TYM AND ALZHEIMER’S DISEASE

More testing needed

Although the test your memory (TYM) test for detecting Alzheimer’s disease is self administered, it was given out by clinic staff to referred clinic attendees with comparisons provided for defined clinical subgroups. The people filling in the questionnaires had already seen their general practitioner, and were seen immediately afterwards by a clinician who could address any concerns. The danger of calling a test self administered in the title of a paper is that it encourages downloading from the internet and doing it at home without interpretation or support. The diagnosis of dementia requires multidisciplinary assessment, often over a period of time.

TYM was administered to a comparatively young population (median age under 70) with potentially high educational levels; memory clinic referrals have not been shown to be representative of the general older population. TYM’s advantage over the mini mental state examination (MMSE) is uncertain as the full MMSE receiver operator curve was not provided. These factors mean that TYM should not be assumed to perform as well in general practice waiting rooms or at home. If this is the intention for this test it must be applied in many different and appropriate settings, with longitudinal follow-up to ensure validity, as well as appropriate support to those completing it.

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Competing interests: None declared.


How specific is TYM?

Is the test your memory (TYM) test specific in discriminating Alzheimer’s disease from other forms of dementia in clinical practice? Only 31 patients had “other forms of dementia and mild cognitive impairment,” 16 having Lewy body dementia, 13 frontotemporal dementia, and two supranuclear palsy; none had vascular dementia.

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Competing interests: None declared.


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Competing interests: None declared.


Too many false positives

Brown and colleagues report 93% sensitivity and 86% specificity for their self administered screening test for Alzheimer’s disease. They conclude that “it is a powerful and valid screening test for the detection of Alzheimer’s disease.” However, doctors and lay people are often confused by such conditional probabilities, and the value of a screening test is best appreciated when statistics are expressed in natural frequencies. For infrequent disorders, even high values of sensitivity and specificity can lead to an unacceptable number of false positives.

The accompanying editorial gives an expected prevalence of 13 cases of Alzheimer’s disease in 1000 people aged 65-69. Using this as the base rate together with the figures for sensitivity and specificity, I calculated test results in natural frequencies. For every individual correctly declared to have Alzheimer’s disease, about 11, on average, will be falsely declared to have this dread disease.

This test is likely to become popular among doctors and lay people, given its ease of administration and the frequency with which the important question “Do I have Alzheimer’s?” arises. The dissemination of the test would be unfortunate because the potential for misunderstanding its results is high, and will lead to many people incorrectly assessing or being told that they have a cruel disorder for which there is no hope.

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Competing interests: None declared.


Age profile?

I wondered why Brown and colleagues have incorporated so many young people in their cross sectional control sample (including 18 year old volunteers whose risk of Alzheimer’s disease is infinitesimal). The presence of ceiling effects and age effects in the control data means that younger people will be more likely to score at the top of the scale—and the psychometric properties of the test your memory (TYM) test could be unwittingly distorted by the inclusion of so many junior participants.

Older people with presumed Alzheimer’s disease tended to score more highly than younger people. That older controls tended to fare worse than younger people is worrying, although the pairwise statistical comparisons between age-matched controls and suspected Alzheimer’s cases are reassuring. However, cut off scores/centile distributions and receiver operator characteristic curves would be helpful for the age groups at highest risk.

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Competing interests: None declared.


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Competing interests: None declared.

Diagnoses can be meddlesome

Nicholl wrote: “Without a diagnosis, patients and carers cannot access the services they need.” Echoing the National Dementia Strategy, she uses this as justification for early diagnosis of dementia.1

We don’t have to organise services in this way. Any diagnosis should always require this careful judgment: Will giving this label to this person at this time do more good than harm? It’s like drawing a line in the sand. Diagnosis belongs to disease theory and is only one of many ways of categorising suffering. The diagnosis of dementia has serious implications for the future of a family; an early firm diagnosis is often elusive and early medical treatments remain marginally helpful. If the key early interventions are social and emotional support then why medicise early symptoms? They should be socialised instead, and the emphasis placed on support services. Why make access to these contingent on a formal medical diagnosis? In our eagerness to do good and to be seen to be doing good, we risk drawing our line in the sand in a place that is meddlesome.

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Competing interests: None declared.

