



special articles

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A. P. PASSMORE AND D. A. CRAIG

The future of memory clinics

Memory clinics have been in existence in the UK for over 15 years. Initially set up for research purposes, these clinics have been transformed by the advent of treatments for Alzheimer's disease. Clinics increasingly provide for early diagnosis, information dissemination, initiation and monitoring of treatment, and education and training. There are variations in clinic design, and availability nationally. There continue to be significant demands on existing services, which have traditionally offered domiciliary care. The valuable contribution of these traditional services deserves greater recognition, as do the benefits provided by memory clinics, which are often not fully appreciated by health care professionals or the public.

Memory clinics, first developed in the USA, began to be set up in the UK in the early 1980s. These clinics provided a focus for patients with dementia. There was specialist assessment, occasionally multidisciplinary, and the more enlightened clinics provided diagnosis and follow-up, information and education. In many cases these clinics were university or academically based to provide for basic research and facilitate clinical trials. Until 1997 there was no specific treatment for dementia, so the clinics had variable recognition. Their value, however, was recognised by the patients and carers who attended. The importance of early diagnosis and explanation should never be underestimated, particularly in dementia. This provides a recognition of the disease area itself and a tangible point of contact for sufferers. It was always likely that approval of a new treatment would affect the National Health Service (NHS), particularly the need for memory clinics.

The licensing of tacrine in the USA provided some indication that symptomatic treatments were likely to become available in the UK, and it was no surprise when donepezil was launched in 1997, with the recognition that services would have to change to take account of this new therapy. The subsequent availability of rivastigmine and galantamine reinforced this view, which has subsequently been recognised by both the National Institute for Clinical Excellence (2001), whose guidance specifically mentions the 'further development of memory clinics', and the National Service Framework for Older People which states that specialist mental health services 'should include memory clinics' (Department of Health, 2001);

however, neither provides any specific guidance about an ideal service model.

Role of memory clinics

Memory clinics have a number of important roles (Box 1).

Early diagnosis

The benefits of early diagnosis are recognised by the National Service Framework (NSF): 'If dementia is not diagnosed early, carers can become demoralised due to lack of recognition and support and having to cope with apparently unexplained behavioural changes (Department of Health, 2001: p. 97). Benefits of early diagnosis listed in the NSF include:

- access to treatments
- planning of future care
- helping families to come to terms with prognosis
- helping understanding of changes in memory, behaviour and personality.

Other benefits are:

- improved quality of life for patient and carer
- information and education for patient and carer

Box 1. Role of memory clinics

Point of referral

Specialist assessment and investigation

Early diagnosis

Education of patient and carer

Counselling of patient and carer

Referral to appropriate agencies

Initiation and monitoring of symptomatic treatments

Advice about the behavioural and psychological symptoms of dementia, and their management

Education of students, postgraduate staff, general practitioners and health planners

Research into disease aetiology and development of new therapies

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- introduction to appropriate services, including the voluntary sector
- delayed entry to institutional care.

Current status

Surveys of memory clinics have confirmed that a large expansion has occurred. Compared with 1993 (when there were 20 clinics), by early 2000 a potential 102 clinics were identified using colleges, the UK directory of services, pharmaceutical industry and individual contacts (Lindesay *et al*, 2002). Of 58 operational memory clinics responding to that survey, more than half (55%) reported that they had been set up since 1997, most of them specifically to deal with Alzheimer's disease. These clinics operate in a variety of ways, and have a wide range of staffing profiles, but are most commonly staffed by old age psychiatrists, nurses and psychologists. Much less evident are geriatricians and other professions allied to medicine. Voluntary organisations have a presence at a fifth of clinics. Referral sources vary, as does the range of patient assessments and review. Most referrals come from general practitioners, psychiatrists and geriatricians. The newer clinics are smaller and less multidisciplinary: they see fewer patients and use shorter assessments, with a focus more on service provision rather than on research and education (Lindesay *et al*, 2002).

In a comparison of memory clinics with traditional old age psychiatry services, it was apparent that memory clinics were attracting a different patient population – patients were younger, had less cognitive impairment, were being seen 2 years earlier in the course of disease, were more independent and living at home. It was concluded that memory clinics identified dementia much earlier and had a potential to make valuable contributions to patient care (Luce *et al*, 2001).

It has also been suggested that memory clinic development is now taking place in the context of clinical governance and the drive for quality improvement, driven strategically by the National Institute for Clinical Excellence (NICE) and the National Service Framework (Phipps & O'Brien, 2002). The push to attract patients with early dementia, again driven by the suggestion that earlier introduction of treatment is better, has resulted in increasing presentation of patients with insight into their condition, and also of those with mild cognitive impairment and, as publicity increases, the 'worried well'. These patients do require a different approach.

It therefore appears that memory clinics are offering a useful service, which is oriented to patient and carer, delivers a service for the general practitioner and helps to give the whole area of dementia a higher profile. The clinics facilitate an early and accurate diagnosis, with its ensuing benefits, and offer the earliest possible introduction to management – both non-pharmacological and pharmacological. It therefore follows logically from NICE guidance that memory clinics in whatever form they operate are necessary to facilitate the introduction and monitoring of therapy, and form an integral part of the care pathway in dementia.

