy position that can be used to engage in public debate about the diagnosis and management of dementia in general practice and provide advice and support to our members.

Diagnosis of dementia – towards earlier and more accurate diagnosis

Cognitive impairment has many causes, and the transition from its onset into a stage where a definitive diagnosis can be made is complex. Whilst Alzheimer’s disease [AD] has been a significant focus of research to date, this is only one cause of dementia – other causes include vascular dementia and Parkinson’s disease as well as the recognised associations with Down’s Syndrome [up to 75% at age 60 or older] and Learning Disabilities [up to 20% over the age of 65 meet the criteria for diagnosis]. Distinguishing between dementia and age related memory loss can also add to the complexities in diagnosis.

There is some evidence to suggest that fewer than 50% of people over 65 years with dementia currently receive a diagnosis. UK research, via retrospective GP case note review, has revealed that the average time from patient presentation to dementia diagnosis is ~18 months but can be up to 4 years. This conceals significant variation in diagnostic rates, the causes of which are not yet fully understood. Attention has been focused on differences in the number of cases diagnosed by different practices; although this may, to some extent, be partly the result of demographic and socio-economic variations.

Early diagnosis of dementia is a challenge: the difficulties in making a definitive diagnosis at an early stage of the condition partially influences the length of the diagnostic pathway although other contributing factors including persistent widespread diagnostic stigma, the need to treat co-morbid conditions, and the importance of excluding treatable (and reversible) causes of memory disturbance such as depression or megaloblastic anaemia are also important. In addition, a lack of ability and confidence in this clinical area by GPs as well as previous restrictions on access to pharmacological treatments, have also contributed to the challenge of early accurate diagnosis.
It is clear that the early onset of memory problems with impaired cognition presents one of the biggest diagnostic challenges for GPs; however as the disease progresses diagnosis becomes increasingly straightforward using a combination of clinical assessment and scanning. There is some evidence that GPs may opt for a period of “watchful waiting” before referring patients for specialist assessment and this may be an appropriate strategy, especially in early stage disease if there is very minimal effect on daily living and function or in people with multi-morbid conditions that complicate the presentation of cognitive impairment. One study found that GPs have considerable difficulty identifying those with Mild Cognitive Impairment (MCI) and mild dementia and generally do not record such diagnoses in medical records; in contrast for moderate–severe disease, GPs are more successful and able to identify about 8 in 10 cases. In addition, GPs’ decisions on when to refer on for assessment may be influenced by their knowledge of the local availability of assessment services which in many areas remain insufficient to meet demand.

**Treatment for people with dementia**

The current pharmacological treatment available for the symptoms of cognitive deterioration caused by Alzheimer’s disease (AD) is the use of acetylcholinesterase inhibitors and the NMDA receptor antagonist, memantine, although the evidence for their effectiveness is mixed and shows that the cholinesterase inhibitors are most effective in mild and moderate AD and memantine in moderate and severe forms of the disease. A recent systematic review of the benefits of cholinesterase inhibitors supported this observation that the effectiveness of pharmacotherapy in AD was dependent on the stage of the disease, being negligible in late stage disease. Both cholinesterase inhibitors and memantine are currently only available to people with AD. However, their use in the mild to moderate stages of dementia has been shown to be cost effective and a recent UK trial also revealed that their continued use in the advanced stages of the disease may be more beneficial than originally thought. The evidence for the use of some non-drug treatments, such as cognitive stimulation and tailored activities, is also strong.

This growing body of evidence underlines the importance of earlier diagnosis of dementia as well as the appropriate recognition and coding on Dementia Registers of the subtypes of dementia. However, although there is some evidence for these interventions stabilising the worsening of symptoms in the different stages of AD, the ultimate progression of the underlying disease is not affected. The best current interventions for AD and other dementias are still based on symptomatic improvement and relatively little has been achieved in terms of tangible [i.e. functional] outcomes for people with dementia.

Earlier diagnosis can enable people with dementia and their families to make more informed choices and decisions about their future care – advance care planning – whilst they still have the capacity to do so. However, not every person with dementia will find the advantages of an early diagnosis outweigh the possible disadvantages. The 2009 Nuffield Council on Bioethics’ report provides a useful moral argument in this area, stating that: “there is a distinction between early and timely diagnosis” and that if a person’s wellbeing is not enhanced by receiving a diagnosis, then it should not be forced upon them.