1 Nicholl C. Diagnosis of dementia. BMJ 2009;338:b1176. (9 June.)

Cite this as: BMJ 2009;339:b2835

Authors’ reply

The test your memory (TYM) test is intended to be self administered by the patient—allowing testing of 10 cognitive skills in minimal operator time—but it needs to be overseen and interpreted by a health professional.2 The test is therefore self administered but not for self diagnosis. It is hard to choose an alternative title which clarifies this without being too long. As a result of the publicity concerning self testing of Alzheimer’s disease: cross sectional study. BMJ 2006;338:b3030. (9 June.)

Cite this as: BMJ 2009;339:b2834

The TYM test is not a diagnostic test. The diagnosis of Alzheimer’s disease needs a proper clinical assessment from a trained professional. The TYM test is an aid in this process but not a replacement for it. Human beings and brain diseases are inherently variable, and a quick memory test which would allow an untrained person to safely diagnose Alzheimer’s disease or distinguish Alzheimer’s disease from other forms of degenerative or vascular dementia is unlikely ever to exist. An experienced clinician may recognise a pattern of scoring on the TYM which suggests Alzheimer’s disease or semantic dementia in many patients.

We include a wide age range of controls because many younger patients have cognitive complaints as a result of epilepsy, multiple sclerosis, and other conditions, and we believe the TYM test may be useful in these patients. The average TYM scores of controls are remarkably stable but do fall off after the age of 70, as do most similar tests. There were no significant differences between older and younger patients with Alzheimer’s disease.

We are well aware of the ethical debate around early diagnosis of Alzheimer’s disease and share many of the concerns of correspondents. Progress towards early diagnosis must be made for several reasons. If a treatment that halts Alzheimer’s disease becomes available, we need a test to identify those likely to benefit.

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Competing interests: None declared.


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INTERROGATION OF DETAINEES

Physicians have been involved

In 2007 I was invited to examine the detainee log of an inmate of Guantanamo to provide a medical opinion on whether the treatment amounted to torture.1 It has now been concluded that it did.2 My scrutiny found that medical staff not only were present during the interrogation but also made no attempt to intervene to stop it. A military radiologist was even flown in to report on a computed tomogram taken when the detainee became seriously dehydrated from hunger strike. Newly declassified legal memos from 2002 and 2005 concluded that certain “enhanced interrogation techniques” did not constitute torture, partly based on the assurance that medical personnel would be on hand to ensure that the techniques used did not cause “severe pain or suffering.”3 The Red Cross report leaked in April details the involvement of medical personnel present at and supplying medical interventions during the use of these enhanced techniques, some of which it describes as torture.4

This seems clear evidence that military medical personnel acted in contravention to the Declaration of Tokyo that a “physician shall not be present during any procedure during which torture or any other forms of cruel, inhuman or degrading treatment is used or threatened.”5 I do not therefore understand how Pope and Gutheil can assert that “physicians limited their involvement in detainee interrogations to such a degree that they prohibited even monitoring an interrogation with intent to intervene” and that “physicians do not design interrogation plans for specific detainees or observe interrogations with the intent to intervene because this undermines the physician’s role as healer.”6

Physicians have no grounds to feel superior to psychologists: to date, no US military physician has had a licence to practise revoked as a consequence of their involvement, whatever the policies of the American Medical Association.

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Competing interests: None declared.

1 Sands P. Torture team. Allen Lane, 2008.
3 American Civil Liberties Union (ACLU). Released: the Bush administration’s secret legal memos. Available at: www.aclu.org/safefree/general/acl_memos.html
5 Pope KS, Gutheil TG. Contrasting ethical policies of physicians and psychologists concerning interrogation of detainees. BMJ 2009;338:b163. (30 April.)

Cite this as: BMJ 2009;339:b2838

Authors’ reply

We appreciate Seltzer’s thoughtful comments.1 In our article “Contrasting ethical policies of physicians and psychologists concerning interrogation of detainees,” we examined the ethical policies of the American Medical Association (AMA) and American Psychological Association (APA).2 What Seltzer describes as our erroneous conclusions are our restatement of AMA’s formal ethical policy.

For example, Seltzer quotes us as saying “physicians do not … observe interrogations with the intent to intervene because this undermines the physician’s role as healer.” However, we wrote: “Priscilla Ray, chair of the American Medical Association (AMA) council on ethical and judicial affairs, stated: ‘Physicians must not conduct, directly participate in,
or monitor an interrogation with an intent to intervene, because this undermines the physician’s role as healer.”

Physicians who conducted, directly participated in, or monitored an interrogation with an intent to intervene violated AMA’s explicit ethical prohibition.

