

Excess cases are more important here because anticipation will relate only to new tumours that have become detectable since the previous screen. Finally, when screening ceases at around age 64-69, the incidence returns to a lower than expected rate.

The most informative analysis in Zackrisson et al's study is the comparison of the cumulative incidence of breast cancer in the screened and the non-screened groups of women born between 1908 and 1922 and randomised between 1976 and 1978.¹ This is a mature cohort with follow-up to 2001 when about 60% of the women had died. The main finding is a 10% increase in the lifetime occurrence of breast cancer (including cancer in situ) in the screened group.

The study's low statistical power precludes an exact estimate of over-diagnosis (95% confidence limits around the 10% estimate are 1% and 18%). Because some women randomised to screening were not screened and some women in the control group were, the intention to screen analysis leads to somewhat conservative estimates of over-diagnosis and of the reduction in breast cancer mortality (around 17%).

To put these numbers into perspective, let us for simplicity assume that they are both correct. In a population where the lifetime risk of breast cancer is 8% and the lifetime risk of dying from breast cancer from age 50 onwards is 2.5%, screening 250 women may prevent about one death from breast cancer. Screening would, however, also lead to the over-diagnosis of two cases. The woman whose death from breast cancer is

prevented receives all the important benefit, whereas the two over-diagnosed women pay part of the price by becoming breast cancer patients and undergoing treatment. We cannot predict, however, which three women these will be.

The trouble is that although we can easily calculate these or alternative numbers based on different sets of data and assumptions, we cannot determine who the three women are. Ideally we should try to identify prognostic factors to distinguish the over-diagnosed cases and reduce the aggressiveness of their treatment. The first step towards this is to appreciate the reality of over-diagnosis and its likely magnitude. Zackrisson et al's study should inspire similar estimations of over-diagnosis in other populations, not only for breast cancer but also for colorectal cancer, prostate cancer, and other cancers, where organised screening or other diagnostic tests are being introduced.

Contributors: HM and ED jointly wrote the commentary.

Funding: None.

Competing interests: None declared.

- 1 Zackrisson S, Andersson I, Janzon L, Manjer J, Garne JP. Rate of over-diagnosis of breast cancer 15 years after end of Malmö mammographic screening trial: follow-up study. *BMJ* 2006;332:689-91.
- 2 International Agency for Research on Cancer. IARC handbooks of cancer prevention. *Breast cancer screening*. Lyon, France: IARC Press, 2002.
- 3 Duffy SW. Some current issues in breast cancer screening. *J Med Screen* 2005;12:128-33.
- 4 Moller B, Weedon-Fekjaer H, Hakulinen T, Tryggvadottir L, Storm HH, Talback M, et al. The influence of mammographic screening on national trends in breast cancer incidence. *Eur J Cancer Prev* 2005;14:117-28.

doi 10.1136/bmj.38768.401030.7C

Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study

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BMJ 2006;332:692-5

Abstract

Objective To test the effectiveness of educational interventions in improving detection rates and management of dementia in primary care.

Design Unblinded, cluster randomised before and after controlled study.

Setting General practices in the United Kingdom (central Scotland and London) between 1999 and 2002.

Interventions Three educational interventions: an electronic tutorial carried on a CD Rom; decision support software built into the electronic medical record; and practice based workshops.

Participants 36 practices participated in the study. Eight practices were randomly assigned to the electronic tutorial; eight to decision support software; 10 to practice based workshops; and 10 to control. Electronic and manual searches yielded 450 valid and usable medical records.

Main outcome measures Rates of detection of dementia and the extent to which medical records

showed evidence of improved concordance with guidelines regarding diagnosis and management of dementia.

Results Decision support software ($P=0.01$) and practice based workshops ($P=0.01$) both significantly improved rates of detection compared with control.

There were no significant differences by intervention in the measures of concordance with guidelines.

Conclusions Decision support systems and practice based workshops are effective educational approaches in improving detection rates in dementia.

Introduction

Inadequate detection of dementia in primary care and poor management have been documented nationally and internationally. People with dementia and their



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families are being denied optimal pharmacological and psychosocial intervention.

We previously developed three educational interventions for use in primary care—an electronic tutorial on a CD Rom, decision support software, and practice based workshops.¹⁻⁵ The decision support software has been incorporated into Egton Medical Information Systems (EMIS) electronic medical record for its subscribers and is now available to about 5000 practices in the United Kingdom. A curriculum for practice based workshops for general practitioners and the electronic tutorial are available for download from the Alzheimer's Society website (www.alzheimers.org.uk).

