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DIAGNOSING DEMENTIA

Dementia currently affects 700,000 people in the UK, yet only 1 in 3 cases receives a formal diagnosis from a doctor.[1] Dementia costs the UK economy £17bn a year and is one of the main causes of disability in later life. A key aim of the Department of Health's 2009 National Dementia Strategy is early diagnosis. This is intended to improve quality of life through increased support, prevention of harm and reduction in care home admissions. This briefing outlines current diagnostic practices, research into newer tools and service provision proposals that aim to increase early diagnosis.

Background

Dementia is a syndrome characterised by the progressive loss of cognitive function. Abilities most affected include memory, reasoning, language, orientation and attention. Patients can show disturbed behaviour and personality changes and have communication problems. In the later stages patients are unable to feed, dress or wash themselves and are highly dependent on carers. There is no cure for dementia and it ultimately results in death.

- The prevalence of dementia rises with age, affecting 1 in 14 people over 65, rising to 1 in 6 in those aged 80 and over.
- With an ageing population, the number of cases in the UK is predicted to rise to 1.4m within 30 years.[2]
- It is estimated that 47% of the UK population (~25 million people) know a family member or close friend with dementia.

Causes of Dementia

Many diseases can cause dementia and while not fully understood, all result in structural and chemical changes in the brain that lead to cell death. The most common subtypes are Alzheimer's disease (AD) and vascular dementia. In advanced age, it is likely that more than one subtype occurs at the same time (mixed dementia). The majority of late-onset dementias (occurring after the age of 65) are not inherited, although some genetic markers have been identified. For example, the ApoE 4 gene is a risk factor for late-onset AD and is associated with one third of cases. Very rare subtypes like Huntingdon's disease are inherited and affect people at a younger age.

Dementia Policy across the UK

A key objective of current UK dementia policy is to improve diagnosis, especially in the early stages.

- The National Dementia Strategy (NDS) for England published in 2009 focuses on three main areas: improving public understanding and awareness, early diagnosis and intervention and quality of care.[3]
- The Scottish government is developing its Dementia Strategy for April 2010 and has made improving early diagnosis a key target for the NHS.
- Wales has recently finished the consultation process on its National Dementia Plan, which aims to ensure a 'timely' diagnosis.

Current Diagnostic Practice

There is no conclusive diagnostic test for the majority of dementias, except by post-mortem examination of brain tissue. Diagnosis is made after assessment using several tools (Box 1) and standard criteria, which include progressive decline in more than one area of cognitive functioning and significant impairment to daily living.

Patients tend to see a GP when they, or more commonly, their carer, notice memory problems and/or decline in function. Diagnosis requires a detailed history from the patient/carer, physical and mental examination and cognitive tests to quantify the degree of impairment. Guidance from the National Institute for Health and Clinical Excellence (NICE) outlines that patients should be referred to specialist services for more detailed tests, diagnosis and treatment. Where family history suggests that dementia is inherited, counselling and genetic testing should be offered. While no drug can slow or reverse dementia, there are treatments (psychological, social, and educational as well as pharmacological) that can help. Diagnosis of subtype is important since some drugs can alleviate certain symptoms of AD while others can cause severe side-effects for patients with other subtypes.

Box 1. Tools for Diagnosing Dementia

Clinical guidelines issued by the National Institute for Health and Clinical Excellence (NICE) state that a diagnosis should be made after;

- **detailed history** from the patient and relative/carer;
- **cognitive and mental state examination** that includes brief cognitive tests, such as the widely used Mini Mental State Examination, and assessment of psychological, behavioural and functional symptoms;
- **medical examination** to exclude reversible causes of cognitive impairment such as depression, infection, adverse medication reaction or drug/alcohol abuse**;**
- **brain imaging** to exclude treatable causes of cognitive impairment such as brain tumours or abscesses and to aid the diagnosis of subtype. There are two types of brain imaging: 'structural' and 'functional'. Techniques used are **CT** scans (computerised tomography), which are the most widely available, and **MRI** scans (magnetic resonance imaging), which are more expensive but provide superior images.

NICE guidelines recommend structural brain imaging in every case, however only 1 in 3 people is scanned as part of his/her diagnosis. Access to functional imaging is limited and mainly used for research purposes (see Issues section).

