Dementia in general practice

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Incidence of dementia: Tasmania

- Now: 5,000
- 2031: 10,000
- 2051: 15,000
Recent Irish study

- Survey of 600 GPs
- GPs reported diagnosing 4 new cases annually
- 90% had received no dementia specific training
- 83% wished for some

(Cahill, 2006)
Recent Australian study

- Diagnosis of dementia not established in **20%**
- MMSE not known by GP in **56%**
- Home safety not assessed in **44%**
- Legal matters not considered in **>50%**
- Most carers felt supported by the GP
- Most carers felt **their own health suffered**

*(Bridges-Webb, 2007)*
Diagnosis

Autopsy findings show diagnosis of dementia made before death in:

- **3%** early dementia
- **24%** moderate dementia
In general practice, nearly **75%** of patients with moderate to severe dementia are **unrecognised** by primary care **physicians** as having cognitive impairment. 

( *Gifford, Neurology*, 1999 )

**20%** of **family** informants failed to recognise memory problems in those fulfilling the criteria for dementia.
How do GPs diagnose dementia?
Usually by doing an MMSE?
MMSE

- Average **sensitivity & specificity** for detecting dementia are 83% & 82%
- If applied to a population of 65-74 year olds, the **false positive rate would be 93%**
- Is dementia score:  < 20 ?
  < 24 ?
- Is annual decline of **3.4** points in AD
- **Score correlates with several clinical outcomes:**
  - Functional status
  - Behavioural change
  - Length of time in hospital
  - Urinary incontinence
  - Mortality
But..

Dementia is about so much more!
GPCOG

- Includes informant history (6 items) and cognitive testing (9 items)
- 67 GPs
- Less than 10 minutes to administer
- Sensitivity 0.85; specificity 0.86

*Brodaty, J Am Geriatric Society, 2002*
Difficulties of diagnosis for GPs

- Lack of **training** (especially for older GPs)
- Symptoms masked by “usual **personality**”
- Lack of **consensus** of diagnostic criteria
- Multiple **forms** of dementia
- Perceived lack of efficacy of **medication**
- Sense of therapeutic **nihilism**
- Need for **corroborative** history
- **Time** needed to be able to make a diagnosis
- Ignorance of **support services**
- Lack of **case managers**
Early diagnosis: crucial

1. An explanation for **carers** (guilt)
2. **Exclusion** of other causes
3. Planning for the **future** (inc. $)
4. Appropriate **management** of other conditions
5. Assistance to maintain **autonomy**
6. Emotional and physical **help for carers**
7. **Crisis avoidance**
Consequences of failure to diagnose

- **Crisis** situations for person with dementia and carers
- Failure to establish **care services**
- Failure to establish **financial** planning
- Inappropriate use of **medical resources**
- For carers: **loneliness and isolation, anxiety, exhaustion, poverty**
Early diagnosis

- Audit Commission survey of 8051 UK general practitioners
- 60% agreed that an early diagnosis is important

(Renshaw, 2001)
Carers’ needs

- Early diagnosis
- Access to treatment
- Ability to plan for the future
- Assistance in coming to terms with the diagnosis and prognosis
- Assistance with care
- Visibility and recognition
Carers

- Want to be told of the diagnosis as soon as possible  
  \( (Kennedy, 1993) \)

- Who felt their GPs had been helpful and supportive: 69%

- Who felt the GPs’ knowledge of dementia was very good: 24%

  \( (UK \text{ Alzheimer’s Disease Society, 1995}) \)
Low detection rate

Reports of relatives of dementia patients:

- GPs are reluctant to make a diagnosis
  (Haley, 1992)
- GPs tend to minimise the problems
  (Huag, 1994)
- GPs tend to focus on the hopeless nature of dementia
  (Chenoweth, 1985)
W.A. Study of communication between carers and GPs (Bruce, 2002)

- Structured interviews
- N=21 live-in carers and 19 of their GPs
- Most referrals occurred after there had been considerable carer stress, or had been precipitated by a crisis
...W.A. study

- Carers failed to discuss their difficulties for many reasons, but predominantly because they saw it as their duty to cope.
- The doctors found it difficult to know how the carers were coping, or when to intervene.
- Some carers resisted the doctor’s efforts.
W.A. study

- **Time constraints** were a significant problem for both groups
Diagnosing Dementia in General Practice

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GPs and Dementia

- General practitioners play a central role in the provision of primary health care to elderly people (Downs, 1996; Brodaty, 1990)

