

A PILOT PROJECT ON A SPECIALIST MEMORY CLINIC FOR PEOPLE WITH LEARNING DISABILITIES

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Introduction

Memory clinics are a well-established component of dementia services for the general adult population. This is in accordance with the National Service Framework (NSF) guidelines for older people (Department of Health, 2001). Most clinics aim to diagnose and treat dementia at an early stage (National Institute for Clinical Excellence, 2001).

The life expectancy of people with learning disabilities is increasing (Richard *et al.*, 1980; Carter and Jancar, 1983) mirroring that of the general adult population. This is mainly as a result of improvement in health facilities, living conditions and general wellbeing.

The prevalence of dementia in people with learning disabilities increases with

age. The prevalence rate for those over the age of 65 years is 21.6% (Cooper, 1997) four times greater than in the general adult population of the same age structure. In addition, people with Down's syndrome show evidence of Alzheimer's dementia at a much earlier age than in the general population (Holland, 2000). Psychiatric symptoms associated with dementia are similar to those seen in the general adult population (Moss and Patel, 1995), resulting in distress to carers, families, and at times in residential placements breaking down.

Diagnosis of dementia in people with learning disabilities is by no means straightforward, particularly in those within the lower IQ ranges. "Diagnostic overshadowing" and hence dismissing of symptoms (Holland, 2000) has further contributed to dementia being under-

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diagnosed in this group of individuals. Since baseline functioning is already impaired in people with learning disability, assessment of baseline functioning levels of all individuals in early adulthood is recommended as good clinical practice (Aylward *et al.*, 1997). When diagnosing dementia, greater emphasis should be placed on changes in behaviour and personality in association with functional change (Aylward *et al.*, 1997), especially in the more disabled population. A combination of direct neuropsychological testing and observer-rated scales is recommended for the diagnosis of dementia in this group of people (Deb and Braganza, 1999). It is also recommended that the task should be carried out by a psychologist who is both familiar with the special testing needs of these individuals and also skilled in the use of appropriate psychometric tests (Aylward *et al.*, 1997).

The diagnosis of dementia at an early stage is important if one is to monitor these individuals in their own environment for as long as possible (Hassiotis *et al.*, 2003) and maintain their quality of life. The development of services for older people with learning disabilities has been identified both in the National Services Framework (Department of Health, 2001) for older people and the more recent UK Government White Paper "Valuing People" (Department of Health, 2001) for people with learning disabilities. In most areas this aspect of the service development is at an infantile stage.

In Hertfordshire (UK), with the closure of three long-stay hospitals and the resettlement of a large number of individuals with learning disabilities in the local community, this poses a particular problem. Currently, the service provisions, both by Health and Social Services are geared mainly to meet the needs of younger adults with learning disabilities.

Aim

The aim of this pilot project was to evaluate the usefulness of establishing a specially designed "Memory Clinic" for the assessment and diagnosis of dementia in people with learning disabilities.

Method

The core team members were a psychiatrist, psychologist and a community nurse from the specialist learning disability team with a special interest in dementia and its treatment. The psychiatrist had undergone further training in the psychiatry of old age.

The memory clinics were held monthly, commencing in July 2003. The appointment letter stated that a family member or carer who was currently closely associated with the service user should accompany him/her. In addition, a Life Questionnaire (modified from the Cambridge Memory Clinic) was sent, requesting it to be completed and brought to the clinic. The Cambridge Memory Clinic (UK) is a clinic for the assessment and diagnosis of dementia in the general adult population.

Each clinic assessment was approximately of 2 hours duration. One hour was spent with the psychiatrist, during which time a full clinical assessment with particular emphasis on eliciting the signs and symptoms of dementia was carried out and a physical examination. The Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975) was administered to those with a mild learning disability during the psychiatric examination. Relevant investigations were requested which included haematological tests and ECG (electrocardiogram). The other hour was spent with the psychologist, when either a

Dementia Questionnaire for Persons with Mental Retardation (DMR) (Evenhuis *et al.*, 1990) or an Adaptive Behaviour Scale (ABS) Assessment (Nihira *et al.*, 1993) was completed. For service users, for whom baseline assessments had been carried out previously, a comparison of results was undertaken. A detailed nursing assessment was carried out, when appropriate. At the end of the clinic, all professionals involved in the assessments discussed the findings, and an action plan was formulated for each individual patient. The details of the assessment and the action plan were communicated to the general practitioners, community nurses and carers.

