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Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model

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SUMMARY

Background The large majority of people with dementia receive nothing in the way of specialist assessment and care at any stage of their illness. There is a particular lack of services focussed on early identification and intervention in dementia where there is the possibility of long-term harm reduction for people with dementia and their family carers. We have developed a model of care that is complementary to local systems of health and social care (The Croydon Memory Service Model [CMSM]). This is a low-cost, high-throughput, generic service to enable early identification and intervention in dementia. It is a multi-agency approach with joint ownership by health services, social services and the voluntary sector with embedded specifically-tailored approaches to primary care and minority ethnic communities.

Method We completed a service evaluation of the introduction of the CMSM in a single borough in South London. Six predefined service goals were set: high acceptability; high appropriate referral rate; successful engagement with people from minority ethnic groups; successful engagement with people with young onset dementia; focus on engagement with mild cases to enable early intervention; and an increase in the overall number of new cases of dementia seen. Mixed qualitative and quantitative methodologies were used including a description and 6-month follow-up of a cohort of 290 consecutive referrals.

Results All key predefined service goals were met: 95% acceptability; 94% appropriate referrals; successful engagement with minority ethnic groups (two-fold greater number compared with that expected from general population demographic data); 17% of referrals under 65 years of age; 68% referrals with mild or minimal dementia severity; and an estimated 63% increase in the number of new cases of dementia seen in Croydon. At 6-month follow up, those referred to the service had decreased behavioural disturbance and increased quality of life compared with baseline.

Conclusions Specific services for early dementia, which deliver diagnosis and care, can be established. These services can increase the numbers of people with early dementia identified and provided with care. Those receiving such services appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia. Next steps should include the establishment of such services in other representative areas and evaluation of their effectiveness in comparison with other models of care. Copyright © 2007 John Wiley & Sons, Ltd.

KEY WORDS — dementia; Alzheimer's disease; early intervention; quality of life; quality improvement; service evaluation; health services research

BACKGROUND

Dementia is one of the most common and serious disorders in later life with a prevalence of 5% and an incidence of 2% per year in those over 65 (Hofman

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et al., 1991; Launer et al., 1999), affecting around 500,000 people at any one time with 200,000 new cases every year in the UK. These disorders cause irreversible decline in global intellectual and physical functioning. The negative impacts on people with dementia and their family carers are profound (Murray et al., 1999; Schneider et al., 1999). Also the economic cost of caring for people with dementia is immense; with the direct costs of dementia estimated at between £7.06 and £14.93 billion in the UK (Lowin et al., 2001), more than stroke (£3.2 billion), heart disease (£4.05 billion) and cancer (£1.6 billion). Service provision for people with dementia has been recognised as a major public health priority in the UK (Department of Health, 2001) and worldwide (Brookmeyer et al., 1998).

In the UK the service most often charged with dementia assessment and care are the old age psychiatric elements of NHS Trusts providing mental health services. However, current models of service provision may be seen to be failing to meet the needs of the vast majority of people with dementia with only 15–20% ever having contact with specialist services (Holmes *et al.*, 1995). The need has therefore been identified to detect and assess more people with dementia, and to do this earlier in their illness (Department of Health, 2001; DeKosky, 2003; Barker *et al.*, 2005).

There is considerable heterogeneity of need in dementia but it is possible to identify two main streams in dementia care: a 'serious mental illness' stream and an 'early intervention' stream. The 'serious mental illness' stream includes people with severe and complex disorders where there are high levels of risk and co-morbidity; these individuals require the resources and skills of old age psychiatric community mental health teams. In the 'early intervention' stream there is early and often uncomplicated disorder with the possibility of early intervention and therefore the prevention of future harm, risk and cost for the patient, their carers and services (Gaugler et al., 2005). With advances in public expectation and in psychological, social and biological treatments in dementia, services are already under pressure from increasing numbers of new referrals from the 'early intervention' stream (Banerjee, 2001). How then to meet this challenge: by replicating existing services ('more of the same') or by generating new models of service delivery and service redesign? One approach has been the establishment of memory clinics (Lindesay et al., 2002; Phipps et al., 2002). The service described here is a development of this approach, designed to maximise service activity and effectiveness while

providing broadly based care as well as assessment in people's own homes.