Future Prospects for Early Diagnosis

Current policy is aimed at increasing 'early' diagnosis – when symptoms of dementia first become noticeable or a 'timely' diagnosis, at the point when the condition begins to have an adverse impact on the lives of patients and carers. To aid early diagnosis, more sensitive assessment criteria are being developed with the help of new diagnostic tools. Research is also focused on tools to:

- detect the 'pre-symptomatic' stages, as the underlying damage is likely to occur long before any symptoms manifest (up to 30 years);
- predict which of those people with 'mild cognitive impairment' (MCI) will develop dementia. MCI describes the state of cognition between normal ageing and mild dementia. The outcome is uncertain since MCI can indicate the early stages of dementia but some with MCI will remain stable or recover.

The ability to detect these stages and to monitor progression is attractive to pharmaceutical companies' drug discovery programmes. Such tools will become important in the clinical setting only if disease-modifying drugs become available. New tools include cognitive tests, biomarkers and brain imaging techniques.

Cognitive Tests

New cognitive tests being developed to evaluate broader aspects of function are more sensitive to mild dementia and are easy and quicker to administer. They include computerised and self-administered tests. For example, the "Test Your Memory" test, which the patient fills out in the clinic, has been evaluated to be more sensitive to AD than the widely used Mini Mental State Examination (Box 1). Preliminary research has shown skills like spatial awareness, multi-tasking, word recall and money management are the first to decline. Tests that assess such abilities could help to identify dementia earlier.

Brain Imaging Technologies

The most promising tools being developed for early diagnosis are structural and functional imaging techniques that identify subtype-specific patterns of damage (Box 1). These include MRI scans that quantify brain volume and density and new tracers for functional imaging. Tracers are molecules labelled with a radioactive substance that attach to specific targets. New tracers show changes, such as reduced chemical activity, inflammation and deposits of toxic proteins.

Biomarkers

Biomarkers are molecules, such as proteins, whose levels in body tissue or fluid reflect the presence of a disease. An ideal dementia biomarker would reflect the deterioration in brain tissue. Research into biomarkers in cerebrospinal fluid (CSF) is most advanced. Analysis of two proteins can distinguish AD from other dementias and can fairly accurately predict who with MCI will develop AD. Research is still needed on how this test works in the general older population. A test for biomarkers in blood would be quicker, cheaper and less invasive but this research in is still in its infancy.

Issues

Advantages and Disadvantages of Early Diagnosis

While some question the value of the early diagnosis of a condition for which there is no specific medical cure, the overwhelming consensus is that early diagnosis is desirable. Surveys by the Alzheimer's Society show early diagnosis is rated as very important by patients and carers. An early diagnosis:

- reduces uncertainty and helps those affected come to terms with the condition;
- allows patients to make financial, legal and care arrangements while they have the mental capacity;
- allows time to access sources of information along with practical and emotional support, like occupational therapy and peer groups;
- allows timely access to treatment and care services;
- aids identification of conditions that often accompany dementia, such as depression and psychosis;
- improves carers' situations and allows patients to stay at home for longer. For example, carer counselling at the time of diagnosis delays institutionalisation by approximately 557 days.[5]

Such evidence suggests that early diagnosis improves patients' and carers' quality of life and postpones care home admission. However, much of this evidence is anecdotal and few studies have been done to verify, quantify or refute these benefits. Early diagnosis will be of even greater importance if and when disease-modifying drugs become available, as they are likely to be most effective in the early stages. The Nuffield Council on Bioethics 2009 "Dementia: ethical issues" report emphasised the need for "timely" diagnosis, when the advantages of early diagnosis and disclosure outweigh the disadvantages. Disadvantages can include:

- increased anxiety, depression, shame and isolation;
- restrictions to employment, insurance cover, driving and other previously enjoyed activities;

- restrictions in care home options or in support services such as rehabilitation which may not be open to those with a diagnosis of dementia.

With pre-counselling, people with dementia can make an informed decision as to whether they want to know the diagnosis.

