Closing the diagnosis gap and improving care: the Primary Care Memory Clinic

Susan Mary Benbow, David Jolley, Ian Greaves, Elaine Walker

The term 'dementia gap' is sometimes used to describe the difference between the number of people known to have dementia in an area and the number of people predicted to have dementia from our knowledge of prevalence rates. The Alzheimer's Society recently carried out a project to map the gap and showed that diagnosis rates vary around the UK (1).

In Gnosall the primary care memory clinic has closed the gap, enabling the GPs to increase the identification and diagnosis of people with dementia in the practice up to the level expected, while at the same time saving money and achieving high levels of patient and carer satisfaction. Key to the clinic's success is the memory clinic team.

The Primary Care Memory Clinic Team

The GP

Sometimes a patient will bring a memory problem to their CP's attention or a member of their family will bring it to light. Alternatively the GP may identify a change in someone's memory when they see them in a consultation or might become aware of it when screening a person from a high risk group eg in a vascular or diabetic clinic. They will then explain to the patient and/ or family member that this needs to be investigated further. They will review the person's past history, assess their present health and treatment for any medical conditions, and arrange any necessary preliminary investigations including blood tests such as thyroid function tests and serum B12 and folite and an ECG (if these have not been carried out recently). Sometimes the review may conclude that there is no need to take this further or that the GP should review the person after an agreed time has elapsed, but in most cases the next step will be to refer the person to the memory clinic, which takes place monthly in the Health Centre, coordinated by the Eldercare Facilitator who is employed by the practice.

The Eldercare Facilitator

The role of Eldercare Facilitator is new, developed specifically in relation to the primary care memory clinic (2), and involving coordination with the GP, the specialist old age psychiatrist and a wide range of other agencies and people. The Eldercare Facilitator arranges to meet the patient, usually at their home and with a family member or another appropriate supporter. She carries out an assessment and gathers further information using an agreed protocol (3), which includes using the clock drawing test (4) and Brief Assessment Schedule Depression Cards (BASDEC) (5). The next step is usually for the patient, preferably with a family member, to come to the next memory clinic. From the GP's identification of a potential problem to attendance at the clinic will normally take 4 weeks, cutting out much of the delay involved in a secondary care clinic, and, since the patient attends their own Health Centre to be seen in the memory clinic, the anxiety and stigma of attending an

unknown mental health unit is minimised. The Eldercare Facilitator acts as a single point of contact within the practice and identifies early crises.

The old age psychiatrist

The primary care memory clinic in Gnosall currently involves two old age psychiatrists who are bought in as independent practitioners, have retired from consultant practice in the National Health Service and subsequently developed portfolio careers. (It would be possible to run the service by bringing in consultant old age psychiatrists from a mental health unit to operate as part of the primary care memory clinic team.) One of the big advantages of the clinic is that the specialist has access to the GP's electronic patient records and, before seeing them, is able to check recent investigation results, current prescriptions, and other information about concurrent and previous medical conditions. If questions arise during the consultation further information is available immediately. On occasions messages are sent electronically to one of the GPs during the clinic, in order that a particular issue can be discussed and resolved.

The specialist and Facilitator together see the patient and family member in the clinic. Often the patient and their carer will choose to stay together, sometimes they may choose to be seen separately. The Eldercare Facilitator's assessment is available to the specialist, and the interview with patient and family member gives the opportunity to extend the assessment, check out any concerns, test the patient's memory, consider whether further assessment is needed (eg a brain scan), and, if there is sufficient information available at this stage, to talk about the diagnosis and future treatment plan. We often use the Montreal Cognitive Assessment (6) as a standardised baseline cognitive test. Approximately 40% of new patients have a brain scan carried out (2011 figures).

It is our normal policy to copy clinic letters to the patient and/ or their carer, provided they agree, and they usually do. The letter is dictated during the clinic session and given to the clinic secretary (a member of the practice staff) for typing. If a diagnosis has been made, this is included in the letter together with details of the treatment plan. By making this available to the family it means that they can play a full role in ensuring that follow up actions take place as planned.

The secretary

The secretary is employed by the practice. She types up the letters and emails them to the specialist using a secure email address for checking. They are then sent out to all concerned.

Other practice staff

As a member of the practice, the Eldercare Facilitator has links with other practice staff and involves them in the person's care as necessary, eg a recent patient was referred to a counsellor; joint visits with a physiotherapist are often helpful where there are concerns about mobility and falls. The practice provides a dementia friendly reception team and those who complete all the tedious administration with codes and regulatory requirements. Good accommodation and computer access along with positive engagement with the consultants makes them feel included, appreciated and welcome. The practice manager is key to all this.