- However, GPs are famously slow to diagnose dementia (Wilkinson, 2004)
There is little Australian data on delays in diagnosing dementia in general practice. In a small qualitative study in 2002 it was found that relatives caring for those with dementia felt that they had to wait a long time before they had a formal diagnosis of dementia. They felt that GPs were reluctant to pursue a diagnosis of dementia in some cases. (Hansen, 2003)
Research Questions

- How do Tasmanian general practitioners understand dementia?
- What are their experiences diagnosing dementia?
- How are these experiences affecting the diagnosis and causing delays in diagnosing dementia in general practice?
Findings

- 13 Interviews conducted with GPs. Rural/Urban, North/South
Holistic Viewpoint

- GPs take a holistic view of elderly patients; **dementia is rarely seen as a discrete disease** entity. Instead it is seen as part of an elderly patient’s overall state of health/illness.

- **Accessing services** and **shortages of services**, arthritis, diabetes, depression, loneliness and heart failure were described as **bigger problems than dementia**

- Dementia is viewed by GPs as being **part of the ageing process**
GPs do not pursue a diagnosis of dementia for the sake of it. Instead, they follow up on dementia if it seems to be impacting negatively on the patient in conjunction with other issues or health problems.
Holistic viewpoint/diagnosis

- Patients are *often observed over a period of time* before the GPs start to attach a label of possible dementia.

- More likely to observe *emotional changes, lack of self care and grooming* or *hear reports from community nurses* about an empty refrigerator or a dirty house than to *observe memory problems*. 
Very often I’d say of the people that I end up doing something about dementia or screening for it, **probably the family is maybe 70% responsible.** They’re the ones who initiate it

*GP 7*

I guess **ageing people never really complain about the dementing process** because dementia is almost **euphoric**, you tend to live with it rather than suffer from it

*GP 1*
Family members/ carers

- However, in some cases family members or carers may **resist attempts by the GP to test for dementia.**

_Sometimes the partner doesn’t want to acknowledge that they (their spouse) might have dementia. … I think **there is a stigma** attached, … relatives of the patients are often worried, particularly children, that they’re going to get it_
I'm interested in trying to let people live a normal life and *not become a patient*. The problem is that we are *medicalising the ageing process*.

I would have many people in a nursing home that I would have hung a label of dementia on, that I wouldn't have had any physical investigations done mainly because they are *now in a happy safe warm environment* and any external influence is not going to have any difference on their progress of dementia.
Medication

- Another factor underlying low rates of early diagnosis is that **GPs are unlikely to consider the use of dementia specific medication** as sufficient reason to actively screen for dementia.

- This is partially related to a **reluctance to prescribe** medications or request testing for what they viewed as a problem related to ageing.
Medication

- However, the main reason for the GPs in this study not viewing accessing medication as being very important, was that they were very skeptical about the value of the medications for dementia.
If you have got Alzheimer’s disease you are really looking at a downhill course. The people that I’ve tried cholinesterase inhibitors on, haven't in my opinion done well.

The drugs that we’ve been promised might be useful are not that brilliant, so you know, you do wonder why you bother at times trying to pick it up early.
Diagnosis unnecessary

- It is apparent throughout these findings that GPs feel there is nothing or very little they can do about dementia.
- This leads to a reluctance to diagnose dementia unless they feel there is a good reason to do so.
- The main reasons described for this were helping families to access services or information about dementia.
- GPs were doubtful that a diagnosis held many benefits for the actual patient.
Some GPs described feeling that there were no advantages to diagnosis in terms of accessing services because the dementia services in their area were booked out.

Other GPs suggested that a diagnosis might actually make it harder to access services such as hospital and residential care.
Conclusion and Recommendations

- GPs have reasons for delaying the diagnosis of dementia.
- They feel unable to treat dementia and have concerns about accessing services.
A Swedish perspective

2001 Swedish study of 128 GPs:

- **<8%** regarded dementia as normal part of aging
- **20%** regarded their own knowledge sufficient to enable them to make a diagnosis
- **71%** wanted to increase their knowledge ((Olafsdottir, 2001))
Early dementia symptoms

- What do you think?
GPs’ dementia knowledge

Symptoms indicating early dementia:

- Memory problems (87% of GPs)
- Personality changes (50%)
- Psychiatric symptoms (47%)
- Cognitive disturbances (45%)
- Delirium (30%)
- ADL changes (22%)
- Somatic symptoms (6%)

(Olafsdottir, 2001)
52% of GPs estimated they managed 80-100% of patients on their own (i.e. <20% were referred to a specialist)
Inclination of GPs to discuss topics with elderly patients:

- General well-being (90%)
- BP (77%)
- Sleep problems (73%)
- **Cognitive problems** (57%)
- Holding a drivers licence (12%)
Disclosure

