Early diagnosis of dementia through the expansion of Memory Clinics
Suzanne Scholz (Nursing and Caring Sciences)

Introduction
The Department of Health (DOH) (2009) identifies how the early diagnosis of dementia would allow people with the condition to receive treatment and intervention to help them live as comfortably as possible from an early stage. In support of this the Government (as recently announced on the BBC News) has unveiled plans to set up ‘Memory Clinics’ in every major town as part of a new strategy costing £150 million over the next two years.

Memory Clinics (MCs), which serve to diagnose and commence early treatment of the condition, were first established in the U.S.A. in the 1970s (Van Hout, Vernooij-Dassen, Hoefnagels and Grol 2001) and were first seen in the U.K. in the 1980s (White 2004), where there are now approximately 246, although there are no official NHS numbers and no specific set standards or models relating to them. The Government strategy suggests that MCs are set to become an evolving feature of the geriatric landscape in the future and whilst the DOH (2005) recognises the importance of involving service users in the decision making process of delivering a person-centred service, it is surprising that only 3% of responses to the DOH (2009) Consultation on National Dementia Strategy came from persons with dementia. Indeed, Cahill, Gibb, Bruce, Headon and Drury (2008) highlight how little is known about expectations and experiences from a user’s perspective, when referred to a MC for the first time and Van Hout et al. (2001) confirm that few studies have been undertaken to evaluate the opinions of MC users.

As a mental health student nurse, I have a particular interest in dementia care and see working in a MC as a career opportunity in the future. I am particularly interested in both service users’ perceived benefits and disadvantages of early diagnosis and their experiences and expectations of attending MCs. This assignment will review available literature regarding the new dementia strategy and the expectations and experiences of service users referred to MCs. It will discuss key areas in the literature, to identify how
mental health nurses can help improve the MC experience for service users and thus support the new strategy.

**Literature Review and Discussion**

To perform this literature review relevant studies were located using a variety of electronic databases: MEDLINE, CINAHL, EMBASE and Google. The search terms used included ‘memory clinic’ ‘dementia’ and ‘assessment’. The databases were searched in January and February 2009 and re-searched in March 2009.

The negative impacts on people with dementia and family carers are profound (Murray, Schneider, Banerjee & Mann 1999). The condition is one of the main causes of disability in later life, with current figures showing that some 570,000 people in England have the condition (DOH, 2009), whilst a further 200,000 new cases are being identified each year across the U.K. (Banjee, Willis, Matthews, Contell, Chan & Murray 2007). Direct costs of dementia to the NHS are approximately £3.3 billion per year (DOH, 2009).

The original concept of MCs was to provide an early diagnostic, treatment and advice service for people with memory impairment and to act as a focus of research into dementia (Van der Carmmen, Simpson, Fraser, Preker and Exton-Smith 1987). The National Service Framework (NSF) (DOH 2001) for older people supports this and stipulates that every specialist mental health service for older people should have a MC to provide this service.

The most comprehensive review of the evidence for approaches to long-term care for people with dementia was carried out jointly by NICE (National Institute for Clinical Excellence) and the Social Care Institute for Excellence (2006). The results confirmed that only about one third of people with dementia received a proper diagnosis, often too late in their illness, with consequent deterioration and reduced opportunity for improving quality of life. The importance of early diagnosis, provision of information, support and treatment, was recognized, and the key priority for further improvement of memory services was established. Following on, in June 2008, the Department of Health
published a consultation paper ‘Consultation on a National Dementia Strategy’, aimed at transforming the quality of dementia care, arising from which, objective two of the National Dementia Strategy became, ‘good quality, early diagnosis and intervention for all’ (DOH 2009). However, noting that only 3% of the replies to this consultation paper came from individuals with dementia, it could be questioned as to whether or not the government’s new strategy regarding early diagnosis and an improvement to MCs adequately considers service users’ opinions.

Nurses are often reminded of how users’ opinions about health care services should be considered important elements for quality management and improvement of services (Berwick 1994). Having dementia should not exclude service users from expressing a viewpoint on the services they require, as we all have equal rights to care and should not be discriminated against because of our age or culture (Arada 2005).