Barriers to Early Diagnosis

Many people with dementia never receive a formal diagnosis. For others, diagnosis is delayed for years after the onset of symptoms or is received only when a crisis occurs. Under-diagnosis is a problem reported across Europe, North America and Australasia. Using the prescription rate of Alzheimer's disease drugs as an indicator of diagnosis (and treatment), the UK was in the bottom third of EU countries in 2007.[1]

There are many reasons why patients are not diagnosed or are diagnosed late. Initial symptoms are often dismissed by patients and healthcare professionals as a normal part of ageing. There is also widespread fear and stigma about the condition that prevents people seeking help, especially among certain cultural groups. Estimates suggest that people wait to see their doctor up to three years after first noticing symptoms.[6] In addition, many people are unaware of the symptoms (70% of carers report being unaware before diagnosis) or are in denial (64% of carers report being in denial about a relative's illness).

The need for increased public awareness and understanding, one of the main themes of the National Dementia Strategy (NDS), is a priority shared by many, notably the Alzheimer's charities, and is the subject of an upcoming scoping study by the Scottish government's campaign *See Me*. The Alzheimer's Society launched its public awareness campaign "Worried About Your Memory?" in 2008. Funded by the Department of Health (DH), leaflets, booklets and posters were available in every GP practice in England. The NDS will be launching a public awareness campaign in early 2010.

The Role of General Practitioners

Primary care can be a key barrier to diagnosis. GPs can be reluctant to make or refer for diagnosis. Reasons for this include a lack of confidence or training (only 31% of GPs believe they have received sufficient training in diagnosis and management)[1], the belief that there is little benefit in diagnosis and concerns about availability of resources for treatment and care. Referring patients to specialists can be difficult and time consuming, and there are also cost disincentives for Primary Care Trusts (PCTs). Uncertainty also exists about the criteria for referral. Many cognitive tests used by GPs are not sensitive to mild dementia, are lengthy to use and are criticised for being prejudicial by education, social class, language skills, race or disability. The Royal College of General Practitioners (RCGP) recognises the need for improved knowledge and skills to aid earlier diagnosis and is developing training resources, such as e-learning modules, for GPs.

The Potential of New Diagnostic Tools

The new diagnostic tools outlined previously could potentially increase early diagnosis. However, it is unlikely that such a battery of new tests would be used in all cases of suspected dementia unless they can be shown to be both cost and clinically effective. Issues of testing include:

- the cost of brain scanning facilities. Currently, it is mainly cases of atypical or early onset dementia or those near teaching hospitals or research centres that receive scans;
- the cost and practicality of using tracers. Commonly used tracers last a short time and so scanners have to be located close to where the tracers are made. The availability of longer-lasting tracers is limited.
- cost and logistics of sampling and analysing CSF;
- attitudes to CSF sampling (called lumbar puncture). Lumbar punctures are routinely performed and well accepted in Scandinavia and other parts of Europe. In the UK, healthcare professionals and the public consider the procedure too invasive.

However, new tools will increase the accurate diagnosis of subtype and mixed dementias, allowing clinicians to determine prognosis and treatment options.

The Potential of Screening

While the prevalence of dementia is high in old age, studies agree that there is currently no evidence of any value in screening to increase early diagnosis. This is due to the lack of a conclusive diagnostic test and the limitations of existing treatments. If disease-modifying drugs become available then the issue of screening may be of more importance. In addition, surveys of healthy older adults report a high refusal rate for screening due to the stigma and potential loss of independence and emotional suffering associated with dementia.

Health Service Provision

There are currently a number of services which can diagnose dementia. Patients can be referred to psychiatrists who specialise in old age, to geriatricians, neurologists or to memory clinics (see below). The DH, along with most stakeholders, acknowledges that the current system lacks clarity about where and by whom the diagnosis should be made. Many secondary services deal with the most severe, complex cases. However, to achieve early diagnosis, patients need referral when symptoms are mild and, using the prescription of AD drugs as an indicator of diagnosis, the provision of such services varies (24-fold) between PCTs across the UK.[6] The need for more investment for easy-to-access specialist services is highlighted by many, including the RCGP and Age UK. In addition, there is no service charged with providing the consistent psychosocial support on which many of the benefits of timely diagnosis may depend.