METHOD

Development of the model of care

An analysis of local need was completed from 1999–2002. This involved the establishment of a multi-agency group including health services, social services and the voluntary sector in Croydon. This group consulted with a broad range of older people with and without dementia, carers and service providers and formulated two key service aims:

- Early identification and engagement with people with dementia and their carers;
- Provision of a comprehensive early assessment, diagnostic and treatment service for people with dementia and their carers.

To deliver this we developed a comprehensive model for early dementia assessment and care in dementia—the Croydon Memory Service Model (CMSM). This involved the introduction into the existing local system of care of an additional low-cost, high-throughput, generic service to enable early identification and intervention in dementia. The model was one of modest extra investment (£230,000 to establish a full-time team of five members for a borough with 46,000 65+) with system redesign to deliver new functions increasing the capacity to diagnose and manage dementia.

The model has at its core generic team working. This removes the rate-limiting step which is imposed when all referrals need to be seen by a particular individual or professional group (Collighan *et al.*, 1993; Herzberg, 1995). In the CMSM the team training is paramount so that any individual, no matter what their clinical background, can complete the initial assessment. The diagnosis is made and the management plan formulated by the multidisciplinary team as a whole. Following this, profession-specific skills can be deployed as needed. Assessment and care is provided in the patients' own homes. The model was designed to maximise efficiency and acceptability and to be easily transferable to and replicable in other areas.

Goals for the service

The multi-agency group set six *a priori* goals against which success could be judged.

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- 1. To have a low refusal rate from those referred—less than 10%;
- To have a low rate of 'inappropriate' referrals defined as having no subjective or objective memory problem or having severe dementia—less than 20%;
- 3. To work for minority ethnic groups as well as the majority—referral rate at least equivalent to their proportion in the population over the age of 65, i.e. 11%;
- 4. To focus on engaging mild cases to enable early intervention—60% mild or minimally impaired or subjective impairment only;
- 5. To engage successfully with people with young-onset dementia—10% under 65;
- 6. To increase the number of new cases of dementia seen per year in Croydon—by 50%.

Quantitative assessment

All those referred to the service and who consented to be seen had a baseline assessment carried out by team members with the measures built into the routine assessment. The baseline interview included measures of:

- Cognition using the Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975) and CAMCOG (Roth *et al.*, 1986);
- Behavioural and psychological symptoms in dementia using the Neuropsychiatric Inventory (NPI; Cummings *et al.*, 1994);
- Disease-specific health related quality of life of the person with dementia using the self-rated DEM-QOL, and carer-rated DEMQOL-Proxy (Smith et al., 2005);
- Activities of daily living using the Bristol Activities of Daily Living Scale (BADL; Bucks et al., 1996);
- Depression using the 15-item Geriatric Depression Scale (GDS-15; Yesavage *et al.*, 1983)

This cohort was then followed-up 6 months later with assessments made blind to baseline assessments.

Qualitative assessment

In attempting a broad assessment of the impact of the service, quantitative data were supplemented by a series of qualitative in-depth individual interviews with three groups: service users (patients and carers); referrers (local general practitioners); and service providers (team members). These were completed by researchers (RW, JC, IS) independent of the clinical team. They were tape-recorded, transcribed

and analysed with the computer programme NVivo used to process the transcripts of the interviews for content analysis. The data from the qualitative interviews will be presented in a separate paper but a summary of the findings is included here in relation to key issues.

RESULTS

The service started in November 2002. We collected data on an 18-month cohort of consecutive referrals to the CMS from 1 November 2002 to 30 April 2004; 290 referrals were made. On the basis of referral data and enquiry (e.g. severity, diagnosis, complexity, area) 27 (9%) were redirected without assessment; 15 (5%) declined assessment, and one (0.3%) died prior to assessment. The 247 remaining referrals were assessed by the CMS and form the cohort described here; demographic characteristics are presented in Table 1.

