

NICE/SCIE Dementia Guidance: Time to Reconsider

In November 2006, the National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence (NICE/SCIE) jointly published guidance on the identification, treatment, and care of people with dementia.¹ This document has been somewhat overshadowed by the concurrently issued recommendations of NICE regarding the use of cholinesterase inhibitors (ChEIs) and memantine for the treatment of Alzheimer's disease (AD).^{2,3} However, as NICE/SCIE guidance is implemented by commissioning bodies, its implications are being brought into sharper focus since, though titled 'guidance', adherence is required rather than optional, and will be used as a marker of a Trust's 'performance'.

The system of NICE guidance in various domains of medical practice is in general to be welcomed. It is helpful to have available a systematic approach to diseases and treatments in order to ensure that practising clinicians are aware of best practice. However, in a subject as complex as medicine, where patients do not always fit neatly into simply defined problems, guidelines may, like all other medical interventions, have unintended adverse effects as well as possible benefits. Often what is offered as guidance becomes de facto a prescription of rigidly-defined limitations against which Trusts are judged.

In the specific case of dementia, the aspiration to effect a seamless transition between the medical/diagnostic and social/pastoral aspects of patient care, to bridge the health care/social care divide, so often previously a stumbling block, is one that all involved clinicians – old age psychiatrists, geriatricians, neurologists – will share; likewise patients, families, carers and patient organisations. However, the care pathway is not so linear as the NICE/SCIE guidance seems to envisage, such that the required service restructuring runs the risk of disadvantaging patients who fall outside the 'typical'. In particular, the proposal that there be 'a single point of referral' for all suspected cases of dementia, to wit generic 'memory assessment services' which may be provided by a 'memory assessment clinic or by community mental health teams' (p10), requires careful examination.

Dementia is not a unitary, homogeneous condition but a syndrome with many different causes. Although neurodegenerative disorders in which cognitive impairment and dementia are the predominant features, the so-called primary dementias, account for the majority of cases, in particular AD, many other neurological and medical conditions may present with cognitive complaints and/or cognitive decline, including cerebrovascular disease, Parkinson's disease and parkinsonian syndromes, multiple sclerosis, epilepsy syndromes, motor neurone disease, Huntington's disease, prion diseases,

HIV, certain autoimmune, endocrinological and inflammatory conditions, and structural lesions such as tumours, subdural haematoma and hydrocephalus, the so-called secondary dementias.^{4,5} Hence, treatment of dementia syndromes extends well beyond simply ChEIs, and the inputs required for patients as disparate as, say, an 80-year-old with AD and a 40-year-old with prion disease or HIV, are manifestly not the same.

In dementia of early onset (arbitrarily defined as occurring before 65 years of age), which recent estimates suggest accounts for 2.2% of all dementia cases,⁶ the differential diagnostic possibilities become even broader,^{4,7} including an increased frequency of genetically-determined diseases such as familial AD, frontotemporal dementia, Huntington's disease, and CADASIL. It was previously acknowledged in a joint report from the Royal College of Psychiatrists and the Alzheimer's Disease Society that patients with early-onset dementia and their families have special requirements and that specialist resources, under the auspices of neurologists, psychiatrists, or jointly in multidisciplinary teams, are required to address them,⁸ conclusions with which NICE/SCIE seem to agree ("specialist multidisciplinary services should be developed", p13).

Most 'memory assessment services' and 'community mental health teams' are under the auspices of old age psychiatrists. It is not clear whether these clinicians have the appropriate training to diagnose and manage neurological conditions, some of which are not even acknowledged as possible causes of dementia in the Diagnostic and Statistical Manual of Mental Disorders (e.g. MND).⁹ Furthermore, even so-called primary psychiatric disorders associated with cognitive decline, such as depression and schizophrenia, may be referred to neurology-led cognitive clinics for assessment. A recent study showed that not less than 20% of referrals to such a clinic over a 5-year period were from psychiatrists.¹⁰

The diagnosis of dementia often requires specialist investigations, including structural (CT, MRI) and functional (SPECT, PET) brain imaging, cerebrospinal fluid studies, neurogenetic testing, neurophysiological studies (EMG, EEG) and sometimes tissue biopsy (brain, bone marrow, skin, rectum) as well as detailed neuropsychological assessment. Some of these are acknowledged by NICE/SCIE (p24-26). Incorporation of such biomarkers into diagnostic criteria is now recommended for AD.¹¹ Again it is not clear whether, outside specialist centres, a 'single point of referral' will be equipped to provide these services.

The heterogeneity and complexity of the dementia syndrome at the clinical, aetiological, therapeutic and prognostic levels^{4,7} argues the need for a flexible yet

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structured approach to case management. Dementia is neither a neurological nor a psychiatric disease – neurology and psychiatry being cultural artefacts and political constructs – but a brain disease. A “single point of referral”, with its connotations of “one size fits all” – so definitively rejected in the sphere of education policy – will not suffice. An integrated care pathway which encompasses the various clinical disciplines with an interest in dementia has been proposed.¹²

The NICE/SCIE guidance is sensible with regards to the provision of care services for elderly people with dementia of neurodegenerative and cerebrovascular aetiology. The problem lies in giving the impression, which

may be acted upon by commissioning bodies, that this is a universal approach to dementia (“recommendations that apply to all types of dementia” p4) irrespective of age or other attendant neurological disorder.

Whatever the original intentions of NICE/SCIE, the consequence of implementation of their guidance by commissioning bodies who may know no better is to marginalise, if not abandon altogether, neurological input into the diagnosis and management of dementia syndromes (neurologists are mentioned only once in the document, in the context of initiation of pharmacological therapy for the cognitive symptoms of AD, p30). We believe that such a prescription will inevitably

lead to a reduction in the quality of service provision for this vulnerable group of patients.

These oversights are easily understandable – wittingly or otherwise, there was no neurologist on the Guideline Development Group or Review Panel – and easily rectified in future guidance. In the meantime, we suggest confusion may be avoided by NICE/SCIE explicitly re-titling their current guidance as applicable to typical dementias in adults over age 65. This would alert clinicians to the need for critical evaluation of all individuals with dementia or cognitive decline, irrespective of age, so that the highest standards of medical care provision are available to all.

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