APA’s ethical policies differed significantly. As our article documented, APA claimed that psychologists, unlike physicians, were uniquely qualified for this work, “knew not to participate in activities that harmed detainees,” and were contributing to national security.

Works appearing after our article’s publication provide additional documentation of how APA’s ethical policies supported psychologists’ extensive, integral roles in interrogations. One example is the 10 minute documentary “No Place to Hide: Torture, Psychologists, and the APA.”

Another example is the open letter to the APA from Amnesty International, Physicians for Human Rights, and 11 other organisations. The letter describes necessary steps to address “the terrible stain on . . . American psychology.” Here is an excerpt:

Any meaningful approach to this issue must start by acknowledging the fact that psychologists were absolutely integral . . . When the Bush administration decided to engage in torture, they turned to psychologists . . . APA leadership has much work ahead to begin to repair the harm they have caused to the profession, the country, former and current detainees and their families.

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Competing interests: None declared.

1. Seltzer A. Physicians who have been involved. BMJ 2009;339:b2881.
4. Open letter in response to the American Psychological Association Board. Available at: http://tinyurl.com/mtq6f

Cite this as: BMJ 2009;339:b2845

OVARIAN CANCER

Not a silent killer

When will ovarian cancer stop being called the silent killer? If it were truly silent, general practitioners could hardly be blamed for missing it. It is far from silent: its noise is difficult to interpret.

Recent studies of newly diagnosed women show that symptoms are common and reported to general practitioners. Although the symptoms are generally non-specific, general practitioners can identify a significant proportion of women requiring investigation. In the GP records of a recent cohort from Devon, soon to be published in the BMJ, 196 of the 212 women with primary ovarian cancer had either a symptom recorded or a mass noted before diagnosis. Eighty eight were referred for investigation on the same day as the first symptom was recorded, with a further 36 within the next week. This leaves a minority of women who experience diagnostic delays in primary care and who would benefit from a lowering of the threshold for investigation.

However, the performance of CA125 measurement has not been studied in primary care. In a recent UK screening trial 8.6% of women had an initially raised CA125 concentration. Most of them had normal results on repeat testing, but in the low prevalence setting of primary care many false positive results would be generated for each true positive.

The potential adverse effects of a false positive result for ovarian cancer are not only the emotional considerations but also the risk of biopsy, or even oophorectomy, to achieve peace of mind. False positive results on ultrasound scanning were less common in the screening trial, so ultrasoundography should remain the preferred investigation in primary care.

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INSTITUTIONAL SAFETY PROBLEM

Where is the NHS Macpherson?

Macpherson found an institutional problem of racism in the Metropolitan Police. The NHS seems to have an institutional problem about safety. Surely the failure of all the safety mechanisms at local, regional, and national levels in Staffordshire demand wider investigation than the narrow focus on the trust by the select committee, and the anecdotal approach of a recent conference.

That the responsible heads of the NHS suggest juniors should “make waves” seems superficial. Senior medical and nursing staff at Stafford tried to make waves, and were not heard. It is surely not for the trust and its staff alone to “stand up for safety.” What was happening at the primary care trust, which commissioned health care from the trust and should have been listening to the community and the staff? Did it not hear or see the waves? Perhaps the local MP has a role in ensuring safe health care for constituents. Is safety of no concern to the strategic health authority? Monitor should have a broader view of performance than purely financial issues, and the Health Care Commission itself seems to have been slow to recognise problems that were common knowledge and of concern to medical and nursing staff. A lot of waves were made, but no one in the organisation with responsibility for oversight was able to see or hear them.

The organisation as a whole seems not to have a systemic approach that makes safety a priority. Unlike flying, health care cannot be made entirely risk free, but present approaches seem to verge on the futile. The chief medical officer reported high risks of a fatal outcome, but in five years seems to have been unable to do anything about a potentially fatal hazard in drug administration. At these accident rates, the NHS’s performance would surely be regarded as unacceptable if it was responsible for running an airline. Airbus and Boeing would be expected to respond more promptly to a design issue.

The NHS, a significant customer, seems unable to exert any power as a commissioner. We need to look further than the problems of what was clearly an over-ambitious trust. Encouraging junior doctors to raise concerns is laudable, but it may take attention away from more fundamental issues. We need something better from our commissioners and higher management.

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Competing interests: None declared.