Memory Clinics

Joint guidelines issued in 2006 by NICE and the Social Care Institute for Excellence recommend the provision of memory services (often called memory clinics) as a single point of referral for early diagnosis. Current availability of memory clinics is not uniform and they vary considerably in approach, quality and capacity. In 2006, there were 131 in England of which 38% were provided within a psychiatric hospital, 27% in community mental health services, 16% in a general hospital, 9% in a primary care centre and 14% in other settings such as universities.[1]

A comprehensive network of these services is a key objective of the NDS. Memory services aim to provide direct access to assessment, diagnosis, information, treatment, care and support. An evaluation of a DH pilot memory service (Box 2) concluded that it is clinically and cost effective, based on reduced use of residential care. It has been used to model the economic case for early diagnosis and intervention. Provision of similar memory services around England is forecast to cost £220m extra per year, but assuming that 10% of care home admissions are prevented, by the tenth year of operation the estimated savings are around £245m.[7] This evaluation is criticised for not taking into account other expenses that will be incurred, such as the increased use of brain scans, the extra support that replaces care home admission, the larger numbers of people using services and the extra staff and training required. While early indications are promising, more research is needed on the impact, costs and best practice of memory services.

Box 2. Croydon Memory Service

The Croydon Memory Service is a memory clinic established in 2004 and cited as an example of best practice. Funded by both Croydon PCT and the local authority, the service now diagnoses ~600-800 patients a year and has seen a 63% increase in new cases.[8] A six month follow-up showed improvement in quality of life along with behavioural and psychological symptoms. The service:

- is staffed by a multi-agency team from health and social services, who can all assess and diagnose;
- provides initial assessment at the patient's home;
- provides medical treatment and information and access to day centres and therapy groups;
- has special initiatives focused on ethnic minorities, such as building relationships with religious groups;
- is a direct part of the local Alzheimer's Society branch;
- has fewer people refusing referral, partly attributed to less stigma being attached to 'memory' than 'psychiatric' or 'mental health' services.

The DH will invest £150m in implementing the NDS in the first two years and subsequent funding will be decided on after further evaluation. Memory services will be commissioned by individual PCTs based on existing services and local requirements and so the timescale of implementation will vary. Numbers of people receiving a diagnosis can be monitored through dementia registers maintained by GP practices and the DH is developing a national baseline audit of dementia services to monitor progress of the NDS.

Research Funding

Dementia research is funded by government, research councils, charities and industry. However, funding significantly lags behind that for other serious medical conditions.

- Neurodegenerative disease research (including dementia) is one of the first 'Joint Programming Initiatives'. Co-ordinated by the European Commission, this allows EU member states to define common research agendas with the goal of maximising efficiency and outcomes from research.
- Through the Medical Research Council (MRC) and National Institute of Health Research (NIHR), government expenditure on dementia research in 2009 was £29.9m, 7% less than in 2008.
- The MRC funds research through MRC Centres and a national network of 'Brain Banks'. The NIHR funds the Dementias and Neurodegenerative Diseases Research Network and the Biomedical Research Centre for Mental Health.
- The MRC and Wellcome Trust launched a joint Neurodegenerative Disease Initiative in 2008, which awarded £17m.
- Following an expert research summit in 2009, the government has identified a range of priority areas including biomedical research and improving access to funding and has formed a new Ministerial Group on Dementia intended to "drive change forward".

Overview

- Dementia affects 1 person in every 88 of the UK population and 10-15% of deaths in those over 65 are attributable to dementia.[5]
- The condition is under-diagnosed with only a third of patients ever receiving a diagnosis or contact with specialist dementia services. Getting a diagnosis has been described as "a battle" by patients and carers.
- Early diagnosis improves quality of life for patients and carers and postpones care home admissions.
- Early diagnosis is not associated with any medical specialty and there are large regional differences in provision and quality of dementia services.

Endnotes

[1] National Audit Office, *Improving Services and Support for People with Dementia*, Jul 2007

[2] Foresight, *Mental Capital and Wellbeing Final Project Report,* Oct 2008

[3] Department of Health, *Living Well with Dementia: a National Dementia Strategy*, Feb 2009

[4] Mittelman *et al*., *Neurology,* 67 (2006), 1592

[5] Audit Commission, *Forget Me Not*, Jan 2000

[6] Alzheimer's Society, *Dementia UK*, Feb 2007

[7] Department of Health, *Transforming the Quality of Dementia Care*, June 2008

[8] Banerjee S *et al*., *Int J Geriatr Psychiatry*, 22 (2007), 782

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