We compared the effects of these three educational interventions on detection rates and concordance with guidelines regarding the diagnosis and management of dementia in primary care.

Participants and methods

Participating practices

We used an unblinded, cluster randomised before and after controlled design. We approached practices in one complete and one part health board area (central Scotland) and in two health authority (London) areas through a combination of local group meetings, letters with follow-up phone calls, and visits to individual practices. Practices were offered financial reimbursement to cover costs up to £900 (€1312, \$1562), depending on the number of partners. Practices had to be using EMIS or GPASS (general practice administration system for Scotland) software for patient records (because our decision support software was written for these software packages) and to document clinical encounters in the electronic record (that is, not just use it for prescribing).

Of the 124 practices approached, 36 entered and 35 (28%) completed the study. Participating practices in London under-represented the area's average for older and male general practitioners and those working alone—groups that are over-represented in London compared with the national workforce of general practitioners (see bmj.com).

Medical records

All practices identified registered patients aged ≥ 75 who had been diagnosed as having dementia or, in the opinion of the general practitioner or specialist, or both, had "probable dementia." Practices conducted electronic searches of their clinical record system for the terms dementia, confusion, memory loss, and cognitive impairment. Medical and nursing staff updated this electronic search manually. Cases were identified before and nine months after the introduction of the educational interventions. When the characteristics of patients at baseline were compared, the profiles of age and sex were similar across all four arms, but the proportion of patients in residential care was lower in the decision support software and control arm practices.

Educational interventions

We tested three educational interventions: an electronic tutorial on CD Rom, decision support software, and practice based workshops with a standard curriculum. They reflect different approaches to adult

Management concordance score (seven items)

- Concerns of carer
- Behaviour problems
- Depression (assessment or treatment, or both)
- Referral to, or involvement of, social services
- Referral to, or involvement of, voluntary organisations
- Anti-dementia (cognition enhancing) drugs
- Review of medication

learning; the electronic tutorial for self directed learning; decision support software for real time, real case learning; and workshops for peer reflection about real cases. Control practices were visited only to collect data. Further details about the development, format, and piloting of the interventions are reported elsewhere.¹⁻⁵

Randomisation

Using a computer generated program, we randomly assigned eight practices to the electronic tutorial, eight to decision support software, 10 to workshops, and 10 as controls. The research team and practices remained blinded to randomisation until after baseline data had been collected.

Outcome measures

Detection rates were based on the case finding exercise described above, which was conducted before and about nine months after the intervention. Data were extracted from the records after the second case finding exercise, unless the patient had died or left the practice.

We transcribed and scrutinised manual and electronic records for the recording of actions considered to be best practice in the diagnosis and management of dementia in primary care, based on evidence based guidelines⁶ and prescription of anti-dementia (cognition enhancing) drugs.⁷

The concordance scores for diagnosis and management were created by counting whether particular items were recorded. We extracted all data at the end of the study, calculating scores for before the intervention

Diagnosis concordance score (10 items)

- Request for blood tests at index consultation
- Request for blood test after index consultation and before diagnosis
- Referral to consultant, nursing, or secondary care at index consultation
- History of patient's symptoms taken at index consultation
- History of patient's symptoms taken after index consultation and before diagnosis
- Cognitive testing completed at index consultation
- Cognitive testing after index consultation and before diagnosis
- Depression considered after index consultation and before diagnosis
- Scan conducted after index consultation and before diagnosis
- Diagnosis disclosed to carer or patient, or both

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Table 1 Number (percentage) of patients aged ≥ 75 diagnosed with dementia before and after intervention (n=280)

	Workshop	Tutorial	DSS	Control
Before*	47 (69)	43 (80)	71 (70)	49 (89)
After	21 (31)	11 (20)	32 (30)	6 (11)
Difference†	6.55, df=1, P=0.01	1.80, df=1, P=0.18	7.31, df=1, P=0.01	—

DSS=decision support software.

*Omits cases diagnosed in another practice.

†Wald test; comparison with control.

up to the time of the baseline search and scores for after the intervention from records from after the baseline date.

Analysis

We assessed the effect of the interventions at the practice level because the data were cluster based, and we conducted analyses on an intention to treat basis. Analyses of all quantitative responses were performed with a general linear model with the arm and time as fixed effects and practice identity as a random effect.

We analysed differences in detection rates by using binary logistic regression to include the cluster effect. These were calculated before and after the intervention, excluding cases previously diagnosed in another practice.

