Blurred lines for our dementia policy?

Political Drive for "Early Diagnosis"

Dementia diagnosis requires ideally observations by a physician over a number of weeks/months to assess deterioration in *planning, learning, memory, language, judgment, higher order perception, or behaviour*

Unfortunately problem has become that "early diagnosis for dementia" viewed by public as "memory testing"

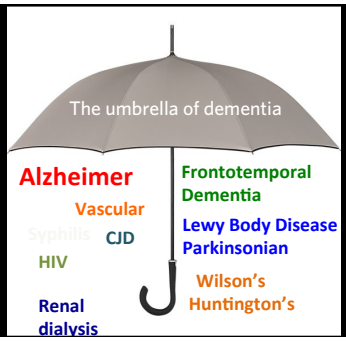
Dementia now grossly publicly misunderstood to be 'memory loss'

Sources:
Le Couteur, Doust, Creasey and Brayne, *BMJ 2013 (September 9)*.
Wilson JMG, Jungner G. The principles and practice of screening for disease. World Health Organization 1968.

- Marketing of "early diagnosis" must consider potential harms of mislabeling
- There are hundreds of different causes of dementia in real life

Common types of dementias globally

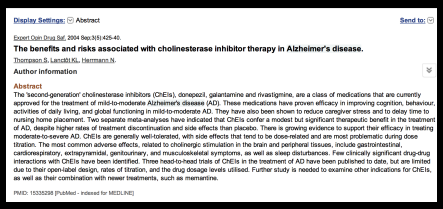
- Alzheimer's disease: 62%
- Vascular dementia: 17%
- Dementia with Lewy bodies: 4%
- Frontotemporal dementias: 2%
- Parkinsonian dementias: 2%
- Other dementias: 3%



There's a critical need to rule out other causes of similar presentations (e.g. *medication side effects, vitamin B_{12} deficiency , depression, underactive thyroid*).

Only 5 to 10% of people with mild cognitive impairment may progress to dementia each year, and as many as 40%-70% of people may not progress or their cognitive function may even improve

- **No drugs reliably prevent the progression of Alzheimer's disease in the majority of patients**
  (90 trials ongoing: International Standard Randomised Controlled Trial Number Registry Oct 2013)
- Cholinesterase inhibitors risks include increased risk of hip fractures, syncope, pacemaker insertion


Display Settings: Abstract Send to:

Expert Opin Drug Saf. 2004 Sep;3(5):425-40.

The benefits and risks associated with cholinesterase inhibitor therapy in Alzheimer's disease.

Thompson S, Lanctôt KL, Herrmann N.

Author information

Abstract

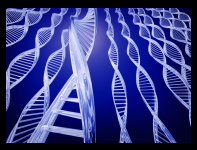
The 'second-generation' cholinesterase inhibitors (ChEIs), donepezil, galantamine and rivastigmine, are a class of medications that are currently approved for the treatment of mild-to-moderate Alzheimer's disease (AD). These medications have proven efficacy in improving cognition, behaviour, activities of daily living, and global functioning in mild-to-moderate AD. They have also been shown to reduce caregiver stress and to delay time to nursing home placement. Two separate meta-analyses have indicated that ChEIs confer a modest but significant therapeutic benefit in the treatment of AD, despite higher rates of treatment discontinuation and side effects than placebo. There is growing evidence to support their efficacy in treating moderate-to-severe AD. ChEIs are generally well-tolerated, with side effects that tend to be dose-related and are most problematic during dose titration. The most common adverse effects, related to cholinergic stimulation in the brain and peripheral tissues, include gastrointestinal, cardiorespiratory, extrapyramidal, genitourinary, and musculoskeletal symptoms, as well as sleep disturbances. Few clinically significant drug-drug interactions with ChEIs have been identified. Three head-to-head trials of ChEIs in the treatment of AD have been published to date, but are limited due to their open-label design, rates of titration, and the drug dosage levels utilised. Further study is needed to examine other indications for ChEIs, as well as their combination with newer treatments, such as memantine.

PMID: 15330298 [PubMed - indexed for MEDLINE]

- There is no doubt that a correct timely diagnosis of a dementia can benefit the person, family and friends. This is in keeping with the view of reasonable professionals.

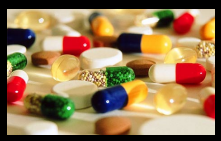
WHO ELSE MIGHT BENEFIT FROM THE DRIVE TO AN EARLY DIAGNOSIS?

Geneticists looking for genes that can be patented



Neuropsychologists selling their memory tests

Pharmaceutical companies looking for more "diagnosed" persons with dementia to increase use of "treatment" drugs



The test

Screening tests can result in "false positives" and "false negatives." It takes time and expertise to correctly assess someone for dementia, which could include….