There are very few empirical studies which have directly observed the process of diagnosis disclosure by professionals – although in some cases this was associated with short term distress, the majority of people did not appear to suffer negative emotional long term consequences. A systematic literature review looking at patient and family experiences of receiving a diagnosis of dementia found that the majority of people wished to know their diagnosis. Most studies show that people express a preference for progressive disclosure with ongoing support.
Screening for dementia

There is no evidence to support the general screening of the population for dementia. Non selective application of a diagnostic test to the whole population above a given age threshold risks generating large numbers of false positives because of the relative low prevalence and in addition would also be likely to increase unnecessary referrals from general practice to secondary care. This view is supported by the National Screening Committee who have said that such a population approach does not meet the scientific criteria for the introduction of a screening programme.26

Any screening of populations at risk for dementia should be clinically, socially, and ethically acceptable to health professionals and the public. Little research is available on questions such as the effect of false-positive screening results for dementia on individuals and their families. One US dementia screening and diagnosis programme showed that patients had high refusal rates for dementia diagnostic workup following positive screening results. Refusals were associated with ethnicity, age, and perception of dementia symptoms. If any benefits of unselected population screening do exist, refusal of further testing could attenuate those benefits. Recent studies have also found perceived negative effects of dementia screening on patients’ living independence, driving privileges, or insurance policies. Costs need to be considered for the individual as well as for the health care system, which needs to balance the expense of screening with medical care expenditures as a whole, giving attention to the relative costs allocated to primary, secondary, and tertiary prevention of the disorder as well as to the other common conditions that cause morbidity but are under-resourced.

Principles

When considering how services should be organised and delivered to achieve the best possible outcomes for dementia patients, the following principles should be used to underpin the development of services:

- Approaches to diagnosis and treatment must be shaped first and foremost by the needs and expressed wishes of the individual patient, their families and carers.
- Interventions to improve the accuracy and timeliness of diagnosis, in particular in the early stages of the disease, and efforts to increase diagnostic rates must be based upon the best possible evidence with regard to the effectiveness and efficiency of different ways of doing this. Routine screening of an unselected population is not supported by the evidence.
- Recognition and treatment of other causes of cognitive impairment is a key role of general practitioners and other health professionals working in primary care.
- Clinicians need to be equipped with the skills and knowledge to identify those people who require further assessment in order to enable an early, more timely and accurate diagnosis and make appropriate referral decisions in conjunction with the patient, families and carers.
- Co-ordination of approaches for referral, assessment, and treatment in particular across the boundary between health and social care is essential.

Proactive case finding as well as appropriate and timely reactive care

In summary, there is a continuing debate about the relative value of proactive and reactive approaches to the earlier and more accurate diagnosis of dementia, in particular in the early stages of the disease.
A proactive risk stratification case finding approach, however, is a pragmatic solution to the challenge of earlier and more accurate diagnosis, to be followed by appropriate referral for assessment and initial treatment by secondary care services. How might this be achieved?

Proposed Directed Enhanced Service

Preliminary proposals by the Department in England include a Directed Enhanced Service [DES] for dementia in general practice. These involve provision for a dementia plan, the purpose of which is “to ensure that …. systems [are] in place to enable a proactive approach:

- In respect of the assessment and diagnosis of those patients who are at risk and may present the early signs of dementia
- To improve the manner in which dementia is diagnosed including the promptness in diagnosis and in the care and support given to such people who are diagnosed as suffering from dementia”

QoF Indicators

The proposed new indicators for the 2014/15 Quality and Outcomes Framework [QoF] include the following for dementia:

1. The percentage of patients with dementia with the contact details of a named carer on their record*
2. The practice has a register of patients who are carers of a person with dementia*
3. The percentage of carers [of a person with dementia] who have had an assessment of their health and support needs in the preceding 12 months*
4. The percentage of patients with a new diagnosis of dementia [after October 1st 2012] who have attended a memory assessment service up to 12 months before the date of diagnosis**

* Supported with qualifications
** Not supported. Achieving this is dependent on services outside GP control. For example, waiting times in the North East are now 4-6 months – something for which GPs should not be penalised.

High risk groups for case finding

For case finding in high risk groups to work, we need firstly to consider which patient subgroups are known to be at high risk of developing dementia.

Studies vary in their estimates, but indicate that as many as 20% of those over the age of 65 with learning disabilities meet the criteria for dementia27, compared to the 1% prevalence rate in the general population at the same age from the Eurodem Consortium28. However, for people with Down’s syndrome the rate is much higher. Studies have indicated that the prevalence rate can be as high as 75% at age 60 years or older29.