Assessment against pre-defined goals

Using baseline data to assess the service against predefined goals, the new service met or exceeded the

Table 1. Demographic characteristics and diagnoses of all those who had a baseline assessment (n = 247) and all those who had a six month assessment (n = 141)

Characteristics	Frequency (%) Baseline (n = 247)	Frequency (%) 6-month follow-up $(n = 141)$	
Gender			
Male	88 (36%)	49 (35%)	
Female	159 (64%)	92 (65%)	
Ethnicity			
Black African Caribbean	21 (9%)	13 (9%)	
South Asian	16 (7%)	9 (6%)	
White European	203 (82%)	118 (84%)	
Mixed race	3 (1%)	0	
Other	4 (2%)	1 (1%)	
Age at referral			
Under 65	45 (18%)	26 (18%)	
65 or over	202 (82%)	115 (82%)	
Diagnosis			
Alzheimer's disease	87 (35%)	64 (45%)	
Vascular dementia	16 (7%)	4 (3%)	
Mixed dementia	53 (22%)	36 (26%)	
Other neurological illness	10 (4%)	3 (2%)	
No illness	74 (30%)	34 (24%)	
Undiagnosed, deceased,	7 (3%)	0	
or declined			
Cognition (MMSE)			
None or minimal 25-30	106 (45%)	66 (49%)	
Mild 19-24	76 (32%)	47 (35%)	
Moderate 10-18	48 (20%)	21 (16%)	
Severe 0–9	5 (2%)	1 (1%)	

first five goals. First, the refusal rate was only 5% [95% confidence interval (95% CI) 3% to 8%] of those referred against a goal of 10%. Second, we had an 'inappropriate' referral rate of 11% (9% prior to assessment and 2% at assessment; 95% CI 9% to 17%). This was within the goal set of 20%. The third goal was that the team needed to serve the needs of people with dementia from minority ethnic groups. We received 44 (18%; 95% CI 13% to 23%) referrals from non-white European ethnic groups, this compares favourably with census population projections for Croydon of 11% for those over 65. The fourth and fifth goals were also met with 182 (77%; 95% CI 68% to 79%) of referrals in the range of mild or minimal severity of impairment (goal 60%) and 45 (18%; 95% CI 13% to 23%) of referrals under the age of 65 (goal 10%).

The sixth goal was a process measure focused on improving patient care by increasing the numbers of people with dementia assessed and treated. Taking routinely collected data for the most recent full year of referrals available (1 September 2004 to 31 August 2005) there were 384 absolutely new referrals to Croydon old age community mental heath teams of whom 227 received a diagnosis of dementia and 296 absolutely new referrals to the Croydon Memory service of whom 189 received a diagnosis of dementia. Reviewing CMS case notes including referral letters and pathways, we estimate that 15% of those referred to the CMS in that year were 'shifted' referrals which if the service did not exist would have been referred to the community mental health teams, yielding 161 new cases of dementia attributable to the activity of the CMS. To attempt to quantify the impact of the team we can therefore make a broad estimate that the numbers of people diagnosed with dementia in Croydon has risen from 255 to 416 per year, an increase of 63% overall (95% CI 57% to 67%) compared with a target of 50%. This estimate is clearly subject to considerable potential error, not least because of the reliance on routinely collected data, but it is a conservative estimate and does indicates a positive direction of growth of numbers of assessments of people with dementia. Taken together these six goals may be useful in the benchmarking and comparison of other models of service provision in dementia.

Care provided

In terms of content of assessment and care, all but seven (3%) of the referrals received a complete assessment; all clinical data presented here are part of the service's routinely collected dataset apart from the 6-month follow-up of those discharged from the service. Detailed feedback on diagnosis was given to all referrals and their family supporters, careful attention was given to the disclosure of diagnosis of dementia and the sharing of information. All those diagnosed as having dementia were assessed along with their carers for formal programmes of individual and group psychological support and offered these if appropriate. All were offered an individually tailored package of care. Pharmacological treatments included anti-dementia medication with 68 (48%) out of the 140 eligible referrals (operationalised as diagnosis of Alzheimer's disease or mixed dementia and MMSE score of 10 or more) established on such medication 6 months after referral.