A form evaluating the service offered was given for completion to the individual and the carer at the end of the appointment.

Results

Over a period of 8 months a total of 12 assessments were carried out. Seven females and 4 males were assessed, the age range being 41 years – 83 years; one being a repeat assessment. In 3 individuals a definitive diagnosis of dementia was made. Six of these service users also had associated Down’s syndrome. In the Downs syndrome group 2 had a definitive diagnosis of dementia and for 1 the diagnosis was inconclusive at the initial assessment; although there was a strong suspicion of a possible diagnosis of dementia. (TABLE I)

1. Mrs. A was a 66 year old lady with mild learning disability, living alone and supported by carers who visited her

TABLE I
Demographic data with diagnosis of patients assessed in the memory clinic

	Age	Sex	Degree of Learning Disability	Associated Problems	Diagnosis
A	66	F	Mild	None	Dementia excluded
B	66	F	Moderate	Depression	Dementia excluded
C	63	F	Mild	Epilepsy and physical health problems	Inconclusive
D	54	F	Moderate	Down’s syndrome and hyperthyroidism	Dementia confirmed
E	60	F	Moderate	Down’s syndrome	Dementia confirmed
F	41	M	Moderate	Down’s syndrome	Dementia excluded
G	83	F	Severe	Recurrent depressive disorder	Pseudo dementia
H	79	F	Moderate	Residual schizophrenia	Dementia confirmed
I	46	M	Moderate	Down’s syndrome	Inconclusive
J	43	M	Moderate	Down’s syndrome	Behavioural problems
K	36	M	Moderate	Down’s syndrome and schizo-affective disorder	Dementia excluded

three times per day. She had a history of recurrent depression, currently in remission. She was referred with complaints of becoming increasingly forgetful.

She scored 13½/30 on the Mini Mental test. Her low score was attributed to the learning disability, and hence her lack of knowledge/ability to answer the questions, rather than to Dementia. On clinical examination there was no evidence of dementia. DMR and ABS assessments were not completed at the initial assessment since she was not accompanied by a carer and both these scales are observer related scales.

Outcome: To be reassessed at the clinic in a year's time. Baseline DMR and ABS assessment to be carried out by the psychologist.

2. Miss B was a 66 year old lady with moderate learning disabilities, living in a residential home. She had follow-up appointments in the psychiatric clinic for depression. She was referred to the memory clinic since her carer was concerned with changes in her behaviour and possible deterioration of memory.

On clinical examination and DMR testing there was no evidence of dementia.

Outcome: Repeat assessment in 1 year's time.

3. Miss C, a 63 year old lady with mild learning disability living in a residential home. She suffered from epilepsy and was on antiepileptic medication. She also had additional physical health problems. Carers had noticed

a gradual deterioration in functioning and a tendency for her to become more forgetful. Hence, she was referred to the clinic. Assessment was suggestive of early dementia, but this was inconclusive due to her added physical health problems.

Outcome: Follow-up in six months. Initial intensive treatment of physical health problems was recommended.

4. Miss D, a 54 year old lady with Downs' syndrome, moderate learning disability, and hyperthyroidism who was living in a residential home. Initial referral was made to psychology for assessment of dementia and she was on a waiting list. She was assessed twice at the clinic six months apart. On clinical examination a diagnosis of early dementia was made. Two assessments on the DMR scale, six months apart, showed a significant deterioration in both cognitive and social functioning, supporting the clinical diagnosis.

Outcome: Thyroid function test was repeated to ensure that her hyperthyroidism was adequately treated. Referred to Psychiatric Outpatient Clinic (learning disability) to commence on anti-dementia drugs.

5. Miss E, a 60 year old lady with moderate learning disabilities and Downs syndrome. She was living with her family. The family had noticed a deterioration in her memory over the previous ten months, e.g. inability to remember the names of close family members, repeatedly asking the same questions, getting muddled with her clothing when getting dressed. On clinical examination a definite diagnosis of Alzheimer's dementia was

made which was substantiated by the DMR scores (comparisons being made to previous scores).

Outcome: Referred to Psychiatry Outpatient Clinic (learning disability) for commencement of anti-dementia drugs.

