Refereed paper

Using routinely collected data to evaluate a leaflet campaign to increase the presentation of people with memory problems to general practice: a locality based controlled study

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ABSTRACT

Background The Alzheimer’s Society wished to raise awareness that people with memory problems may benefit from early assessment and diagnosis, so that appropriate measures could be put in place and management improved.

Objective To use routinely collected data to determine whether a leaflet campaign to raise awareness of memory problems would result in increased presentation of people with memory problems to their GPs.

Method A locality was identified which met the criteria for locating the pilot intervention. A neighbouring locality was identified which used the same secondary care service and could serve as a comparator. Anonymised routinely collected computer data were gathered before and after the intervention.

Results The intervention locality had a much greater proportion of elderly patients and a higher proportion had memory problems recorded at baseline (OR 1.67; 95% CI 1.47–1.91; P<0.001). In both localities just under 40% of people with memory problems had blood tests. Approximately 80% would be referred to secondary care, and this was more likely for those in the intervention group (OR 1.29; 95% CI 0.99–1.93; P=0.044).

However, the use of antidepressants was greater in the control locality; 34% vs 9% (OR 0.19; 95% CI 0.13–0.27; P<0.001). Whilst the absolute number of people prescribed cholinesterase inhibitors was greater and increased more in the intervention practices, the proportion of people with memory problems prescribed was not significantly greater (OR 1.21; 95% CI 0.77 – 1.89; P=0.38). The increased prescribing in the intervention practices was due to people restarting therapy. From a lower baseline there was a greater increase in the control locality for all variables for which we had a before and after measure.

Conclusions During a leaflet campaign the recording and management of memory problems increased. However, there was greater improvement in the control locality. This study demonstrates the importance of including a control group and the strengths of routine primary care data.

Keywords awareness raising, computer data, memory problems
Introduction

Patients with memory problems may benefit from assessment and treatment. Assessment may identify problems which can be rectified. These include physical health problems, which are easily detected by simple blood tests, or depression. Diagnosis of dementia is a specialist task best done by experienced clinicians with access to appropriate sophisticated investigations, which usually requires referral to a memory assessment service. Much can be achieved through team work which includes primary care. In the UK the use of drug treatment for dementia has been an area of controversy since the National Institute for Health and Clinical Excellence (NICE) rejected the proposal that antidementia drugs should be more widely used. However, even if the place of some therapeutic agents remains undecided, if diagnosis is delayed people with memory problems and their carers may remain unsupported for much longer than necessary. It is consequently generally recognised that early diagnosis may benefit treatment and management strategies in dementia.

The Alzheimer’s Society wanted to assess the effect of a leaflet campaign, which they subsequently launched nationally, to encourage people with memory problems to attend their GP. They planned to pilot this campaign in an area where the society was active and could offer additional support should additional people and their carers be identified as a result of this programme. Further criteria were that the area should have an above average population of over 55-year-olds and an active memory clinic. The campaign was run by the local branch of the Society and focused on distributing leaflets to public buildings such as libraries, pharmacies and general practice and dental surgeries, as well as through branch activities, community centres and on request. There was also a direct mailing to general practitioners (GPs) to tell them about the campaign. The evaluation of the campaign was carried out from a number of perspectives: response rate to the Society by phone and post; referral to their branches; and by monitoring the impact on GP services. A copy of the leaflet is shown in Figure 1.

In the UK, primary care is highly computerised and aggregated routine data used to monitor achievement of quality targets are in the public domain. Computers are used at the point of care with data entry largely completed by clinicians. A national system of registration allows patients to register with a single practice: electronic prescribing, electronic communication of pathology results and the introduction of pay for performance (P4P), based on data collected for usual clinical care, have all led to an improvement in data quality.

Figure 1 Alzheimer’s Society leaflet: Worried about your memory?
This report describes the use of routine data to measure the impact of this leaflet campaign on local GP services.