Cohort study

All those interviewed at baseline were approached for follow-up 6 months after referral and 141 (57%) were re-interviewed (82 refused or were uncontactable; seven were too ill and nine had died). Demographic data on the follow-up cohort are presented in Table 1. Data on clinical state at baseline and 6 month follow up are presented in Table 2. At 6 month follow-up 131 of the baseline referrals had been discharged by

Table 2. Clinical characteristics of baseline and 6 month assessments and comparison statistics, entire cohort (n = 237)

Measure [domain]	Baseline assessment (total $n = 237$)	Six month assessment (total $n = 141$)	Paired statistical tests	P-value (n)
	Mean (SD) [n]	Mean (SD) [n]		
MMSE [Cognition]	22.5 (5.7) [235]	23.3 (4.9) [135]	Wilcoxon $z = -1.02$	$0.128 \ (n = 135)$
GDS-15 [Depression]	3.4 (3.2) [168]	3.2 (3.1) [95]	Wilcoxon $z = -1.79$	0.073 (n = 85)
DEMQOL [Quality of life]	89.6 (14.1) [197]	91.5 (12.5) [109]	t-test $t = -2.21$	0.029 (n = 101)
DEMQOL proxy [Quality of life]	94.5 (14.9) [181]	99.2 (13.9) [86]	t-test $t = -2.08$	0.041 (n = 84)
BADL [Activity limitation]	7.6 (7.7) [196]	8.2 (8.2) [93]	Wilcoxon $z = -2.39$	0.090 (n = 92)
NPI [Behavioural disturbance]	13.0 (13.5) [190]	9.0 (12.6) [91]	Wilcoxon $z = -1.68$	0.018 (n=90)

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the service. Our main clinical objective was to improve the quality of life of the people with dementia seen. We measured quality of life using DEMQOL and DEMQOL-Proxy (Smith *et al.*, 2005). The DEMQOL and DEMQOL-Proxy data were normally distributed but other measures were not, non-parametric tests were therefore used for all other statistical tests of change used. At follow-up there were statistically significant improvements in both self- and proxy-rated quality of life and in behavioural disturbance; there was also a marginal improvement in depression.

DISCUSSION

These data provide preliminary support for the value of establishing services for early identification and intervention in dementia that can work with other local services. This evaluation suggests that such services can increase the numbers of people with early dementia assessed and provided with care. Those receiving the service appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia.

These data must be interpreted with great care. The follow-up rate is low leading to potential response bias. This may be a function of this being a true service evaluation where there was no selection. There was also no control group; it may be that the change observed is the nature of quality of life in dementia with referral at a time of stress and that spontaneously remitting. However, it is also important to consider these data in context: there has to date been no evaluation of any dementia service which has measured quality of life impact, so these data are at the least a novel contribution to the evidence base.

Performance against goals set

The refusal rate of 5% of those referred against a goal of 10% compares well with a refusal rate of between 15% and 20% in our community mental health teams for older adults and up to 36% refusal rates in working age adult mental health referrals (Killaspy *et al.*, 2000). Data from the qualitative interviews of patients, carers and GPs suggested that this low refusal rate seemed to have been influenced by the 'memory service' having less stigma attached by those referred and referrers compared with the normal service which was more defined as 'psychiatric' or by its focus on 'old age'.

It feels far more invasive to get the psychogeriatricians to descend on them, the psychogeriatricians are excellent, but...it looks far more aggressive...but these much more subtle early memory losses where the patient has got insight, the memory service feels a far more logical step, where we can say 'look we are going to do a very thorough assessment and see if there is actually a significant memory problem' rather than saying 'I think you need to see an elderly care psychiatrist'. (quote from GP, qualitative interview).

