COMMUNICATING A DIAGNOSIS OF DEMENTIA

Jemima Dooley
PhD Student, University of Exeter Medical School
Professor Rose McCabe
Professor of Clinical Communication, University of Exeter Medical School
Dr Nick Bass
Senior Clinical Lecturer UCL, Consultant Psychiatrist, East London NHS

ShareD study team: Professor Gill Livingston, UCL; Dr Maya Soni, University of Exeter
ShareD Research Project: Communication in Memory Clinics

- Shared Decision Making in Mild to Moderate Dementia
- April 2014-April 2017
- Video recordings of diagnostic feedback and follow-up meetings in Memory Clinics
- Examining how diagnoses are delivered and decisions are made
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Devon (n=96 meetings)</th>
<th>London (n=68 meetings)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinicians (n female)</td>
<td>n=8 (4 female)</td>
<td>n=12 (6 female)</td>
</tr>
<tr>
<td>• Psychiatrists</td>
<td>n=6</td>
<td>n=11</td>
</tr>
<tr>
<td>• Geriatricians</td>
<td>n=2</td>
<td>n=1</td>
</tr>
<tr>
<td>Dementia</td>
<td>n=34</td>
<td>n=45</td>
</tr>
<tr>
<td>• AD</td>
<td>n=19</td>
<td>n=25</td>
</tr>
<tr>
<td>• Vascular</td>
<td>n=4</td>
<td>n=7</td>
</tr>
<tr>
<td>• Mixed</td>
<td>n=7</td>
<td>n=5</td>
</tr>
<tr>
<td>• Other/Unspecified</td>
<td>n=4</td>
<td>n=8</td>
</tr>
<tr>
<td>MCI/VCI</td>
<td>n=27</td>
<td>n=9</td>
</tr>
<tr>
<td>Depression/Anxiety</td>
<td>n=11</td>
<td>n=3</td>
</tr>
<tr>
<td>Other</td>
<td>n=8</td>
<td>n=0</td>
</tr>
<tr>
<td>No diagnosis/Further Tests</td>
<td>n=16</td>
<td>n=10</td>
</tr>
<tr>
<td>Cognitive Test Score</td>
<td>ACE-R (n=85)</td>
<td>ACE-R (n=38)</td>
</tr>
<tr>
<td></td>
<td>Dementia: 69 (SD: 9.9; 48-90)</td>
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<tr>
<td></td>
<td>No dementia: 83 (SD: 9.8; 56-98)</td>
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<tr>
<td></td>
<td>MMSE (n=20)</td>
<td>Dementia: 65 (SD 15.9; 28-94)</td>
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<tr>
<td></td>
<td>Dementia: 20 (SD 5.9; 7-28)</td>
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<tr>
<td></td>
<td>No Dementia: 24 (SD 7.8; 15-29)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>47% female</td>
<td>60% female</td>
</tr>
<tr>
<td>Age</td>
<td>75 (44-92)</td>
<td>77 (52-91)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>98% White</td>
<td>71% White, 16% black, 6% Asian</td>
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</table>
Key issues in Delivering a Diagnosis of Dementia

- Life-changing, degenerative illness
  - One of the greatest fears of older adults (Bond and Corner 2001)

- Complicated diagnostic process
  - No one test to diagnose

- Potentially impaired patient insight
  - Short term memory difficulties
Communicating a Diagnosis of Dementia

68 audio and video recordings
- AD: 40 (59%)
- Vascular: 8 (12%)
- Mixed: 9 (13%)
- Unspecified: 6 (9%)
- Other: 5 (7%)

3 NHS trusts, 19 clinicians (53% female; 84% psychiatrists)

Average meeting length: 28:33 (08:25 - 01:04:05)
Stages of Dementia Diagnosis Delivery

1. Elicit Patient’s Orientation
2. Review the History
3. Feed Back Test Results
4. Deliver the Diagnosis
Elicit Patient’s Orientation

Occurs in 81% of meetings (n=56)
• Average 00:55 (range 00:05 - 03:40)

Ensuring Shared Knowledge of the Purpose of the Meeting

• “do you know why you’re here?” n=27
• “do you remember you had some tests” (for e.g.) n=13
• “the purpose of this meeting is..” n=16
Do you know why you’re here? – Video Clip
Do you remember? – Video Clip
“Do you know why you’re here?”

DR: what expectation did you have of coming here today?

PT: somebody that would help with my memory

DR: oh right (. ) yes well that's what that's what we do

PT: mm

“Do you remember..?”

DR: right so I don’t know if you remember me I’m Dr (NAME) I came to see you at home

PT: you did?