Method

We carried out a literature review to identify evidence for early presentation of patients with memory problems to general practice and the impact of leaflet campaigns on quality improvement. We searched the principal bibliographic databases Medline and Embase. We examined the reference lists and ‘related articles’ from Medline searches.

We identified an intervention locality, which referred to the same specialist service as a neighbouring control locality. The two localities shared local prescribing policy and availability of secondary care services.

We evaluated the intervention using routinely collected GP computer data. We opted to use areas of the record which we expected to be reliably recorded:14,17,18

1 The recording of diagnosis or problem title of any type of memory problem or dementia. We grouped together the people with coding ranging from recording of forgetfulness through to formal diagnosis of dementia.

2 The recording of the investigations for treatable causes of memory problems. GPs commonly carry out a ‘dementia screen’ to identify treatable causes or comorbidities in people with memory problems. Electronic links from pathology labs to GP computer systems facilitate their recording in the clinical record. These investigations are recommended as best practice.1 We decided to count people who had four or more recommended tests simultaneously as having had these investigations.

3 GPs may start people with memory problems on antidepressants if they consider the condition likely to be ‘pseudo-dementia’. We therefore decided to look at new starters on antidepressants, and people who had computer record entries suggesting that they had been questioned using standardised exercises (such as the Hospital Anxiety and Depression Scale, the Beck Depression Inventory and the nine-item Patient Health Questionnaire (PHQ-9) depression rating scale) to assess whether they were depressed.19

4 We expected to see people who present with memory problems being referred to secondary care. It is national policy to refer people with impaired cognitive function for assessment, ideally in a memory clinic.1

5 Finally, we reported on the use of antidementia drugs. The pros and cons of their use other than in moderate or moderate to severe cases has been reported in the introduction. We wanted to see if the campaign was associated with any increased prescribing.

We agreed within the research team (which included representatives of the Alzheimer’s Society) a dataset likely to identify the changes (Box 1). We looked at rates of recording for the ten months before and after the leaflet campaign of our target dataset.

We collected anonymised data from general practice computer systems using Morbidity Information and Export Syntax (MIQUEST). MIQUEST is a Department of Health sponsored application which allows data extraction from the different brands of GP computer system.20

We aggregated the data and processed it using an established methodology.21 This involved creating a large, single data table, with controlled metadata headers for each column of data and one line per patient.22 The individual patient’s identity is pseudonymised – replaced by a unique number which can only be decoded within the originating practice. These data were transferred into a statistical package for analysis (SPSS version 15). We used descriptive statistics to describe these data and odds ratios (OR) with 95% confidence intervals (95% CI) and the probability of this happening by chance (P values) to compare control and intervention practices.

We obtained consent from a medical research ethics committee to conduct this evaluation. Individual practices that supplied data provided written consent.

Box 1 The dataset to evaluate the impact of the memory problems leaflet campaign

Demographic details Year of birth, gender, ethnicity

Problem titles Confused, forgetful, Alzheimer’s, dementia, depression (as diagnosis or symptom), stress, panic disorder, anxiety, change in personality, senile/pre-senile organic psychosis, schizophrenia, obsessive–compulsive, alcohol and drug dependence, mental health ‘exception codes’

Investigations Rating scales for depression, blood pressure, full blood count, renal function, liver function, cholesterol and lipids, thyroid function tests

Therapy Antidepressants, antipsychotics, antianxiety, hypnotics and anxiolytics therapy

Referral Routine and emergency referral codes
Results

The 14 intervention practices had a combined population of 88,924. Their mean list size was 6352 and the practice size ranged from 2837 to 11,717. The control locality consisted of seven practices and had a smaller population of 53,863. The mean list size of the controls was 7695 and they ranged from 2708 to 11,912. The proportion of those over 55 years old was above the national average in the intervention practices, whereas in the control locality the population over 65 years was below the national average (see Figures 2 and 3). Ethnicity recording was poor and so is not reported. In the intervention practices it ranged from 0% to 2.7%; in the controls from 0% to 4.7%. Overall, only 0.7% of the intervention and 1.1% of the control practices had records of ethnicity.