Memory clinics: topical issues

Referral

There remains a problem with recognition of the full extent and implications of dementia; this applies to the public and also to many health care professionals. This has led to difficulties in patients presenting for diagnosis. Referral usually begins with the recognition by a carer that a memory problem has developed and is becoming more significant, perhaps in terms of daily functioning. This realisation may occur when memory loss has been present for some time – the average duration of symptoms on presentation to the Northern Memory Clinic was 2.6 years (Luce *et al*, 2001). The general practitioner may then be consulted. It should be possible to confirm a memory problem at that stage, and perform routine blood screening. However, general practitioners may not know about the recommended tests, and may not be aware of available memory clinics or local services, or of the benefits that referral to such services provides.

Clinic structure

There is no definition of what constitutes an ideal memory clinic. Clinics may be structured to provide either assessment or treatment, although many provide both. They are usually consultant-led. There is probably a need to evaluate clinics to prove definitively the benefits for patients and the NHS. With the NICE guidance, clinics are trying to cope with the demands of new referrals, but the major problem for many clinics is trying to deal with the demands for monitoring of therapy. The need to see large numbers of review patients is clogging up clinics, which in turn leads to longer waiting lists. Almost two-thirds (64%) of clinics reported increasing referral rates and 87% had a waiting list for initial assessment (Lindesay *et al*, 2002). Strategies to deal with this include shared care initiatives, separate assessment and treatment clinics, and enhancement of the role of specialist nurses.

Funding

Where memory clinics exist and are providing a good service, a waiting list is likely to build up, creating an additional barrier to early diagnosis. Development of innovative services or expansion of existing services, however, will require funding. Many of the established clinics have been set up within existing services with no extra funding; this may sometimes be to the detriment of the existing services. Other clinics have received specific new funding from health authorities, who have realised that management of dementia is not just about drug treatment but about early diagnosis and service provision. Some clinics have received grants from the pharmaceutical industry. It seems strange that a common condition such as dementia receives so little recognition from NHS planners and purchasers, particularly when the benefits of services such as memory clinics that provide early diagnosis are apparent.



Effect on traditional services

If memory clinics have to be funded from within existing budgets, the other services might suffer. There is thus a clear need to show that memory clinics produce benefits. The study from Newcastle by Luce *et al* (2001) is perhaps the best attempt to compare services. There is a valid argument that efficiently run community services operating according to clinical governance standards (response within 2 weeks) offer excellent care. A rapid response in the patient's home does afford accurate diagnosis and serves to introduce an immediate management plan that is tailored to the patient and carer. From a primary care perspective this achieves the objectives of diagnosis and management. How early that diagnosis is made in the course of the disease does still depend on the general practitioner referral, which in turn can be said to depend on how well educated the general practitioner is about the benefits of early diagnosis. The Newcastle study certainly showed that memory clinics were seeing patients 2 years earlier in their disease (Luce *et al*, 2001). Traditional services can also influence attitudes through educating general practitioners about dementia, including the appropriate initial haematological tests, and attract referrals early in the course of the disease.

Education

Part of the problem with the current arrangements, particularly the NICE guidance, is that dementia management sits mainly within secondary care. This has a perverse influence on education about the condition, particularly in primary care. General practitioners have no real incentive to educate themselves about dementia or the latest treatments for dementia, because of the requirements to initiate and monitor treatment in secondary care and the need to develop shared care protocols if general practitioners are to take over prescribing. The development and subsequent implementation of shared care protocols remains difficult. Therefore, unlike the vast majority of medical conditions about which general practitioners have to have some knowledge, and where diagnosis and some initiation of treatment are possible in primary care even when specialist referral is necessary, dementia is treated very differently. Dementia is not a difficult condition to detect: most cases are due to Alzheimer's disease, and some diagnoses of vascular dementia are obvious, e.g. after stroke. Yet we have a system in place that actively discourages general

practitioners from taking an interest in a condition for which the management strategies are community-based. This has a major impact on educational initiatives, and will also influence general practitioners' attitudes towards dementia and their opinions about referral for assessment. We are already witnessing an increased demand for memory clinic services, so that waiting lists are growing. This seems at variance with the NSF recommendations about early detection and diagnosis of dementia. One solution would be to encourage primary care involvement, but this would not be immediately possible owing to the need for education about dementia and its treatment. The forthcoming NICE review will provide an opportunity to redress this situation, focusing on the needs of patients and carers and the statements within the NSF for older people.

The need for early diagnosis of dementia, with the ensuing benefits including pharmacological intervention, is widely accepted. The NSF clearly states that hospital-based services should include memory clinics (Department of Health, 2001). The NICE guidance means that memory clinics form an integral part of the care pathway in dementia. The increasing rates of referral to memory clinics imply that these clinics are delivering a good service. Their benefits should receive greater recognition and publicity, and it would be appropriate to increase their numbers, as suggested by the NSF. This will require funding initiatives. Such developments will give real recognition to dementia and its impact on patients and carers, along with changes in attitudes and significant educational benefits.

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***A. P. Passmore** Senior Lecturer in Geriatric Medicine, Department of Geriatric Medicine, Queen's University, Whitla Medical Building, 97 Lisburn Road, Belfast BT9 7BL, **D. A. Craig** Lecturer in Geriatric Medicine, Department of Geriatric Medicine, Queen's University, Belfast