6. Mr. F a 41 year old gentleman with moderate learning disabilities and Down's syndrome was referred for baseline assessment of cognitive functions from the Psychiatric Outpatient Clinic. He was living in a residential home. Both clinical examination and DMR assessments did not suggest a diagnosis of dementia.

Outcome: Reassess in the Memory Clinic in 1 year's time.

7. Miss G was an 83 year old lady with severe learning disabilities and a recurrent depressive disorder. Referred for an assessment due to deterioration in functional skills noticed by her carers in the residential home where she lived. On clinical examination she was found to be clinically depressed. The DMR assessment did not support a diagnosis of dementia.

Outcome: The treatment of her depression was optimised.

8. Miss H, 79 years old with moderate learning disabilities and residual schizophrenia. The reason for referral to the memory clinic was that over a period of four months carers at the residential home had noticed a deterioration in her memory. She herself had complained that she was becoming more forgetful, confused and finding it difficult to comprehend

simple tasks or commands and less interactive with fellow residents.

On clinical assessment a diagnosis of dementia was made which was supported by the scores on the DMR assessments; comparisons being made with previous scores.

Outcome: Referred to Psychiatric Clinic (learning disability) for commencement of anti-dementia treatment.

9. Mr. I, a 46-year-old gentleman with moderate learning disabilities and Down's syndrome, who was living in a residential home. Presented with a history of becoming more lethargic and having more "stubborn days" than before. Carers also noticed a subtle personality change in that he had become more rigid and quite inflexible in his ways.

On clinical examination a definitive diagnosis of dementia was not made, although there was a strong suspicion of its possibility. This was supported by the DMR tests.

Outcome: To be reassessed at the clinic in six months' time.

10. Mr. J was a 43 year old gentleman with moderate learning disabilities and Down's syndrome. He presented with an increase in physical aggression and targeting particular members of staff and residents, at the residential home where he lived. Carers had also noticed an increase in his obsessive behaviour. He was initially seen at the Psychiatric Outpatient Clinic and referred to the Memory Clinic for an assessment. He refused to attend the clinic in person and the carer turned up, since his

behaviour was causing great concern.

Outcome: Referred to the Intensive Assessment and Treatment team for close monitoring of mental state and behaviour. Repeat assessment in Memory Clinic in six months.

11. Mr. K, a 36 year old gentleman with moderate learning disabilities, Down's syndrome and schizo-affective disorder. He was referred to the Memory Clinic for a baseline assessment by his carers from the residential home where he lived.

On clinical examination and DMR assessments there was no evidence of dementia.

Outcome: Reassess in Memory Clinic in 1 year's time.

12. Repeat-assessment of Miss D.

User/Carer Satisfaction Survey

Areas covered in both surveys were similar.

- (1) If the reasons for referral to the memory clinic had been explained.
- (2) The ease or difficulty in obtaining an appointment.
- (3) The appropriateness of the venue and the facilities used.
- (4) Any difficulties in completing the Life Questionnaire.
- (5) If the questions presented at the clinic were easily understood.
- (6) The friendliness of the staff.
- (7) If follow-up arrangements were explained clearly at the end of the clinic.

82% of questionnaires were returned. The feedback from both users and carers was generally very positive. Some found it a useful forum to discuss problems and issues relating to the individual service users. Some found it reassuring that a diagnosis of dementia was excluded. Others found it educational and that they had received important information on dementia.

Discussion

Twelve assessments were carried out over a period of 8 months (one being a repeat assessment). The diagnosis of dementia was made on clinical examination and supported by psychological assessments (DMR and ABS). These two instruments are both observer-rated scales and were administered by a psychologist from the learning disability team. We found that the ABS, though a very comprehensive instrument, was time consuming. Hence we are currently exploring the possibility of using the modified CAMDEX informant interview (Ball *et al.*, 2004) in the future. The modified CAMDEX (Cambridge Examination for Mental Disorders of the Elderly) is an informant based interview which enables a diagnosis of dementia to be made in those individuals with a pre-existing learning disability (Ball *et al.*, 2004).

Computer Tomographic (CT) and Magnetic Resonance Imaging (MRI) scans were not done as a routine, but only if there was a clinical indication. We were of the opinion that this could be quite stressful and frightening for some of the service users.