As mental health nurses, adopting a person-centred approach to care is important in attempting to enter into and to understand the experimental world of the person with dementia in order to respond in a helpful and supportive way (Kitwood 1997). Cahill et al. (2008) agree that there is a need to hear the voices of people with dementia, to gain a better understanding of the dilemmas and the difficulties they are experiencing. Although many dementia sufferers, in practice, already have suspicions about their memory loss, and as Clare, Roth and Pratt (2005b) highlight, they are aware of their memory problems and difficulties, many service users attending a MC for the first time experience anxiety and uncertainty about what will happen during the assessment. The Cahill et al. (2008) study confirms this, describing almost half of the participants as negative and feeling distressed at having spent several months waiting for an appointment, a view shared by Hill, O’Brien, Morant and Levy (1995), who describe memory and cognitive assessment as a stressful experience for service users.

Reducing stress and anxiety prior to assessment may improve the number of service users attending MCs, as only 15-20% of people with dementia ever have contact with specialist services (Holmes, Cooper and Levy 1995). As Banerjee et al. (2007) suggest, current
models of service provision may be failing to meet the needs of the majority of people with dementia. It does appear that MC Services are inconsistent throughout the UK and vary from trust to trust, with some focusing more on research into new drug therapies, than early therapeutic interventions, a view supported by Passmore and Craig (2004). This is hardly surprising as currently the NSF (National Service Framework) gives no specific guidelines for establishing a MC (White 2004), nor does it provide any guidance as to what exactly constitutes a MC (Phipps and O’Brien 2002).

Whilst the DOH (2005) acknowledges how older people concerned about memory loss need easy and quick access to supportive diagnostic assessment, it does identify a weakness of the traditional MC model, as being too hospital focused with a lack of integration with local services. Indeed, the service often relied on for dementia assessment is the traditional psychiatric element of NHS trusts providing mental health services. The absence of more comprehensive research into current MC services suggests that more research is required in order to establish how best to deliver a more consistent user-friendly approach.

The Research Governance (2005) framework for health and social care provides a context for research and for the effective transfer of learning and best practice to improve care. NICE (2007) guidelines also recommend that trials should be undertaken on the efficacy of a range of social support interventions for vulnerable groups of people in relation to mental health. Perhaps further research could include not only best practices and improvements for MCs, but also consider whether there should be a new separate early intervention MC service. Rather than an expansion of the existing inconsistent MCs, a new service could be considered especially to meet the government’s new strategy, aimed specifically at delivering a uniform approach to the requirements of the early stages of dementia, which is often seen as a less complicated disorder than moderate to severe forms of the disease (Gaugler, Kane, Kane and Newcomer 2005). The development of a model of care aimed at meeting the needs of early dementia sufferers may be one way of delivering a consistent service. This has been trialed by Banerjee et al.’s (2007) ‘Croydon Memory Service Model’, that recommends how memory assessment could be provided in
the patient’s own home, thus lowering stress and anxiety, and also how service users’ quality of life after diagnosis can be improved by having a management plan formulated by a multidisciplinary team.

Currently MCs can provide individuals with an early diagnosis, which, for some, could be considered a positive intervention. Bamford et al. (2004) suggests how this early diagnosis can give the individual an increased understanding of their problems, access to support and opportunity to develop positive coping strategies or plan short term goals. Indeed, many service users in practice have indicated that early diagnosis of dementia would mean they could plan for the future by putting things in order, such as making a will and appointing a power of attorney.

Another benefit of early diagnosis is the initiation of psychosocial support (Burns and Iliffe 2009). In order to promote access to support, NICE guidelines now suggest a variety of therapeutic and social interventions implemented by a care coordinator and aimed at helping dementia suffers lead a more fulfilling life. The Clare et al. (2005b) study, although limited to a 12 month time period, found that if interventions are accepted, then people with early stage dementia may change and adapt their coping strategies over time, thus improving their well-being. However, it could be argued that all too often in practice the dementia sufferer, in the early stages of the disease, has very little external help from different agencies, relying on support and care from close family and friends. Often these ‘careers’ have insufficient information and advice on how to further manage the symptoms of dementia (Van Hout et al. 2001). Winless (2006) supports this view and highlights how help from services is more commonplace in moderate to severe forms of the disease. Clare, Wilson, Carter, Breen, Berrios and Hodges (2002) stress the importance of establishing whether it is the case that cognitive rehabilitation interventions have a negative impact on well being in order to ensure that service users are protected from unnecessary harm.