DR: I did indeed [yes ]

PT: [and how] long ago was that

DR: oo now you’ve got me
Occurs 80% of meetings (n=55)

Average 3:50 minutes (range 00:15 – 26:30)

Prior History has been taken:
- Reviewing to see if further developments
- Building rapport
- Eliciting patient stance
Reviewing the History – Video Clip
DR: what I’m hearing from the report that my colleague (NAME) wrote and speaking with (NAME) as well is that ever since your husband sadly died some years ago

PT: three [years]

DR: [yes ] you’ve had sort of some difficulties that have come and go but when they’ve been there they’ve caused you to have problems with memory and concentration

PT: oh well it’s the when something happens or anything I’m I sort of afterwards think oh I’ve lost my cool you know er [which shou]ldn’t be I wouldn’t be nasty

DR: [a ha ]

PT: or any[thing bad]

[yeah and ]

DR: do you lose your cool more easily these days

(0.5)

PT: no not really really I’m..
Feedback Test Results

Results fed back 95% (n=66)
- Tests fed back 78% (n=54) – after diagnosis n=5
  - Average time spent 00:47 (00:05-05:10)
- Scan fed back 88% (n=51) – after diagnosis n=13
  - Average time spent 01:29 (00:05-13:05)

Feedback includes indication of consequences
- Prepares patient for the diagnosis (Maynard, 2003)
- Can help gauge diagnosis reaction
Test Feedback – Video Clip
**Test Feedback**

DR: (name) did the tests again this time. hhh (0.8) it does seem that things have got quite a bit worse with the memory.

PT: w worse

DR: yes yeah I mean you did okay on some of the test but. hh I think a lot of the test you- you- (.) you struggled quite a bit with. hh so there was quite a big change from (.) from the time before.

PT: yeah yah I didn’t know (inaudible) the old age can come [in as well] you know

DR: [mm]

DR: yeah I mean I think- I think what we’d say is is that is that (. ) it is (. ) the problems are more than we would expect for someone [of you’re a:ge.]

PT: [mm er]
Diagnosis

Occurs 98.5% (n=67)
Average time spent on diagnosis discussion: 02:38 (00:20 – 10:10)
  • Approx 9% of average length of meeting

Framed as a **logical conclusion** given **accumulation of evidence**.
  • Cite patient experience and/or test results
Diagnosis

- No avoidance of “D” word (e.g. Karnieli-Miller et al, 2012)
- “Shrouding” bad news (Maynard, 2003)
  - Delay, hesitation
  - Softening: “very early stage” “mild problems”
- Uncertainty
  - Hedging: “probably..”/“I think that..” n=50 (74%)
- Don’t assume prior knowledge
  - “we call this a dementia” n=25 (37%)
- Acknowledging prior concerns/stigma of diagnosis
  - “some people find this scary” n=21 (31%)
Alzheimer’s Disease Diagnosis – Video Clip
Mixed Dementia Diagnosis – Video Clip
Alzheimer’s Disease

DR: it's certainly at the mild or early end of the spectrum of memory problems.
PT: [yeah]
DR: .hh and the commonest cause for a scan like this and the memory difficulties that we're measuring on the test would be something called Alzheimer's disease.
PT: that I'm starting Alzheimer's
DR: yeah
PT: that's horrendous.

Mixed Dementia

DR: .hh and I think you are in the early stages of a dementia.
PT: oh dear
DR: now what dementia means is memory problems it’s the sort of term that we use to describe all sorts of different types of memory problems I think in your case you’ve got what I would call a mixed dementia now by that I mean that you have partly it’s due to a change in your brain that we call Alzheimer’s disease and partly it’s due to what we call vascular dementia so that’s the blood [supply to the brain]
CR: [that’s right yeah ]
PT: oh
DR: so it’s a combination of factors now that’s actually very common lots of people we see do have this
DR: obviously it’s not something that you know people want to be told
Key issues in Delivering a Diagnosis of Dementia

- Life-changing, degenerative illness
  - Shrouding of diagnosis
  - Stepwise approach to diagnosis delivery

- Complicated diagnostic process
  - Hedging language
  - Illustrate accumulation of evidence

- Potentially impaired patient insight
  - Elicit patient orientation
  - Don’t assume knowledge of what dementia is
Next Steps

• Continue with analysing dementia diagnosis feedback

• Analyse MCI/VCI and depression/anxiety diagnosis feedback

• Analyse patient and companion interviews, and clinician focus groups

• Shared Decision Making coding

• Relationships with sociodemographic variables and cognitive test scores
Thanks for Listening

jmbd201@exeter.ac.uk  r.mccabe@exeter.ac.uk
@sharedDMdementia
http://medicine.exeter.ac.uk/research/healthserv/shared/

With thanks to Maya Soni and Penny Xanthopoulou (Devon), and Sarah Robertson, Rachel Bedder and Cate Bailey (London) for data collection

References:
Bond, J. and Corner, L. Researching dementia: are there unique methodological challenges for health service research? Dementia, 2001, 1: p.141-156