Memory clinic follow up

The specialist, GP and Facilitator together coordinate follow up care, support and treatment and review the patient and their carer as necessary. This may take place at their home or in the clinic. The Facilitator takes a lead in linking with other agencies, and has an in depth knowledge of locally available services, particularly third sector services. She will take people to visit services and the fact that she is well known locally is a big advantage. She acts as a contact point for families between clinics and liaises with the specialists as necessary by phone, email and in the clinic. She is part of the primary health care team and makes the system much more efficient. She completes forms and ensures treatment recommendations are enacted. Figure 1 shows the major communication flows in the clinic and the pivotal role of the Facilitator. Each clinic involves on average 8 patients of whom two will be new and attending for the first time. Approximately one quarter of patients referred to the clinic are treated with anti-dementia drugs.

Advantages and disadvantages of the primary care memory clinic

From the point of view of the patient and their family, the primary care memory clinic removes some of the barriers to diagnosing dementia by bringing specialist expertise into primary care and partnering the specialist with the GP and primary care staff. The patient gets many of their health care needs met in the primary care environment and is usually comfortable and familiar with this environment. Thus dementia services are not perceived to be different and this reduces the anxiety that inevitably accompanies concerns about cognitive decline, and alleviates the stigma of attending a psychiatric clinic and or a dinic associated with older age. The clinic endeavours to establish a partnership with patient and family, by putting them in possession of the necessary information to take the difficult decisions that are necessary when someone is living with dementia and by making the Eldercare Facilitator and other primary care staff available to support them in doing this. The care plan and treatment plan is negotiated with the family who take responsibility for its enactment. This takes trust, especially when discussing sensitive matters about finances, value judgements about care inputs and legal and other responsibilities. GPs have often built this trust by caring for intergenerational members over many years.

For the GP the clinic offers a quicker and more integrated service. The specialist is on site and available to discuss difficulties and dilemmas. The service has been shown to save money: the primary care memory clinic at Gnosall was costed at less than £11,500 in its sixth year of operation compared with an expected £133,000 for a secondary care based service and at the same time it saved money in terms of the practice's use of older people's mental health services and overall use of secondary health care (7). The service also attracts high levels of satisfaction from patients and families who use it (unpublished report for the Alzheimer's Society Hearts and Brains project). Secondary care expertise enables both the GP and public to feel confident in a service that adds value to the diagnosis. The GP maintains responsibility for the patient's care and, with close support through improved communication by telephone or e-mail, can enact consultant recommendations,

engage in shared care prescribing and action referrals to appropriate other agencies or for investigations. The GP provides a holistic review of how the dementing process affects the management of other co-morbidities, which can reduce hospital and outpatient referrals. Family medicine and mutual respect is the hallmark of general practice, and GPs feel better about this than the tick box medicine that is such a familiar part of their working day.

From the specialist's perspective, GPs frequently know the patient and their family well and can contribute to the softer information about the family dynamics, social circumstances and community values and the practice computer is a source of valuable up-to-date information.

Disadvantages are that some old age consultants might feel that they would be happier within their own comprehensive assessment team and might feel isolated in primary care. The consultants in primary care have access to the complete patient primary care computer records but they might have to enter their notes twice to fulfil the corporate governance requirements of the Trust. The capacity of consultants to provide this service might also be in conflict with some of their other roles in research, administration or teaching. Integration is based on trust, communication and respect on all sides. Trust administration must not be destabilised, so the clinic requires accurate financial evaluation, especially if the existing service requires remodelling. There will always be a need for more specialist assessment but this can be included as part of the care plan and an appropriate hospital based service used. This is discussed in the three tiers model paper (8).