Of the 11 people assessed, three (27.2%) had a definitive diagnosis of Alzheimer's dementia. These rates are comparable to the results of the initial assessment

and diagnosis of dementia at a Memory Clinic for people with learning disabilities (Hassiotis *et al.*, 2003). The individuals, where a definitive diagnosis of dementia was made, were referred on to the Psychiatric Outpatient Clinic (learning disability) for treatment. This was done in accordance with the accepted Trust protocol on "Prescription of anti-dementia drugs for people with learning disability". Hence the role of the Memory Clinic was only for assessment and diagnosis.

In one individual the presentation was of "pseudo dementia" and the recommendation was to treat her depression more rigorously. For the 63 year old lady who had physical health problems, an initial assessment though suggestive of dementia was inconclusive due to her poor physical health. In Mr. I who had moderate learning disabilities and Downs syndrome the initial assessment was inconclusive, although there was a strong suspicion of the possibility of dementia. In both these cases 6 monthly follow-up assessments were recommended instead of the customary annual check-up.

The referrals to the memory clinic were of two categories. Either for baseline measurement of cognitive functions, particularly in those with Down's syndrome, or due to concerns raised by carers or families that the individual was showing a deterioration in cognitive function. This indicated that there was some awareness already existing amongst carers and family members of the long-term memory problems that could arise in people with learning disabilities. However, education of carers, families and professionals in identifying early signs of dementia must remain a priority. We felt that the Memory Clinic fulfilled this function and feedback received from a carer confirmed the educational value/benefits of the clinic. The carer felt that it

provided her with good information on dementia and in particular what signs and symptoms to look out for. It was also stated that it was a good forum to discuss any concerns regarding the service user, and the carer felt that the service user was getting the best possible help.

Valuing People (Department of Health 2001) recommends that people with learning disabilities should access generic mental health services, as far as possible. In Hertfordshire, Memory Clinics for the general population take varying formats. Some are only assessment clinics, others are for treatment and a few others for both. The Mini Mental Test (Folstein *et al.*, 1975), as recommended in the National Institute for Clinical Excellence (NICE) guidelines for treatment with anti-dementia drugs, would be an appropriate test only for those with borderline IQ and very mild learning disabilities. In this pilot study we were unable to use this test for any of the individuals successfully except for one. This confirmed our view that the Mini Mental Test is not an appropriate instrument for the majority and may have some value only for those with minimal disability. If people with learning disabilities were to access generic services, the assessment process/instruments used would need to be modified in the majority of cases.

Moreover, the professionals involved in the assessment process would need to be specially trained in dealing with the issues related to identifying and interpreting the significance of changes in function, behaviour and personality in people with learning disabilities. The specific needs of this group of patients must be carefully considered before such a process is adopted. Perhaps, the way forward might be the use of generic services only for those in the mild/borderline range, and the specialist learning disabilities service should undertake "specialist memory

clinics” for the people with more severe degrees of disability. The authors found that such specialist clinics were useful in that these assessments were longer (2 hours each), comprehensive, structured and focussed on the diagnosis of dementia in this population. A standard learning disability psychiatric outpatient clinic would not provide this opportunity (Hassiotis *et al.*, 2001), nor would a busy generic memory clinic.

This pilot memory clinic was set up by re-organisation of existing resources, especially in terms of professional time. This was largely due to the special interest of the professionals involved in the project. However, to maintain this project in the future, additional resources especially in terms of professional time, need to be identified.

Collaborative working between professionals from generic services and learning disabilities service should be encouraged especially in developing guidelines on shared protocols with general practitioners for the prescribing of anti-dementia drugs, information leaflets for carers and training for carers and families. In addition, the two services should explore the possibility of joint working in the development of inpatient facilities, day care, day hospital and respite facilities.

Recommendations

1. Assessment at generic memory clinics will be appropriate only for a few people with borderline / mild learning disabilities. To facilitate this process they may need to be supported by a professional from the specialist learning disability services.
2. The assessment of the majority of

individuals with learning disabilities needs to be carried out by professionals with expertise in the field of learning disability. This includes psychiatrists, psychologists and community nurses.

