Advance Care Planning and dementia

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19 March 2013
Aims for this session

- Consider palliative & end of life care issues in the context of dementia
- Symptom burden
- Recognising the end
- Planning ahead
- PhD study
Death and dying

• Demographic trends are changing the modern experience of death and dying.
• Increasingly, this involves protracted decline due to progressive chronic co-morbidity and age related frailty, including dementia.
• The changing character of mortality poses singular challenges:

  for personal and social adaptation to an uncertain but negatively anticipated future

  for social and economic management of scarce health care resources.
End of life and dementia

• Around 500,000 people die in England each year
• 30% of those over the age of 60 will die with dementia
• 70% prefer to die at home

BUT in dementia:
• Only just over 20% achieve home death
• 20% die in Residential Care
• 56% die in hospital
  – Each spends an average of 34 days in their final year of life.
  – More than 50% have between 2 and 5 admissions in their last year of life
• People with dementia are:
  – more likely to die in the acute hospital
  – less likely to receive hospice or palliative care
  – less likely to have their spiritual needs considered when they die

(Sampson et al 2006)

• 54% of complaints in acute hospitals relate to care of the dying/bereavement care

(Healthcare Commission 2007)
When does a person stop living with dementia and start dying with dementia.......?

<table>
<thead>
<tr>
<th>CONDITION</th>
<th>FORECAST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stone is wet</td>
<td>Rain</td>
</tr>
<tr>
<td>Stone is dry</td>
<td>Not raining</td>
</tr>
<tr>
<td>Shadow on ground</td>
<td>Sunny</td>
</tr>
<tr>
<td>White on top</td>
<td>Snowy</td>
</tr>
<tr>
<td>Can’t see stone</td>
<td>Foggy</td>
</tr>
<tr>
<td>Swinging stone</td>
<td>Windy</td>
</tr>
<tr>
<td>Stone jumping up and down</td>
<td>Earthquake</td>
</tr>
<tr>
<td>Stone gone</td>
<td>Tornado</td>
</tr>
</tbody>
</table>
Sentinel events preceding active dying in late stage dementia!

- Recurrent pneumonia or urinary tract infections
  - infections not responding to anti-biotics
- Frequent fevers
- Increased eating/swallowing problems
  - weight loss/cachexia
- Unhealed skin ulcers

Up 50% of people with dementia will die <6mths
Functional Assessment Staging (FAST)

6a. Requires assistance in dressing

6b. Requires assistance in bathing properly

6c. Requires assistance with mechanics of toileting (such as flushing, wiping)

6d. Urinary incontinence

6e. Faecal incontinence

7a. Speech ability limited to about half a dozen words

7b. Intelligible vocabulary limited to a single word

7c. Ambulatory ability lost

7d. Ability to sit up lost

7e. Ability to smile lost

7f. Ability to hold head up lost

Reisberg B (1988) Functional Assessment Staging (FAST)
Psychopharmacology Bulletin, 24: 653-659
‘Delivering Choices’ - Advance care planning

Not happening because of:

• Carer exhaustion and denial
• Silo practice
• Difficulty in predicting death

Outcome:

• Stress for carers and patient
• Inappropriate resuscitation attempts
• Inappropriate admissions to acute hospitals

What is advance care planning?

ACP is a voluntary process of discussion and review to help an individual to anticipate their preferences for future care in the event they lose capacity. NICE Guidance recommends that people with dementia should have the opportunity to discuss and make decisions about their future care while they have capacity.

- Advance Care Plan (ACP)
- Advance Statements (AS)
- Advance Decisions to Refuse Treatment (ADRT)
- Living Will
- Lasting Power of Attorney (LPA) x 2
- And now.....Anticipatory Care Plan (AnCP)
And ACP in dementia?

However, there is a lack of evidence about the effectiveness of advance care planning in relation to patients with dementia or consideration of the singular issues raised by this disease.

In relation to ACP, dementia highlights ethical and practical dilemmas which require wider exploration:

- Window of opportunity
- Motivation to make an ACP
- The nature of ‘self’ and ‘future self’
- Present ‘autonomous’ self V future ‘incapacitated’ self
- Realistic anticipation all relevant future contingencies
- Own decisions and proxy decisions
- Empowering or disempowering
- Decisional regret
Themes in the literature

- Cognitive impairment and mental capacity
- Advance care planning and decisions about life sustaining treatment
- Advance care planning in dementia compared to other groups
- Family carers and decision making
- Professional attitudes
- Education of professionals and relatives

Harrison Dening K et al (2011) Advance care planning in dementia: A review. International Psychogeriatrics. 23:10, 1535-51
Phase one: Modified Nominal Groups

Explore whether people with dementia and their carers were able to generate ideas about the choices they may wish to make for their future care.

*Ranking*

**Carer group**
- No unnecessary prolonging of life

**People with dementia group**
- Maintaining family links

**Dyad group**
- No unnecessary prolonging of life

*Discussions themes*

- Control at the end of life
- Family contact towards the end of life
- Dignity and respect
- Prolonging of life unnecessarily
Nominal Group: Conclusions

• Already a divergence of views
• When present, carers influenced the person with dementia
• People with dementia did not consider end of life care issues

Implications

• Direct approach
• Guidance for practice
• Agreement in views

Phase two: Cross sectional study

- 100 dyad interviews:
  - Caring context
  - Life Support Preferences
- Nested qualitative semi-structured interviews

**Three scenarios**
- As you are today...
- Stroke and coma
- Advanced cancer

**Three Treatments**
- Antibiotics
- CPR
- Tube feeding
Results thus far....

- Twenty five dyads (25 PWD/25 carers)
  - The mean age of PWD = 80.6
  - The mean age of Carer = 66.2
- MMSE of PWD (Mean 25.2; range 20-29)
- Gender PWD (M=12 F=13)
- Gender Carer (M=5 F=20)
- A wide range of ethnic backgrounds were represented as were levels of education.
Most agreement was found on rating current health state on LSPQ.

In all health scenarios lowest agreement was found for resuscitation and tube feeding which had the lowest levels of agreement in treatment choices.

Scenario 2 (stroke and coma) showed low agreement ($\kappa = 0.332; P=0.052$).

Scenario 3 (advanced cancer) showed moderate agreement ($\kappa = 0.478; p=0.005$) treatment issues.
We will now extend to a full study with 100 dyads and also examine contextual factors that influence agreement.

Site 1: North London
Site 2: Cambridge and Peterborough
Site 3: Leicestershire and Rutland
Site 4: West London

What next?
Multivariate analysis

Agreement on Life Sustaining Treatments
Quality of care-giving relationship
Carer burden and distress

Whilst the study requires more power, results suggest that carers may not be able to consistently predict the treatment preferences for the person with dementia and this has implications for the reliability of proxy influence on end of life care of a person with dementia.
Thank you for listening

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