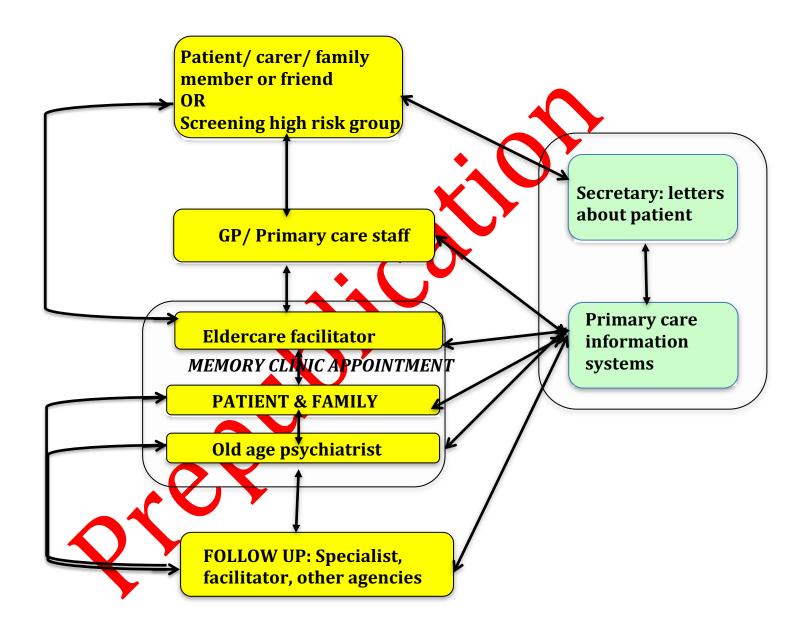
Conclusion

This is an innovative model, which is efficient, integrated and better for patients. It provides excellent quality markers for early diagnosis and medical management of people with dementia. The best of secondary care is merged with the best of primary care to keep the patient in the community, support their identity and improve their journey. Pre and post diagnostic support, befriending and the provision of an intelligent companion in the Eldercare Facilitator is beneficial. Care planning, personalisation and outcome based treatment inputs allow the family to monitor and performance manage their relative's care. The financial benefits are initially difficult to conceive but can be appreciated if the cost alternatives are reviewed through individual cases. Patient held care plans created in the community reduce length of stay in hospital as it is easier to upgrade a care plan than create a new one in an acute setting. Setting out triggers for urgent care access and stopping procedures of limited value are all efficiencies. Early crisis intervention and single point of contact are offered by the Eldercare Facilitator and the reassurance of a twilight and week end telephone system are all common sense improvements. The quality metrics combined with financial efficiencies make this sort of service delivery very attractive. The model described here is not unique (9, 10): it differs from the model evaluated by Meeuwsen and colleagues (11) which involved assessment, investigation and diagnosis remaining outside primary care, but, nevertheless, showed that primary care can provide a good service for its patients with dementia.

Primary care provision is notoriously diverse, separately funded and difficult to engage. The take up of enhanced services is voluntary in primary care and a lot of GPs are struggling with their existing workload. Rates of uptake of between 50-60% are quoted for the Directly Enhanced Service for dementia symptom recognition. This is designed to reduce the dementia gap but the recently announced fall in the expected prevalence data will have a far greater effect. Scotland, where dementia coding is better especially for those in nursing and residential homes, leads the way. Unification of primary care delivery has lots of advantages. The federations of practices, either with the formation of super practices as a result of practice mergers or the formation of General Practice Provider Organisations, allow the engagement of primary care in the commissioning process. These structures enable universal access and offer both resource and administrative support for the development of safe community services and primary care. The federations can recruit a capable workforce outside the regulations of their primary care contracts and be innovative in supporting struggling practices to safer, high quality service delivery. The role of the GP as a commissioner can potentially cause conflicts of interest, as the public might perceive GPs to be benefitting from commissioning. This can be overcome by employing the Prime Provider model, where the commissioners set out service specifications that include community delivery. The main Trusts bid at procurement and assume responsibility for contract delivery. The primary care organisations subcontract with the Trusts to deliver the community service specifications.

The primary care memory clinic team is an innovation that has been developed and evaluated in one practice. It has the potential to be rolled out over a much wider geographical area, and offers a way for GPs to improve diagnosis rates, cut costs and improve the quality of the service to people with dementia and their families.





References

1. Alzheimer's Society UK. Diagnosis rate data. 2012 [12 September 2013]; Available from:

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1665.

- 2. Greaves I, Greaves N, Walker E, Greening L, Benbow SM, Jolley D. Gnosall Primary Care Memory Clinic: Eldercare facilitator role description and development. Dementia. 2013.
- 3. Gnosall Health Centre. Gnosall Memory Clinic: the basics. 2013 [9 May 2013]; Available from:

http://www.gnosallsurgery.co.uk/website/M83070/files/Gnosall Memory Minic - The Basics April 2013.pdf.

- 4. Agrell B, Dehlin O. The clock-drawing test. Age and Ageing 1998;27(3):399-403.
- 5. Adshead F, Cody DD, Pitt B. BASDEC: a novel screening instrument for depression in elderly medical inpatients. BMJ. 1992;305(6850):397-.
- 6. Nasreddine Z. Welcome to the Montreal Cognitive Assessment. 2003 [12 September 2013]; Available from: http://www.nocarestorg.
- 7. Clark M, Moreland N, Greaves I, Greaves N, Jolley D. Putting personalisation and integration into practice in primary care. Journal of Integrated Care. 2013;21(3):105-20.
- 8. Jolley D, Greaves I, Greaves N, Greening L. Three tiers for a comprehensive regional memory service. Journal of Dementia Care. 2010;18(1):26-9.
- 9. Lee L, Hillier LM, Stolee P, Neckman G, Gagnon M, McAiney CA, et al. Enhancing Dementia Care: A Primary Care–Based Memory Clinic. Journal of the American Geriatrics Society, 2010;58(11):2197-204.
- 10. Brooke P, Naidoo M, Rice D. The Newbury Memory Clinic Project. Final Report July 2005. 2005 [11 October 2013]; Available from: http://www.falklandsurgery.co.uk/memory/The Newbury Memory Clinic main report.pdf.
- 11. Meeuwsen EL Melis RJF, Aa GCHMVD, Golüke-Willemse GAM, Leest BJMD, Raak FHJMV, et al. Effectiveness of dementia follow-up care by memory clinics or general practitioners: randomised controlled trial. BMJ. 2012;344.