The relative risk of patients with Parkinson’s Disease (PD) developing dementia is 5.1 times that of the controls (95% CI, 2.1–12.5). Increasing age, later age of onset of PD, longer duration of PD symptoms, the presence of hallucinations, and impairment of memory and language function are all predictive factors for the development of dementia in patients with PD30.
Dementia case finding might also be targeted specifically at those living in residential care homes and nursing homes. It has been estimated that between 36.5% and 54% of those with dementia live in care homes.

**Routine Health Checks**

Practices are currently incentivised under QoF to carry out routine health checks for some categories of patient with long term conditions. This provides an opportunity to proactively case find for possible dementia. However, such assessment should be limited to groups of patients at high risk of developing dementia, for instance people with learning disabilities.

**Reactive Diagnosis**

Although there is a role for proactive case finding, reactive diagnosis will continue to be key. Where patients and/or their families present with symptoms of possible dementia, it is vital that action is taken as soon as possible to exclude any treatable causes of dementia and to refer on if appropriate for more detailed assessment to confirm the diagnosis.

**Proposed Policy Recommendations:**

1. Support risk profiling and case finding in principle – but not general screening of the practice population
2. Support the introduction of an appropriate Directed Enhanced Service (DES) for dementia, based on the principles set out above
3. Support the continuing development of QOF indicators for dementia based on earlier, more accurate diagnosis and the principles outlined above

**Approved by RCGP Council February 2013**

1 Unlocking Diagnosis: The key to improving the lives of people with dementia. All-Party Parliamentary Group on Dementia report 2012. It should be noted that this Parliamentary Group is provided with secretarial support from the Alzheimer’s Society, and should not necessarily be considered an impartial contributor to the debate around dementia. The RCGP issued a press release in response to the Group’s report which is available online here: [http://www.rcgp.org.uk/news/2012/july/rcgp-response-to-appg-report-on-dementia.aspx](http://www.rcgp.org.uk/news/2012/july/rcgp-response-to-appg-report-on-dementia.aspx)
2 The Prime Minister’s Dementia Challenge, launched in March 2012 outlines a number of commitments including increasing diagnosis rates: [http://dementiachallenge.dh.gov.uk](http://dementiachallenge.dh.gov.uk)
3 Jeremy Hunt: attitudes towards dementia need to change - Health secretary says doctors are refusing to carry out tests because they believe it is pointless. Guardian, 15th Jan 2013: [http://www.guardian.co.uk/society/2013/jan/15/jeremy-hunt-attitudes-dementia](http://www.guardian.co.uk/society/2013/jan/15/jeremy-hunt-attitudes-dementia)
6 RCGP Clinical Priority on Dementia: [http://www.rcgp.org.uk/clinical-and-research/clinical-resources/dementia.aspx](http://www.rcgp.org.uk/clinical-and-research/clinical-resources/dementia.aspx)
Why so little progress? Perhaps there has been too much focus on findings that might be the product of a selection bias for people with dementia who have been admitted into various clinical services. There is the real danger of residual confounding or inadequate attention to the fact that apparent protective factors might only be markers for some other less measurable, more fundamental, mechanism for risk or protection. This mistake has been made for other disorders: most apparently, hormone replacement therapy seemed to have a protective effect against heart disease in observational studies, but in trials was shown to cause harm. The same has also happened for Alzheimer’s disease - e.g. in trials of anti-inflammatory drugs, and vitamin-based and endocrine-based interventions. Current drugs for treating dementia modify symptoms but not the disease. Medications to enhance cognition are approved in the United States only for AD and Parkinson disease dementia (PDD); their use is even more limited in the United Kingdom. Some individuals receiving cholinesterase inhibitors (for AD or PDD) or the N-methyl-D-aspartate receptor antagonist memantine (for AD) have improved cognitive and functional scale scores. However, changes in scale scores are difficult to translate into clinical gain. Nonpharmacological therapies such as psycho-social interventions are reported as effective, but similar caveats apply as with medication. Many preventative approaches would be better aimed at the total older population to shift the entire risk distribution.


The UK NSC policy on Alzheimer’s Disease screening in adults (Jun 2010). Available at: http://www.screening.nhs.uk/alzheimers


Dementia UK (2007), Dementia UK: A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King’s College London, for the Alzheimer’s Society. London: Alzheimer’s Society.