1. O’Dowd A. Staff concerns at Mid Staffordshire trust were “lost in a black hole”. BMJ 2009;339:b2297. (4 June.)
Sitting leaders ask you to stand up for safety

If junior doctors follow the recommendation of medical leaders and stand up for the safety of patients will they receive support from those leaders?

“Staff concerns about safety at Mid Staffordshire trust were ‘lost in a black hole’.”

The evidence suggests that whistleblowers who report concerns are treated no better in the NHS now than at the time of the scandal at Bristol Royal Infirmary. Medical leaders are responsible for the culture of silence. To become a medical leader one needs to compromise principles for expediency to meet the demands of politicians (in an organisation or government) with the power to advance or destroy a career. Medical leaders lack moral authority because few of them have taken the risk of speaking out on their way to the top. They are too often complicit in concealment of problems to protect their organisations or political masters.

Fiona Godlee spoke at the conference and represented the BMJ. The BMJ has removed from its website articles that have appeared in the paper journal purely to avoid the risk of the journal being sued for libel. The articles have not been retracted because there are no grounds for retraction of truthful reports. Does the BMJ want junior doctors to take the risk of losing their careers by speaking out when it is afraid of the financial cost of speaking?

Liam Donaldson also spoke at the conference. I have had correspondence and meetings with the chief medical officer to discuss misconduct by doctors, but I am left with the impression that he is unwilling or unable to act when the allegations involve senior medical leaders. Yet Sir Liam wants junior doctors to be brave enough to speak about problems.

The motivational speeches of medical leaders to junior doctors seem to be like the pep talks of generals to soldiers at the Somme before the troops went over the top and the leaders returned to their chateau for lunch. Medical leaders must now lead from the front and share the risks.

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Competing interests: None declared.

Grove and colleagues advise general practitioners how to manage asymptomatic patients with incidental lymphocytosis and ultimately chronic lymphatic leukaemia, recommending repeat blood counts at 2-4 weeks and 3 months and then referral to a haematology clinic.

This rational testing does not sit comfortably with the less rational cancer waiting times target that patients with a suspicion of cancer should be seen within 15 days. The suspicion of cancer in this case was extremely high from the outset but did not warrant urgent referral. Asymptomatic patients with monoclonal gammapathy are a similar example. These examples highlight ongoing clinical concerns with all inclusive cancer targets.

The lead cancer clinicians for the west of Scotland have expressed their concerns that cancer targets come both with a clinical cost and at the expense of audit of treatment and outcome. Yet clinical audit underpins cancer networks and is the key to service improvement. The delivery of cancer services should be refocused on the results of clinical audit rather than the ever increasing demands of targets.

Cite this as: BMJ 2009;339:b2815

Summary care record

The Royal College of General Practitioners now seems to support the summary care record. As a college member, I am concerned that it may not have dealt comprehensively with enrichment—the addition of important information such as a disease summary, drug treatments, and allergies to the record. Bolton local medical committee opposes the enrichment of summary care records without explicit patient consent because of concerns about confidentiality.

Patients need to know what is happening to their data. Let them decide. No enrichment without explicit patient consent.

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Competing interests: None declared.


2 Cole A. Sharing patient data should not be based on implied consent. BMJ 2009;338:b2441. (16 June.)

Cite this as: BMJ 2009;339:b2812

Time for continuity of record

Most lay people assume that the NHS is a national health outfit that works together to look after them. They do not appreciate its tribal nature, with warring factions unwilling to communicate vital information about drugs and allergies to fellow health professionals. It is time we dragged ourselves into the 21st century communications age. General practitioners no longer work 24 hours a day 7 days a week doing their personal on call. Continuity of the patient record is needed now that we do not have continuity of personal care.

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Competing interests: I am RCGP clinical lead, NHS Dorset.


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Joy of shared health records

The summary care record is a step towards a truly shared health record away from the fragmented jumble of paper and partially computerised records in most of the NHS. This area has been using shared records for a decade. I can view what has happened to my patients when they are seen by my colleagues working out of hours, in palliative care teams, in community nursing, and medical outpatients. More importantly these colleagues have access to the information that enables them to do their job more safely and efficiently. Most importantly my patients get better care, and they know it.

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Competing interests: MC is associate clinical lead (IT), NHS Bradford and Airedale.

1 Cole A. Sharing patient data should not be based on implied consent. BMJ 2009;338:b2441. (16 June.)

Cite this as: BMJ 2009;339:b2814