The recorded prevalence of memory problems increased with age. Just under 1% of the population (0.8%, n=1186) were recorded in GP information systems as having memory problems. The proportion rose to 2.5% of the population over 55 years old: 2.9% of women and 2.1% of men. The intervention locality had nearly the twice the prevalence of memory problems and dementia recorded at baseline (OR 1.67; 95% CI 1.47–1.91; P<0.001). The difference in recorded prevalence between the intervention and control practices was almost entirely accounted for by the increased proportion of over 85-year-olds with memory problems in the intervention group (Table 1). The proportion of people presenting with memory problems in all other age bands was similar in both groups of practices, varying by less than 0.1%.

However, the rise in recording of memory problems was faster in the control than in the intervention practices. In the intervention locality there were 287 (0.32%) new ‘incident’ cases recorded in the before period and 369 (0.42%) in the after period. The rate of recording of cases rose by just under one-third (29%). In the control locality there were 78 (0.15%) incident cases before the intervention and 128 (0.24%) after, a rise of just under two-thirds (64%).

Young people with memory problems were much more likely to have had investigations for treatable causes than people without memory problems in the

Figure 2 Age–sex pyramid comparing the intervention population with the English 2001 census population

Figure 3 Age–sex pyramid comparing the control practice population with the English 2001 census population
same locality; with increasing age people with memory problems are no more likely to be investigated than those without (Table 2). The rate of investigation of patients with and without memory problems was consistent between both localities. Overall, just under 40% of people with memory problems had blood tests; there was no difference in this between the localities (OR 0.95; 95% CI 0.72–1.25; \( P = 0.71 \)).

There was greater than threefold use of anti-depressants in the control group (Table 3). In all age groups the control practices were roughly three times more likely to start antidepressants with people who had memory problems compared with those who did not. By way of contrast, the intervention locality was much less likely to implement antidepressant therapy with those with memory problems. Of people in the control group with memory problems, 34% (108/316) were newly prescribed antidepressants compared with 9% (78/870) in the intervention practices (OR 0.19; 95% CI 0.13–0.27; \( P < 0.001 \)). Depression screening tools were so infrequently used in both groups (<0.1%) that these data could not be analysed.

There was a record of 16.1% (8658/53863) of the control population and 16.7% (14856/88924) of the intervention group having been referred to further care at some time. However, many of these codes were non-specific with less than 15% of the referrals specifying psychiatric referral. The largest single group of the specific relevant referral codes was referral to a psychiatrist: 1.6% (1147/88924) and 1.1% (591/53863), for intervention and control groups respectively, fell into this category. The use of non-specific codes for referral (‘Referral for further care’ was the most common) meant analysis below the level of referral was not possible.

Overall 82% of people with memory problems were referred to secondary care. Of people in the intervention group, 83.4% \( (n=739/886) \) were referred to

<p>| Table 1 Recording of memory problems by age band in intervention and control practices |</p>
<table>
<thead>
<tr>
<th>Age band</th>
<th>Intervention locality</th>
<th>Control locality</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Memory problem n (%)</td>
<td>No memory problem n (%)</td>
</tr>
<tr>
<td>&lt;54</td>
<td>66 (0.1)</td>
<td>59 233 (99.9)</td>
</tr>
<tr>
<td>55–64</td>
<td>71 (0.6)</td>
<td>12 379 (99.4)</td>
</tr>
<tr>
<td>65–74</td>
<td>111 (1.3)</td>
<td>8723 (98.7)</td>
</tr>
<tr>
<td>75–84</td>
<td>–12 (5.2)</td>
<td>5716 (94.8)</td>
</tr>
<tr>
<td>≥85</td>
<td>310 (13.4)</td>
<td>2003 (86.6)</td>
</tr>
<tr>
<td>All</td>
<td>870 (1.0)</td>
<td>88 054 (99.0)</td>
</tr>
</tbody>
</table>