- GPs who would always, or often, discuss the diagnosis and consequences of the diagnosis with the patient: 57%

- GPs who would discuss the diagnosis and its consequences with a relative at the next visit: 52%

(Olafsdottir, 2001)
Disclosure

British study:
- Would disclose terminal cancer: 95%
- Would disclose dementia: 39%

(Vassilas, 1998)
GPs’ satisfaction

When managing someone with dementia:

- With the specialist clinic: 43%
- With community services: 24%

(Olafsdottir, 2001)
PAS Cognitive Impairment Scale

Scores:
0 = Correct answer
1 = Incorrect answer, refused to answer
? = Not asked due to sensory/motor impairment
Psychogeriatric Assessment Scales (PAS)

- I am going to name three objects. After I have said them, repeat the names. Remember what they are, as I will ask you again in a few minutes.
- Apple, Table, Penny.
- Could you repeat the three items for me?
- Repeat until all three items are learned—stop after 5 unsuccessful attempts.
QUESTION 1

- I am going to give you a piece of paper. Would you please write any complete sentence on that piece of paper? (if sentence is illegible, ask can you read it for me and copy onto a sheet)
- Sentence should have subject and verb & make sense.
- Correct is a score of 0
- Incorrect or refusal is a score of 1
- Not asked (eg sensory or motor impairment)?

1
Now what are the three items I asked you to remember?

Score 0 for each object remembered, 1 for each item not remembered or the person refuses.
Please listen carefully to the following name and address, and then repeat it.

John Brown, 42 West Street, Kensington

Please go on remembering the name and address; I will ask you about it later.
I am now going to say the names of some people who were famous and I would like you to tell me who they were or why they were famous in the past.

Score is 0 for each person correctly identified and 1 for an incorrect answer or refusal to answer.
- **Charlène Chaplin** (actor, comedian, film star, comic)
- **Joseph Stalin** (Soviet, Russian, WW2 leader, communist leader)
- **Captain Cook** (explorer, sailor, navigator, discoverer)
- **Adolf Hitler** (German, Nazi, WW2 leader)
New Years Day falls on what date?

- For a correct answer score is 0
- For a wrong date, does not know or refusal score is 1.
- Not asked?
QUESTION 5

- What is the name and address I asked you to remember a short time ago?

- Answer: John Brown 42 West Street Kensington

- Score 0 for correct answer
- Score 1 for not mentioned or subject refuses
- Not asked?
QUESTION 6

- Here is a drawing. Please make a copy of it here.
- Hand the person the paper with 2 intersecting five sided figures; point to the space underneath it to copy.

- For a correct copy score is 0
- Incorrect or refusal to copy score is 1
- Not asked?

15
QUESTION 7

- Read aloud the words “CLOSE YOUR EYES” and do what it says.

- Score 0 if subject closes eyes
- Incorrect or refusal score is 1
- Not asked?

16
QUESTION 8

- Now read aloud the words “COUGH HARD” and do what it says.
- Score 0 if subject coughs
- Incorrect or refusal score is 1
- Not asked?
QUESTION 9

- *Tell me what objects you see in this picture?*
- *Hand the four object sheet to the person. The order objects are identified is not important.*
Items seen in picture are:

- Kettle
- Telephone
- Scissors
- Fork

- Score 0 for correct
- Score 1 for object not mentioned or subject refuses
- Not asked?
How to calculate PAS score:

Add Questions 1 to 9

Number of Boxes with ?

- If ? = 0, then “Basic Total” is the Total Score.
- If ? is not 0, proceed to step below:

\[
\frac{21 \times \text{Basic Total}}{(21 - ?)} = \text{Score:}
\]

FINAL SCORE:
Dementia

As the regular pattern, there is:

- Poor planning and judgment
- Inability to initiate
- Failing in functions (aside from physical reasons)
- Inability to draw clock face
- PAS score $\geq 5$

Two or more ticks = strong suspicion of dementia
Ethical issues for general practitioners

- Differentiation between normal aging and cognitive impairment
- Disclosure of diagnosis
- Perceived lack of treatment efficacy
- Lack of care resources
- Development of competence
GPs and dementia

1. General practice is mostly private enterprise, but subsidised by the federal government. Time constraints are of the essence.

2. General practitioners need time and expertise to make a diagnosis.

3. Carers are tired, time poor and try to be dutiful.
4. General practitioners need help: ACAT, practice nurses, hospital
5. Carers need education
6. Carers need support
7. The new funding tool for RACFs needs a diagnosis of dementia