A HISTORY FROM THE PERSON HIMSELF

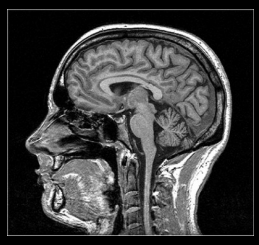
A HISTORY FROM SOMEONE CLOSE

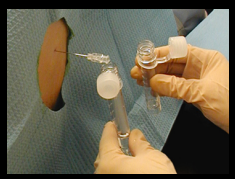
INFORMAL OR FORMAL PSYCHIATRY

A PSYCHIATRY, CLINICAL GENETICS, GENERAL MEDICAL, OR NEUROLOGY SPECIALIST OPINION

A CT BRAIN SCAN

A MRI SCAN





CEREBROSPINAL FLUID FROM A LUMBAR PUNCTURE

A BRAINWAVE SCAN

A "false positive" occurs when person who doesn't have dementia "fails" or scores poorly on test.

This is called test's *sensitivity*.

A "false negative" happens when person who does have dementia "passes" or scores well on test.

This is called test's *specificity*.

Source:
Mitchell AJ, et al. Clinical recognition of dementia and cognitive impairment in primary care: a meta-analysis of physician accuracy. Acta Pscyhiatr Scand 2011;357:165-175).

Professional concerns about handling the diagnosis correctly

Concerns about harms associated with diagnosis:

- → anxiety and depression
- → stigma
- → losing health insurance coverage, driving privileges, or employment
- → effect on family finances and emotions
- → affects identity, leading to feelings of loss, anger, uncertainty, and frustration
- → diagnosis of dementia related illness affect roles and relationships within family and wider social networks

The diagnosis process – some hard facts

Nearly 50% of people who have positive results on screening for cognitive impairment refuse subsequent diagnostic evaluation.

Identification of early dementia by family physicians highly variable

Diagnostic process in the wrong hands can be distressing, alarming, stigmatising as well as costly ($5,000 one off cost)

This is a problem as dementia is the illness most feared by people over 55 years

Is genetic testing the answer?

- Geneticists' claims that *genetic testing* is important for prevention and treatment of Alzheimer's in populations is exaggerated
- Only know about genes for rare conditions: Early Onset Familial Alzheimer Disease, Frontaltemporal dementia, Huntington's Disease
- Genes and dementias sorted out in 500 families but 35 million people world-wide have dementia

Source:
Loy CT et al. Genetics of dementia. Lancet August 6 2013

Therefore there is no doubt that resources have to put into counselling for the diagnostic process itself, that this should be in the hands of appropriate professionals, and there must be an adequate level of properly financed post-diagnosis care and support.

..but pressure from the "Dementia Prevalence Calculator" and its ambitions *aka* targets

HOW MORE PEOPLE WITH A DIAGNOSIS CAN BE ACHIEVED TO ASSIST THE 'STAKEHOLDERS'

- 2011 Canadian Census reported 5 million people 65 years and older living in Canada.
- Thus, using new DSM-5 definition, estimated number of people in this age group with *minor neurocognitive disorder* would be
  16% X's 5 million = 800,000.
- Number is higher if younger groups added.
- Add to 747,000 with dementia diagnosis in Canada
- DSM-5 definition of *minor neurocognitive disorder* inflates number with dementia in population

Source
Flicker LA et al, Memory loss. Med J Aust 2012:196:114-117.

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"BIOMARKERS"

"Take just one initiative – Bio Bank. More than half a million people have volunteered to take part in this providing blood samples, getting their vital signs checked, so we can see how diseases like dementia get signalled. The plan is to use Bio Bank to take brain scans of up to 100,000 people – allowing us to see the earliest stages of Alzheimer's and other diseases. That is the kind of ambition we're seeing here in the UK ambition that should give hope to people right around the world.|
(David Cameron 11 December 2013) #G8Dementia

No large scale population studies have suggested

- association between any biomarkers and dementia or underlying neuropathological abnormality
- WHICH ARE sufficiently robust to use in routine clinical practice despite decades of research

Biomarkers become less accurate in older people in whom dementia is most common and diagnosis is most contentious

Despite paucity of evidence, biomarkers and amyloid scans are entering everyday practice, particularly in memory clinics

- But amyloid scanning does not predict cognitive functioning in older people

Sources:

Brayne et al. Making Alzheimer's and dementia research fit for populations. Lancet 2012;280:1441-1443

Noel-Storr AH et al. Systematic review of the body of evidence for the use of biomarkers in the diagnosis of dementia. Alzheimers Dementia 2013;9:e96-205

The pitch

The reality

31 October 2010 Last updated at 16:30

Share

Councils' body says cuts threaten home care for elderly

"Virtually all" councils in England and Wales could be forced to end home help for elderly and disabled people, the Local Government Association has said.

The LGA, which represents 422 authorities, has warned MPs budget cuts may result in services being restricted to those with "critical" needs.

A £3bn funding shortfall could affect people with dementia, Parkinson's disease and diabetes, it said.

Care Services Minister Paul Burstow said it was "wrong to scare people".

But shadow health minister John Healey said: "This shows you cannot

The LGA says people with dementia, Parkinson's and diabetes face losing support in their homes

Related Stories

Blurred lines which need some definition fast…