<p>| Table 2 Numbers and proportion of people with and without memory problems who have had four or more investigations post-intervention |</p>
<table>
<thead>
<tr>
<th>Age band</th>
<th>Intervention locality</th>
<th>Control locality</th>
</tr>
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<tr>
<td></td>
<td>Memory problem n (%)</td>
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</tr>
<tr>
<td>&lt;54</td>
<td>11 (16.7)</td>
<td>3310 (5.6)</td>
</tr>
<tr>
<td>55–64</td>
<td>22 (31.0)</td>
<td>2925 (23.6)</td>
</tr>
<tr>
<td>65–74</td>
<td>54 (48.6)</td>
<td>3197 (36.7)</td>
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<tr>
<td>75–84</td>
<td>128 (41.0)</td>
<td>463 (43.1)</td>
</tr>
<tr>
<td>≥85</td>
<td>105 (33.9)</td>
<td>790 (39.4)</td>
</tr>
<tr>
<td>All</td>
<td>870 (100)</td>
<td>88 054 (100)</td>
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secondary care compared with 78.4% (n=254/324) in the control group (OR 1.29; 95% CI 0.99–1.93; \( P = 0.044 \)). Referral was much more likely than investigation (40%) or antidepressant prescription (16%).

The rate of referral in the intervention locality was static, changing from 313 referrals pre-intervention to 320 in the ten months after. The referral numbers in the control group grew over the same period from 61 to 96 by approximately 150%. However, the intervention practices referred a much higher proportion of those with a new diagnosis of memory problems – 94% (497/529) for the intervention practices and 78% (135/174) for the controls.

The intervention locality increased the number of individuals prescribed cholinesterase inhibitors by about one-third (100 to 137); in the control locality prescribing more than doubled (16 to 42). Whilst the absolute number of people prescribed cholinesterase inhibitors was greater and increased more in the intervention practices, the proportion of people with memory problems prescribed was not significantly greater (OR 1.21; 95% CI 0.77–1.89; \( P = 0.38 \)). The increase in the prescription of antidementia medication in the intervention practices appears to have been due to patients who had ceased to comply restarting medication.

### Discussion

#### Principal finding

Routinely collected general practice computer data demonstrates how the recording, investigation, referral and treatment of patients with memory problems changed during the leaflet campaign organised by the Alzheimer’s Society.

The intervention locality had a higher baseline recording of memory problems, referred more of these patients to secondary care and prescribed cholinesterase-inhibitors to more individual patients. However, overall they investigated their patients no more than the control locality and prescribed antidepressants to people with memory problems less often.

Although the age–sex profiles of the intervention and control locality were different, they were similar in their recorded prevalence of memory problems, rate of investigation, use of antidepressants, referral and use of cholinesterase. What differences existed were principally in the management of over-85-year-olds; an age group highly pertinent to this study.

#### Implications for practice

A leaflet campaign may have a role in improving quality in localities that are already achieving a good standard of care. The intervention practices were more likely to record memory problems, refer and prescribe antidementia medications. Currently the general practice financially incentivised, quality-based contract has possibly improved the standard of care, but it may lack incentives once practices have achieved their quality points. This type of campaign may empower patients to navigate their way more effectively around the National Health Service. However, other stimuli were changing the control practices at a faster rate, although they were starting from a lower base.

