An audit of younger patient referrals to a memory clinic

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With memory services generally set up to cope with the demands of an older age group, meeting the needs of younger patients with dementia has its difficulties and there is a possibility of service saturation. Dr Richards and colleagues describe their audit of a memory assessment service in Cornwall, which highlights the urgent need for more thorough screening assessment in primary care of younger patients before they reach the memory clinic.

Young-onset dementia is a growing concern, with a large proportion of the population currently within this ‘at risk’ age group. As memory services are generally set up to cope with the demands of an older age group, there is a possibility of service saturation if ways of implementing adequate screening are not explored. Meeting the needs of younger patients with dementia also has its difficulties, as there are few specialist providers of care and regional differences in funding arrangements. This is particularly problematic in rural areas where numbers and distances add further to the cost of care.

This audit aims to review referral rates and diagnostic practice within the Tamar Memory Assessment Service, a semi-rural service in Cornwall, for a population of 15,000 elderly.

The significance of this study is that 89 (81%) of the people referred did not have a dementia, including 7 people who disengaged, yet the assessment process would have impacted on clinical and administrative time. So there is an opportunity to put screening measures in place at this point.

Introduction

Despite its origins dementia is primarily recognised as a disease of old age. However, a recent update by the Alzheimer's Society estimates there are 42,325 people under the age of 65 years with early-onset dementia in the UK. More men are affected than women and the prevalence of dementia is higher in black and minority ethnic groups.1,2

The population of Cornwall is described as gradually increasing and demographically changing. The population of Cornwall is described as gradually increasing and demographically changing. Figures from the Early Onset of Dementia Prevalence for Cornwall and Isles of Scilly (Projecting Older People’s Information System) propose in 2015 there will be 154 people in Cornwall who have a young-onset dementia.

Pre-senile, or young-onset dementia applies to people diagnosed with dementia before the age of 65 years. As observed by Rossor, et al. this arbitrary cut off has no specific biological meaning but represents a sociological separation in terms of employment and retirement age.3 As retirement age is increasing, the divide between young-onset and late-onset dementia may need to be reviewed.

In some ways receiving a diagnosis of dementia in later life might be more acceptable. Whereas a diagnosis of dementia when a person is under 65 years old highlights issues such as employment, finances, childcare and the dependability of being a...

Figure 1. Number of referrals of patients aged under 65 years

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life partner. Historically there have been few appropriate care resources for this younger age group who do not fit nicely or even willingly into older persons’ services. Some care homes are not registered to provide care for under 65s and day care facilities are extremely limited or overlooked completely.

Diagnosing a younger person with a dementia is more problematic as the differential diagnosis is expansive and they are more likely to have a rarer form of dementia. This can equate to an extensive period of cognitive testing and other investigations before a diagnosis is reached.

Alzheimer’s disease is the most common dementia in younger and older people and accounts for almost a third of young-onset dementia cases and two-thirds in later onset cases. In younger people it is more likely to be familial and genetically heterogeneous.

Methodology
The memory assessment database was scrutinised for people who were aged under 65 years at the point of referral from 2005 to 2013. Initially a template was used to gather the required data by electronic search using RIO and CCUBE (electronic note systems). Microsoft Excel was then used to create a spreadsheet from which to form graphs and comparisons. Data gathering was completed by the authors. Percentages have been rounded up or down to the nearest whole number. Figures may not total due to rounding.

Results
One hundred and ten people under the age of 65 years were referred to the Caradon Memory Assessment Service between 2005 and 2013; this represents about 10% of the database. The youngest was female at 43 years old and the oldest male and female were both 64 years old. Women made up 43% (n=47) and men 57% (n=63) of the group studied. The mean age for males and females was 57 years.

The referral chart (see Figure 1) shows an upward trend, particularly in more recent years, with six referrals in 2005 and 28 in 2013. Most people (91%) were referred by their GP. The next most frequent referrer was the Adult Mental Health Team (5%), two people were referred by the stroke service, two were sent from the local neurology department for follow up, and the remainder came from the community hospital and Parkinson’s service. There were no self-referrals.

Assessments
All patients had a full assessment, including presenting history, past medical history, blood tests and mental state examination. Of the people who were fully assessed 100% had a history of the presenting complaint, past and current medical history and a mental state examination. Ninety-three per cent had full dementia screening blood tests specifically requested by the memory service.

Cognitive tests
Most people had their memory initially tested using the Addenbrooke’s Cognitive Examination Revised (ACE-R) or Addenbrooke’s Cognitive Examination III (ACE-111) (see Table 1). For the purposes of this audit they were viewed as the same test. People referred before 2009 would have been tested using the Mini-Mental State Examination (MMSE). In total 102 people were tested. One person (not included in Table 1) was tested by other means in the psychology department. People not tested did not complete the whole assessment process.