Identification of treatable physical and psychiatric causes, treatment of co-morbid conditions and instigation of pharmacological symptom treatments, could also be
considered positive interventions of early diagnosis (Burns and Iliffe 2009). As Cahill et al. (2008) identify, participants attending a MC for the first time hoped they might get ‘something to slow down the process’ of memory loss. Certainly in practice it is evident that service users expect to be prescribed medication after receiving a diagnosis, but as NICE guidelines stipulate drugs are not cost effective in the early stages of dementia, this expectation can only be met if service users are prepared to participate in clinical trials / research into new drugs.

Does this fact bring the ethics of early diagnosis into question? And what is the efficacy of the drugs available in early diagnosis (Coombes 2009)? Is the government using the MC expansion to identify early stage dementia participants for trials into new drugs, to ease the financial burden to the NHS in the future if these drugs become effective? The Lindstrom et al. (2006) study confirms how willing, newly diagnosed dementia suffers are to try new medications, whilst Lindesay (1995) identifies how MCs have been too research orientated, offering little in terms of treatment and advice for dementia, thus supporting such a theory.

It could be argued that early diagnosis of dementia, without access to drugs to slow down the process, will lead individuals diagnosed with dementia into longer more enduring periods of uncertainty (Iliffe and Manthorpe 2004). This is evidenced in practice, whereby service users with dementia often fear the unknown, questioning what path their illness will take and how it will affect them and their loved ones. Bender (2003) acknowledges this fear in individuals making a decision to seek help for memory problems. If a diagnosis brings about such fears it has to be questioned whether service users actually want early intervention at a MC.

A study by Holyroyd Turnbull and Wolf (2002) explored the experiences of people receiving a diagnosis of dementia and concluded that people with dementia had definite views about being told their diagnosis. Robinson, Clare and Evans (2005) revealed how important the receipt of a diagnosis was for people to ‘make sense’ of memory losses and ascribe meaning to cognitive changes. Similar research identified that sharing a diagnosis
also offered the opportunity for the person to express their fears, gather information about dementia, and discuss the nature and prognosis of the illness (Husband 1999, Marzanski 2000).

However, individuals in practice often appear not to want a diagnosis, feeling their memory loss is not a problem and is simply a consequence of old age. The findings of Moniz-Cook, Manthorpe, Carr, Gibson and Vernooij-Dassen (2006) support this view, noting how some participants seeking a MC assessment, still believed that their lives had a sense of purpose, meaning and pleasure for themselves and others and were therefore reluctant to receive a diagnosis.

Pinner and Bowman (2002) suggest this desire not to know is related to experience or perceived consequence of dementia including rapid decline of physical and mental ability and possible loss of home. These views are consistent with the double stigma that is often attached to dementia (Vernooij-Dassen, Moniz-Cook, Woods, De Lepeleire, Leuschner, Zanetti 2005).

If an individual is not expecting a dementia diagnosis, a positive diagnosis may come as a shock to them (Vernooij-Dassen et al. 2006). These individuals may have concerns about becoming a burden to their carers, but they also experience feelings of wanting to ‘hold on’ to their roles in social relationships, wanting to ‘remain valuable’ to others, feeling ‘sad’ and ‘frightened’, which Woods (2001) sums up as perceived vulnerability in social identity.

On the other hand, a study by Van Hout et al. (2001) identifies how a MC diagnosis of dementia had no effect on some participants, a finding shared by Clare et al. (2005b), who suggest that contact with the MC has little impact on dementia sufferers who often are unable to remember what was said to them. These findings bring into question other ethical aspects of diagnosis, such as the individual’s ability to consent and make decisions on their own care and support the fact that decisions to receive a diagnosis should be made on an individual basis relative to consent and capacity of the individual.
(Pratt and Wilkinson 2003). Indeed, some dementia sufferers in practice do struggle to remember what has been said to them during the assessment, and rely on carer support for clarification.

This raises the importance of carer involvement in the diagnosis process, a view supported by the DOH (2009) that highlights the importance of listening to and respecting carers’ views in a medical and diagnostic setting. Whilst confidentiality and service user empowerment (Cheston, Bender and Byatt 2000) need to be considered, so too does the impact of the individual’s dementia symptoms on their family carers’ well being.