The low rate of 'inappropriate' referral suggests that with appropriate liaison and preparation, primary care can use such a service appropriately. The service was not overwhelmed by inappropriate referrals as had been feared. The high level of referral of people from minority ethnic groups is encouraging. This suggests that specific strategies of tailoring access to care for people with dementia from minority ethnic groups can be successful. Our approach included the building of relationships with temples and churches to overcome the stigma of mental health services and so enable acceptability of referral and assessment.

The finding that 77% of the referrals were in the early stages of dementia or had subjective impairment only and that the service was successful in identifying people with young-onset dementia (i.e. those under 65 years of age) are also positive. This is in line with reports that memory clinics can identify cases two years earlier than normal old age psychiatric services (Luce *et al.*, 2001). This again provides support for the acceptability of the new service for referrers and those referred in the specific groups targeted including young-onset dementia.

Being the sort of person that faces up to reality as I see it, I went and saw my doctor and he referred me to the memory service and so that was the starting point really (quote from person with dementia, qualitative interview). Then he (the GP), one time he just happened to say about you know 'would you like to be referred to the memory clinic?' And we thought well we have got nothing to lose so we said 'yes, we would' (quote from carer, qualitative interview).

Finally goal six was an attempt to address one of the major concerns in dementia care—that there is a large pool of unmet need where individuals do not have their dementia diagnosed. If dementia is not diagnosed then the person with the dementia and their family carers are denied the possibility of planning for their future or of availing themselves of the help, support and treatment which may be available. Therefore increasing the number of people with dementia diagnosed is,

in and of itself, an important goal. Again the CMSM met the goal set. It may of course, be that this increase in people seen was simply a secular trend with referrals increasing all over the country in response to a general increase in population and primary care demand for early identification of dementia. We did not collect equivalent data in other areas that would have allowed us to test this hypothesis. At the very least the increase in referrals is positive in terms of absolute numbers seen and the CMSM provided a way of processing these cases without compromising the other obligatory work of the local community mental health teams for older adults.

The cohort study

In the cohort study the findings of statistically significant improvements in quality of life and in behavioural disturbance and a marginal improvement in depression are novel data that are worthy of attention. While they are in no way definitive and may even represent the natural history of such variables in dementia, they do provide a further layer of evidence to support the value of the service model. Further support for its potential value in terms of patient improvement comes from the observed 4-point improvement in NPI score. While these data do not have the strength that comes from a randomised controlled trial, the improvement observed is substantially higher than the 3.9-point worsening over a 6-month period expected without treatment (Morris et al., 1998) and also compares favourably with the 1.7-point net relative effect reported for cholinesterase inhibitors alone compared with decline in placebo groups from meta-analyses (Trinh et al., 2003).

It is interesting that the improvements in quality of life were not associated with improvements in cognition or activities of daily living, giving further support to the lack of association of such specific variables with quality of life (Banerjee *et al.*, 2006). Improving the quality of life of people with dementia must be the overall goal of dementia services and the direction of change observed here is therefore encouraging. The importance of generating data on the quality of life impacts of treatments for dementia has been clearly identified (AD2000, 2004). The data presented here complement suggestions that memory clinics can improve the quality of life of carers of people with dementia (LoGiudice *et al.*, 2001).

CONCLUSIONS

The data presented here need to be interpreted with caution. This is essentially a detailed single case study of the introduction of a new service. The feasibility of establishing such services depends on the availability of the funds needed (£230,000 p.a. here) to pay for it. These data provide support for the value of establishing services for early identification and intervention in dementia which are complementary to local mental health of older adults services. This evaluation suggests that such services can increase the numbers of people with early dementia assessed and provided with care. Those receiving such services appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia. Next steps will include the establishment of such services in other representative areas and evaluation of their effectiveness in comparison with other models of care. In a culture where, despite policy pronouncements (Department of Health, 2001), dementia care is accorded a low priority, securing funding for such development and its evaluation is a complex challenge.

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KEY POINTS

- Services to enable the early identification and treatment of people with dementia can be established.
- The Croydon Memory Service Model appears to have high acceptability, accessibility, and effectiveness in increasing the numbers of people provided with diagnosis and care in a population.
- Those receiving such services appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia.

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