Half the people fully assessed were offered more in-depth psychometric testing by a clinical psychologist using a range of assessment tools and 20% had a functional assessment by an occupational therapist. Fourteen per cent were referred to neurology where the diagnosis was felt to require more in-depth medical assessment (eg lumbar puncture).

Neuroimaging and other investigations
Forty-three people (39%) did not have a brain scan. This included one person who refused and one who did not attend the scan appointment and then disengaged. Of the people that received neuroimaging, MRI (32%) was favoured over CT (23%) in this age group. A combination of MRI and

<table>
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<th>Cognitive test</th>
<th>ACE-R / ACE-111</th>
<th>MMSE</th>
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<tr>
<td><strong>Overall male / female mean</strong></td>
<td>82/100</td>
<td>24/30</td>
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Table 1. Cognitive test scores
SPECT (32%) was also popular. Two people had SPECT scan only (see Figure 2).

**Types of scan**

Usually CT scans are adequate to exclude space-occupying lesions, but in younger people MRI is superior for pinpointing diagnostic patterns of brain degeneration and signal change which may highlight inflammatory disorders such as multiple sclerosis (MS). The most common diagnostic combination in this review appears to be a structural MRI and functional SPECT and this was used in five out of the seven people (71%) diagnosed with Alzheimer’s disease. Seventy-four per cent of people not offered a scan received a diagnosis of either depression or no mental illness and it was felt scanning was not clinically indicated.

**Electroencephalography (EEG)** was used as a further tool for nine people primarily to rule out complex partial seizure activity as a differential diagnosis. Use of EEG as an investigative adjunct can also be useful in detecting the slowing or loss of alpha rhythm in neuro-degenerative conditions.

**Diagnosis**

Nineteen per cent of people referred and assessed received a diagnosis of a dementia. Six per cent had Alzheimer’s disease, 5% vascular dementia, 3% fronto-temporal dementia, 3% alcohol-related dementia, 1% dementia in MS and 1% had an ‘unspecified’ dementia (i.e. not sub-typed). Ten per cent of people had Mild Cognitive Impairment (MCI) and 30% were depressed. Seven per cent were not completed. ‘Other’ accounted for 14% of diagnosis.

‘Other’ diagnoses included: delirium, amnestic syndrome due to use of alcohol, ‘functional unclear’, bipolar disorder, organic personality and behavioural disorder due to brain damage (stroke), and ‘unclear’.

Seventeen per cent of people had no evidence of a mental illness. One person was referred to the service for genetic counselling rather than for assessment. Ten people have not received a diagnosis, seven completely disengaged or were unable to be contacted; others moved away. Three people were still in the diagnostic process.

The youngest people diagnosed with Alzheimer’s disease were a male and female both aged 52 years and the oldest was a 64-year-old female.

Seventy-four per cent of people not offered a brain scan received a diagnosis of either depression or no mental illness and it was felt scanning was not indicated.

**Treatment and outcomes**

All the people diagnosed with Alzheimer’s disease were offered pharmacological treatment with cognitive enhancers. The memory assessment service routinely runs a programme of cognitive stimulation therapy as a non-pharmaceutical intervention. This was offered to everybody diagnosed with a dementia or mild cognitive impairment (MCI), either in a group or as a one-to-one session.

Twenty two (65%) of the people diagnosed with depression were either given advice about medication directly or via their GP, they were also informed of how to contact their local counselling service.

Eleven people were diagnosed with MCI. One person improved and was discharged. Nine people had a yearly review and at the time of writing remain stable. One person was discharged and had not been referred back.

No one who was given a diagnosis that was not a dementia has to date been re-referred because of their memory.

Five per cent of the total population died. That included two females with Alzheimer’s disease; the youngest was 54 years old and had been diagnosed only two years previously. One male with alcohol-related dementia, one with MCI and a female with frontotemporal dementia also died. A male and a female with Alzheimer’s disease were receiving 24-hour care as well as a male with vascular dementia.

**Discussion**

This is our first audit to report the prevalence of dementia and...
differential diagnosis in a pre-senile population in a community-based memory assessment service. The referral chart shows that there has been a steady rise in referrals over nine years, although only a small percentage concluded with a diagnosis of a dementia.

The report demonstrates that since 2005 the Tamar Memory Assessment Service had 110 referrals for people under the age of 65 years suspected to have a dementia. This has resulted in 21 (19%) people so far actually diagnosed with a dementia, which is higher than national expectation. Thirty three per cent of those people were diagnosed with Alzheimer’s disease which is within expectation.