3. These assessments may be carried out either in general (learning disability) psychiatric out patient clinics or specially designed “memory clinics” for people with learning disability. The latter would be the recommended option for reasons given previously.
4. The individual clinic assessments would take approximately two hours in which a detailed clinical examination and initial psychometric tests are carried out, e.g. DMR, ABS, modified CAMDEX.
5. Education of families and carers in identifying symptoms suggestive of dementia in people with learning disability needs to be a priority.
6. Information regarding the availability of the memory clinic needs to be disseminated to the various establishments, e.g. residential homes, day care services, to enable carers to make referrals early.
7. The Mini Mental Test (Folstein *et al.*, 1975), as recommended in the NICE guidelines for treatment with anti-dementia drugs, would be an appropriate test only for those with borderline IQ and very mild learning disabilities.

Summary

The aim of this pilot project was to evaluate the usefulness of establishing a specially designed "Memory Clinic" for the assessment and diagnosis of dementia in people with learning disabilities. Eleven assessments were carried out over a period of eight months. A diagnosis of dementia was made in three cases (27.7%); pseudo dementia in one (9.01%). The diagnosis was inconclusive in two cases. In five individuals the diagnosis of dementia was excluded. The use of the Mini Mental Test was unsuccessful, in this study.

Assessment at generic memory clinics and the use of the Mini Mental test would be appropriate only for a few individuals within the borderline/very mild learning disability. The majority of individuals with learning disability need to be assessed by professionals with expertise in this field and preferably in "specialist memory clinics" identified for this purpose.

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References

- Aylward, E. H., Burt, D. B., Thorpe, L. U. and Dalton, A. (1997). Diagnosis of Dementia in Individuals with Intellectual Disability. *Journal of Intellectual Disability Research*, 41, 152 – 164.
- Ball, S.L., Holland, A.J., Huppert, F.A., Treppner, P., Watson, P. and Hon, J. (2004). The modified CAMDEX informant interview is a valid and reliable tool for use in the diagnosis of dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research*, 48, 611 – 620
- Carter, G. and Jancar, J. (1983). Mortality in the Mentally Handicapped: A 50 year survey at the Stoke Park Group of Hospitals (1930 – 1980). *Journal of Mental Deficiency Research*, 27, 143 – 156.
- Cooper, S. A. (1997). High Prevalence of Dementia among people with Learning Disabilities not attributable to Down's syndrome. *Psychological Medicine*, 27, 609 – 616.
- Deb, S. and Braganza, J. (1999). Comparison of rating scales for the diagnosis of Dementia in Adults with Down's syndrome. *Journal of Intellectual Disability Research*, 5, 400 – 407.
- Department of Health (UK) (2001). National Service Framework for Older People. (Executive Summary). London: Department of Health.
- Department of Health (UK) (2001). Valuing people; A New Strategy for Learning Disability for the 21st Century, London: Department of Health.
- Evenhuis, H. M., Kengen, M. M. F., Eurlings, H. A. L. (1990). *Dementia Questionnaire for Mentally Retarded People*. Zwammerdam, The Netherlands: Hooge Burch Institute for Mentally Retarded People.
- Folstein, M. F., Folstein, S. E. and McHugh, P. R. (1975). 'Mini-Mental State': A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189 – 198.
- Hassiotis, A. and Walker, Z. (2001). Setting up a Memory Clinic. In: Z. Walker and R. Butler, (Eds.). *The Memory Clinic Guide*, London: Martin Dunitz.

- Hassiotis, A., Strydom A., Allen, K., Walker, Z.** (2003). A Memory Clinic for older People with Intellectual Disabilities. *Ageing and Mental Health*, 7, 418 – 423.
- Holland, A. J.** (2000). Ageing and Learning Disability. *British Journal of Psychiatry*, 176, 26 – 31.
- Moss, S. C. and Patel, P.** (1995). Psychiatric symptoms associated with dementia in older people with learning disability. *British Journal of Psychiatry*, 167, 663 - 667.
- National Institute for Clinical Excellence** (2001). *Guidance on the use of Donepezil, Rivastigmine, and Galantamine for treatment of Alzheimer's disease*. London: NICE.
- Nihira, K., Leland, H. and Lambert, N.** (1993). *Adaptive Behavior Scale - Residential and Community*, 2nd Edition. Austin, Tx: Pro-Ed.
- Richards, B. W. and Siddiqui, A. Q.** (1980). Age and mortality trends in residents of an institution for the mentally handicapped. *Journal of Mental Deficiency Research*, 24, 99 -105.