Concordance scores for diagnosis and management before and after the intervention were not directly comparable as they comprised counts of actions taken over two different lengths of time: the period before the intervention could be as long as 12 years, whereas the period after the intervention was about nine months. Thus we examined differences in baseline concordance scores across the four arms of the study and then repeated the analysis for scores after the intervention.

Results

The 35 practices reported 683 eligible patients—equivalent to a prevalence of dementia of 5.2% among the 13 068 registered patients aged ≥ 75 . Of these there were a total of 450 valid and usable records (see bmj.com).

Detection rates

Cases identified after the interventions represent 31% of all cases diagnosed in the practice based workshops arm, 20% in the electronic tutorial arm, 30% in the decision support software arm, and 11% in the control arm (table 1). This difference was significant for the workshop and decision support software but not the tutorial on CD Rom (see bmj.com).

Concordance with recommendations

There was no significant difference in mean concordance scores for the recommended approach to establishing a diagnosis (table 2) or recommended management (table 3) for patients diagnosed by the current practice before or after intervention.

Discussion

Principal findings

This study of the effectiveness of educational interventions relating to dementia in primary care found a significant improvement in rates of reported cases of dementia with decision support software and practice based workshops compared with control. (The decision support software is a relatively simple and practical intervention to implement.) We found no difference in concordance with guidelines regarding the diagnosis or management of dementia.

Explanation of results

The lack of evidence of improved concordance with guidelines regarding the diagnosis may be due to the relatively low number of cases identified after the intervention and the relatively few cases in the control arm. This led to reduced power, although we could still identify important differences with which to assess changes in approaches to diagnosis before and after the intervention.

The lack of significant changes in concordance with guidelines regarding diagnosis and management may be a function of relying on the medical record; practitioners may have improved their practice but did not record it. There may have been advantages in providing practitioners with the concordance form at the outset of the study. There is some indication that the more distinct the diagnosis the better the quality of

Table 2 Mean (SD) diagnosis concordance scores before and after intervention

	Workshop	Tutorial on CD Rom	DSS	Control	P value
Before*	3.2 (2.4), n=47	3.1 (2.4), n=43	2.8 (2.2), n=71	2.8 (1.9), n=49	0.4†
After‡	3.5 (2.4), n=21	3.6 (1.4), n=11	3.1 (2.4), n=32	3.3 (2.0), n=6	0.4§

DSS=decision support software.

*Valid records diagnosed in current practice before intervention.

†F=0.97, df=3,179 for overall difference between groups.

‡Valid records diagnosed in current practice after intervention.

§F=0.95, df=3,46 for overall difference between groups.

Table 3 Mean (SD) management concordance scores before and after intervention

	Workshop	Tutorial	DSS	Control	P value
Before*	2.5 (1.7), n=58	2.5 (1.7), n=84	2.0 (1.6), n=115	1.9 (1.6), n=64	0.05†
After‡	2.3 (1.5), n=112	1.5 (1.4), n=102	1.8 (1.4), n=163	1.3 (1.3), n=73	0.3§

DSS=decision support software.

*Means include all valid records of patients diagnosed before intervention in current and previous practice.

†F=2.6, df=3,284, for difference between arms.

‡All valid records.

§F=1.2, df=3,418, for difference between arms.

What is already known on this topic

General practitioners face difficulties in diagnosing and managing dementia and need training and education

Various educational approaches are available

What this study adds

Decision support systems and workshop formats are effective in improving detection of dementia in primary care

record, a finding that does not bode well for the quality of dementia-related record keeping in primary care.⁸

The lack of change in concordance with guidelines regarding the diagnosis and management of dementia is consistent with findings by others on the broader use of decision support systems.⁹⁻¹⁰ This might be because adherence to generic algorithms is not appropriate to decision support systems,¹¹⁻¹³ or because it requires adaptation to ensure patient centred consultations. There also may have been insufficient training in the use of the decision support systems.¹³

Strengths and weaknesses of the study

Our results show the value of including multiple sources and types of outcomes in the assessment of effectiveness. A potential weakness is that our approach was randomised at the level of practice, thus removing any effect of local opinion leaders from influencing the diffusion of innovation. The curriculum may also have benefited from involvement of patients and carers.

Unanswered questions and future research

Our research tested each intervention in isolation, and the extent of their combined effectiveness should be explored. Further research might usefully explore the potential additive effect of combining locality initiatives with practice based initiatives. In a multicultural society there is a need to test the effectiveness of interventions with the full range of ethnic groups. Within our patient led NHS it is timely that patients and their carers also

contribute not only to the evaluation of such interventions but also to their development.