It is also significant to note that 89 (81%) of the people referred did not have a dementia. A low threshold for referral of this age group could lead to saturation of services as each assessment requires at least four hours clinical and administrative input in addition to the cost of investigations. This poses a dichotomy as the National Dementia Strategy recommends early diagnosis, treatment and support, but over-enthusiastic referral of this age group could divert and put a strain on current resources.

It is possible that the name ‘Memory Assessment Service’ is seen as easy access for GPs looking for suitable alternatives to neurology. However, because many services are primarily designed to diagnose dementia in the elderly, the younger group may not receive the expertise or appropriate aftercare. If the service was called a ‘Dementia Clinic’, it may receive fewer younger referrals, but also probably fewer older referrals, as they may be put off by the name.

A closer working relationship with neurologists and more fluid systems for transfer of care between services may reduce this stigma and also support the psychiatrist in diagnosing rarer dementias.

There was a relatively low rate of scanning (59%) in the group we audited. However, scanning is routinely used (as per NICE guidance) to investigate memory loss locally and this low level is more a reflection that scanning was not felt to be clinically indicated.

With the main diagnostic outcome being depression, investigation for dementia would be put on hold until the depression had been successfully treated. If, on further assessment, there remained significant memory problems, the dementia pathway would be reinstituted. It is worth re-iterating that diagnosing dementia is on clinical assessment of symptoms rather than the changes on a scan.

Whilst old age psychiatrists will be able to diagnose younger patients with depression, they may not be particularly familiar with treatment options, counselling regimes or anti-depressant doses in this group, or have the infrastructure to follow them up with suitably experienced community psychiatric nurses. Handing over care to other teams or back to GPs may also lead to mistakes or delays that do not help the depressed patient. More thorough screening measures in primary care to rule out depression and anxiety would allow patients to be directed to a more appropriate care pathway and free up assessment time in the memory service.

Such screening measures should include a formal memory assessment (e.g. MMSE, 6CIT, GP-cog, etc) which may help separate those patients with subjective rather than objective memory loss. This should then raise the possibility of a functional illness, which could be further assessed with depression screening tools such as the Patient Health Questionnaire (PHQ-9), or Hospital Anxiety and Depression Scale (HADS). These tools are valid, easy to use and quick to administer.

As shown in other studies, the variety of differential diagnosis is greater in a younger age group and requires a robust clinical approach combined with good informant collaboration, if available. Interestingly, nobody was
diagnosed with dementia with Lewy bodies. The range of possible diagnostic outcomes can lengthen the wait for a definitive diagnosis. One male who was diagnosed with Alzheimer’s disease elsewhere waited nearly three years for a definitive diagnosis.

This broad diagnostic landscape is important to bear in mind as it heralds the possibility of reversible or curable cognitive problems. This audit presents evidence for more thorough screening as no one diagnosed with depression, an absence of mental illness, stress or anxiety has been re-referred for deterioration in their memory or cognitive abilities, so far.

Young-onset Alzheimer’s disease generally shares the same neurobiology as later-onset disease; however, there is an increased probability of a genetic cause. Although referrals to genetics services were available very few families took these up.

All carers of younger patients with a dementia were referred to a local peer support group. This is the only age-specific service available for this group in the area, and although very successful, the service has limited time and energy to campaign for improved resources. However, they do frequently input into local service developments and literature content.

Conclusions and recommendations
Undoubtedly the risk of developing a dementia increases with age but the possibility of young-onset dementia needs to be considered by GPs when presented with someone who is complaining of memory loss.

Equally, the possibility of an alternative diagnosis and more effective screening measures could reduce the potential saturation of existing dementia services. This does present a significant challenge, as an early diagnosis of a dementia is essential not only to ensure timely treatment, but also to enable the person and their family to make appropriate plans for the future.

As the number of people in Cornwall aged between 40 and 64 years is almost 200,000, the expectation is that there are around 270 people in the region with an early dementia, rather than 154 predicted by prevalence rates for the rest of England.

Limitations of this audit are that the numbers are based on referrals and the true figure of younger people with a dementia in this area may be higher. On the other hand, there were a significant number of false positives. Also, it is unknown what happened to the people who disengaged.

Dementia as a result of a genetic or metabolic disease was not particularly significant in this audit, but that might also be due to the small sample size.

A larger study using data from across the Cornwall Memory Assessment Services may give a more accurate picture of diagnostic trends and subsequently inform service resources that need to be in place.

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Declaration of interests
No conflicts of interest were declared.

References