Conclusion

Whilst there is a great deal of literature on dementia diagnosis, there is not a significant amount on the benefits, or otherwise, to the service users of early diagnosis through the use of MCs, thus questioning whether the government strategy is evidence based. As nurses are constantly reminded that clinical practice should be evidence based to ensure more effective decision-making (Mantzoukas 2008), should this not apply to Government strategies?

Rather than being born out of service users’ opinions, it would appear the huge cost of dementia care has influenced the development of the National Dementia Strategy (Burns and Liffe 2009). Research into dementia could be seen as vital in order to address the rising financial burden to the economy. As this review’s finding show, existing MCs have been research orientated and unless an improvement to services is apparent the government’s £150m investment could be seen as a direct investment into promoting research. But is the investment sufficient to improve the service delivered to the 200,000 people being diagnosed each year? As identified, many individuals in the early stages of the disease currently receive limited help from services with their care resting on family and friends, who may receive little or no training or guidance, nor any reward for their efforts.
Is early diagnosis a key to providing an improvement to services that will be of benefit to dementia sufferers and their carers? It is acknowledged that further improvements to MC services are needed, but a lack of literature offers little guidance on how to proceed with these improvements. This review identifies how MCs currently are too hospital focused, inconsistent and lack guidelines and/or models of care. Additional research is recommended to identify how MC’s can best meet service users’ needs and support The National Dementia Strategy’s aim to provide good quality early diagnosis for all. Further, in order to encourage an early diagnosis, many of the fears, stigma, and anxieties identified in the review need to be addressed. This could be achieved by identifying a model of care specific to early diagnosis that aims to address these concerns and increase the number of individuals seeking a diagnosis. It could be suggested that a comprehensive model of care should include support before the individual attends a memory assessment. Pre-assessment contact with the individual at their home could be the starting point of building a therapeutic relationship and promoting future safety during uncertainty. Using a person-centred approach in a helpful and supportive way the nurse should aim to understand and address the dilemmas and difficulties the individual is experiencing. The nurse could explore with the individual their feelings, perceived vulnerabilities and anxieties, involving the carer and family if the individual so wishes.

Providing written information before diagnosis about dementia and the services of the MC would allow individuals an insight into the illness, assessment, treatments and services available. In order to address the ethics of early diagnosis at a pre-assessment meeting, the service user could be informed that medication will not be available specifically to improve their memory loss, but also be advised about how they can participate in medical research so that future generations may benefit. This would enable the individual to make an informed decision on whether to obtain a diagnosis and ensure levels of expectation are not raised. If the individual’s capacity has been established and they do not wish to pursue a diagnosis, then their right not receive a diagnosis at this time should be respected (Marzanski, 2000).
If on the other hand a diagnosis is sought and improvements to services and care delivery are made, the nurse can reassure the service user that a positive diagnosis will result in access to a variety of services for them, their family and carer. These services would be detailed in robust care plans formulated by a MDT and delivered by a care co-ordinator in conjunction with health, social services and voluntary agencies and would include all aspects of care including care package, finances, legal issues and carer support. This would enable the individual and their carer to plan for the future and work with professionals to develop coping strategies.

In order to monitor the quality of services being delivered, service users’ opinions should be sought. A recommendation for practice could be the use of feedback forms enabling the service user and their carers to make comments, suggestions or complaints about the service they receive. This would ensure services meet with the service users’ needs and thus promote quality management.

Empowering the individual with dementia, putting them at the centre so that they are in control, with a system that delivers the outcomes that they need will enable the nurse to support the best interests of the service user.

References


Cahill, S. M., Gibb, M., Bruce, I., Headon, M. and Drury, M. 2008. ‘I was worried coming in because I don’t really know why it was arranged’: The subjective experience of new patients and their primary caregivers attending a memory clinic’, Dementia 7: 2, 175-189.


Lindesay, J. 1995. ‘Memory clinics, past, present and future’, *Alzheimers Research* 5, 97-100.


Marzanski, M. 2000. ‘Would you like to know what is wrong with you? On telling the truth to patients with dementia’, *Journal of Medical Ethics* 26, 108-113.