The leaflet campaign may have improved compliance in people who had discontinued therapy. All of the people who were additionally prescribed cholinesterase inhibitors were recorded as having been

### Table 3 Numbers and proportion of people with and without memory problems who have been newly prescribed antidepressant therapy

<table>
<thead>
<tr>
<th>Age band</th>
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<tr>
<td></td>
<td>Memory problem n (%)</td>
<td>Memory problem n (%)</td>
</tr>
<tr>
<td></td>
<td>No memory problem n (%)</td>
<td>No memory problem n (%)</td>
</tr>
<tr>
<td>&lt;54</td>
<td>7 (0.0)</td>
<td>3271 (5.5)</td>
</tr>
<tr>
<td>55–64</td>
<td>9 (0.1)</td>
<td>1178 (9.5)</td>
</tr>
<tr>
<td>65–74</td>
<td>15 (0.4)</td>
<td>844 (9.7)</td>
</tr>
<tr>
<td>75–84</td>
<td>26 (1.3)</td>
<td>657 (11.5)</td>
</tr>
<tr>
<td>≥85</td>
<td>21 (3.0)</td>
<td>281 (14.0)</td>
</tr>
<tr>
<td>All</td>
<td>870 (100)</td>
<td>88 054 (100)</td>
</tr>
<tr>
<td></td>
<td>12 (19.7)</td>
<td>2947 (7.1)</td>
</tr>
<tr>
<td></td>
<td>12 (31.6)</td>
<td>856 (13.7)</td>
</tr>
<tr>
<td></td>
<td>23 (46.9)</td>
<td>453 (12.8)</td>
</tr>
<tr>
<td></td>
<td>33 (33.7)</td>
<td>255 (13.8)</td>
</tr>
<tr>
<td></td>
<td>28 (40.0)</td>
<td>92 (14.6)</td>
</tr>
<tr>
<td></td>
<td>316 (100)</td>
<td>53 547 (100)</td>
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prescribed this medication prior to the ‘before’ period. It is also of interest that, despite NICE guidance regarding limiting their use,7 the number of prescriptions for cholinesterase inhibitors is increasing.

Comparison with the literature

The Alzheimer’s Society has been active for many years in raising the profile of older people with dementia and memory problems in older people. These issues have been reflected in important recent reports23–25 and in the controversy surrounding anti-dementia drugs. It is feasible that the audit of routinely collected data might form an additional tool in raising standards not incorporated within these reports.

There is some literature about the use of community led leaflet campaigns as a quality improvement tool. Previous campaigns, for example the ‘Defeat Depression’ campaign, have often concentrated on direct communication with and education of GPs and other primary care professionals, rather than focusing on supplying patients with information backed up by other information provision.26 Similar approaches have been tried with asthma and have also shown apparent success.27

Limitations of the study

The study demonstrates the strengths and weaknesses of routinely collected data. Demographic details were strong, with the exception of ethnicity recording. It is hard to interpret apparent changes in prevalence combined with improvement in data quality. With computerised laboratory links pathology data are largely complete, though other investigations, such as brain scans, may just be reported in hospital letters and not coded in the general practice computer record. Computerised referral, and more recent changes in the general practice contract to encourage the use of screening questionnaires, may improve these data. We did not look at any link between health economic status and prescribing.28

Call for further research

Comparing a single locality and its neighbour has limitations. We were informed that contamination was unlikely, as the two clinical communities had their own meetings etc. However, it is likely that some ‘cross-border’ communication between community, staff and patients occurred. It would have been better if the intervention could have been implemented at a single practice level. This intervention might better be tested using a cluster randomised design.

Conclusions

A community based campaign may have a role in improving the quality of care; during this campaign recording and management of memory problems increased. Routinely collected data can be readily collected from practices and processed to evaluate a quality improvement initiative, though these data have limitations. This study highlights the strengths of routinely collected data in providing useful information about people with memory problems and the importance of including a comparator group in studies.

ACKNOWLEDGEMENTS

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REFERENCES


20 NHS Connecting for Health. MIQUEST. www.connectingforhealth.nhs.uk/systemsandservices/data/miquest


ETHICS

We obtained consent from Thames Valley Research Ethics Committee to conduct this evaluation.

CONFLICTS OF INTEREST

None.

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