We thank the practices and carers who participated in this study and the people with dementia who consented to their records being scrutinised; Richard Simpson for his early involvement with the study; Ken Collins; members of the research advisory group; and Campbell Software Solutions. Additional resources were supplied by the North Central Thames Research Network and the Scottish Executive. We also thank Jane Mallinson for preparing the manuscript and Eryk Grant for his professional support.

Contributors: See bmj.com.

Funding: Alzheimer's Society through the Alexander and Christina Dykes Project Grant.

Competing interests: SI has received research funding from pharmaceutical companies producing drugs used in the treatment of Alzheimer's disease.

Ethical approval: Local ethics committees.

- 1 Iliffe S, Wilcock J, Turner S, Bryans M, Downs M. Educational interventions for dementia care: their development and content. *Gerontologist* 2002;42(S1):66.
- 2 Iliffe S, Austin T, Wilcock J, Bryans M, Turner S, Downs M. Design and implementation of a computer decision support system for the diagnosis and management of dementia syndromes in primary care. *Methods Inf Med* 2002;41:98-104.
- 3 Iliffe S, Wilcock J, Austin T, Walters K, Rait G, Turner S, et al. Dementia diagnosis and management in primary care: developing and testing educational models. *Dementia Int J Soc Res Pract* 2002;1:11-23.
- 4 Wilcock J, Iliffe S, Walters K, Rait G, Austin T, Turner S, et al. The development of an evidence-based curriculum for dementia care training in general practice. *Educ Ageing* 2003;17:217-36.
- 5 Turner S, Iliffe S, Downs M, Bryans M, Wilcock J, Austin T. Decision support software for dementia diagnosis and management in primary care: relevance and potential. *Aging Ment Health* 2003;7:28-33.
- 6 Eccles M, Clarke J, Livingston M, Freemantle N, Mason J. North of England evidence based guidelines development project; guideline for the primary care management of dementia. *BMJ* 1998;317:802-8.
- 7 National Institute for Health and Clinical Excellence. *Guidance on the use of donepezil, rivastigmine, and galantamine for the treatment of Alzheimer's disease*. London: NICE, 2001.
- 8 Jordan K, Porcheret M, Croft P. Quality of morbidity coding in general practice computerized medical records: a systematic review. *Fam Pract* 2004;21:396-412.
- 9 Suchman LA. *Plans and situated actions: the problem of human-machine communication*. Cambridge: Cambridge University Press, 1987.
- 10 Eccles M, McColl E, Steen N, Rousseau N, Grimshaw J, Parkin D, et al. Effect of computerised evidence based guidelines on management of asthma and angina in adults in primary care: cluster randomised controlled trial. *BMJ* 2002;325:941-4.
- 11 Fugelli P. Trust—in general practice. *Br J Gen Pract* 2001;51:575-9.
- 12 Fahey T. A missed opportunity. Letter. *BMJ* 2002;325:941.
- 13 Purves IN. Clarification and lessons from this study. Letter. *BMJ* 2002;325:941.

(Accepted 23 February 2006)

Blade Runner

Sometimes it happens during sign-in rounds: I hear nurses and physicians experienced in caring for patients talking about "cystics." There, I will say it only one more time. People have diseases, they are not defined by them. "Are you a smoker?" the novice sometimes asks a patient.

I tell them, "Smokers don't quit. People who smoke—they can quit!"

Five years ago, during morning sign-in rounds, we discussed a patient with cystic fibrosis: 35 years old; likely to die soon; not cooperative, not happy, often angry, sometimes lashing out at healthcare workers, clerks, and residents. Not a "good patient."

"Thirty five is pretty good survival for a cystic," someone said.

"Not really," I replied. "I am over 35, have three young children, and am looking forward to seeing my grandchildren. Who would be satisfied to die at 35?"

So now, sometimes, when discussing the care of patients with cystic fibrosis I ask the house staff if they have seen the film *Blade*

Runner, a hardboiled detective thriller set in the future. A small group of replicants, synthetically engineered humans created as soldiers and enormously gifted physically and intellectually, return to earth to find their "creator," desperate not to die in the prime of their lives, at the age of 25. They find their creator and, overcome with rage at his inability or unwillingness to help them, kill him.

Perhaps in the future, if therapies capable of prolonging life become available to a rich and fortunate few, almost all of us shall feel the pain and frustration that comes from living with the knowledge that we will in some sense die prematurely. In the meantime, I shall continue to recommend *Blade Runner* to every person who uses the term "cystic."

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