Advance Care Planning and dementia: Feasible?
Results of a doctoral study
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Advance care planning involves discussion of future care preferences to develop an understanding of an individual’s wishes in the event that they are unable to make decisions for themselves (National Council for Palliative Care 2007)

NICE Dementia QS5: People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer, about the use of advance decisions to refuse treatment, advance statements, Lasting Power of Attorney, Preferred Priorities of Care
Literature Review

- 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

Phase one

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

Carer group
No unnecessary prolonging of life

People with dementia group
Maintaining family links

Dyad group
No unnecessary prolonging of life

Divergence of views
When present, carers influenced the person with dementia
People with dementia found it difficult to consider end of life care issues

Phase two

- Cross sectional study
- 60 dyads
- Interview:
  - Caring context (quality of relationship, carer burden and distress)
  - Life Support Preferences

<table>
<thead>
<tr>
<th>Three scenarios</th>
<th>Three Treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>As you are today</td>
<td>Antibiotics</td>
</tr>
<tr>
<td>Stroke &amp; coma</td>
<td>CPR</td>
</tr>
<tr>
<td>Advanced cancer</td>
<td>Tube feeding</td>
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</tbody>
</table>

- Nested qualitative semi structured interviews
Results - demographics

PWD

- Age (range 58 to 93 years with a mean age of 79.2 years (SD 6.8))
- MMSE (range 20-29, mean 25.4 (SD 2.4))
- Gender PWD (M=26 F=34)
- Living with spouse 37 (62%)
- White British 38 (63%)
- Diagnosis – Alzheimer’s Disease 40 (67%)

Carer

- Age range of carers was 39 to 93 years with a mean age of 66.6 years (SD 12.8)
- Gender Carer (M=5 F=20)
- White British 42 (70%)
- Relationship to PWD being spousal 35 (58%)

A wide range of ethnic backgrounds were represented as were levels of education.
Active versus No Active Treatment

*Here and Now*

**PWD**
- Antibiotics (98%)
- CPR (88%)
- Tube feeding (65%)

**Carer**
- Antibiotics (93%)
- CPR (82%)
- Tube feeding (30%)

PWD, largely, wanted active treatments
Carers were generally, good at predicting treatment preferences

\[ k = 0.03; \text{PABAK} = 0.40, \text{P} = 0.005 \]  
\[ k = 0.30; \text{PABAK} = 0.30, \text{P} = 0.0002 \]  
\[ k = -0.02; \text{PABAK} = -0.60, \text{P} = 0.61, \text{NS} \]
## Active versus No Active Treatment

*Severe Stroke and Coma*

<table>
<thead>
<tr>
<th>PWD</th>
<th>Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics (50%)</td>
<td>Antibiotics (67%)</td>
</tr>
<tr>
<td>CPR (57%)</td>
<td>CPR (73%)</td>
</tr>
<tr>
<td>Tube feeding (50%)</td>
<td>Tube feeding (66%)</td>
</tr>
</tbody>
</table>

Only half PWD preferred active treatment

Carers tended to over predict the preference for intervention

\[ k = 0.20; \text{PABAK} = -0.20, P = 0.006 \]

\[ k = 0.25; \text{PABAK} = -0.12, P = 0.002 \]

\[ k = 0.022; \text{PABAK} = -0.60, P = 0.62, \text{NS} \]
### Active versus No Active Treatment

**Advanced cancer, 6 months to live**

<table>
<thead>
<tr>
<th>Treatment</th>
<th>PWD</th>
<th>Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics</td>
<td>47%</td>
<td>55%</td>
</tr>
<tr>
<td>CPR</td>
<td>30%</td>
<td>31%</td>
</tr>
<tr>
<td>Tube feeding</td>
<td>37%</td>
<td>37%</td>
</tr>
</tbody>
</table>

Only one third of PWD wanted active treatment. Carers were generally good at predicting treatment preferences.

- **PWD**
  - Antibiotics (47%)
  - CPR (30%)
  - Tube feeding (37%)

- **Carer**
  - Antibiotics (55%)
  - CPR (31%)
  - Tube feeding (37%)

*(k = -0.03; PABAK = -0.52, P = 0.32, NS)*

*(k = -0.07; PABAK = -0.45, P = 0.83, NS)*

*(k = 0.20; PABAK = -0.22; P = 0.0009)*
Factors that influence good prediction

- In future scenarios, at best, carers’ ability to accurately predict the treatment preferences of a PWD were moderate to low.

- Perceived carer burden and relationship quality had no influence on a carer’s ability to predict treatment preferences of a PWD.

- The more psychologically distressed a carer was the less able they were able to predict treatment preferences of the PWD in future scenarios and where the treatment was more aggressive, i.e. CPR and tube feeding.
Uncertainty of PWD for life sustaining treatment

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Scenario 1 As you are today</th>
<th>Scenario 2 Severe stroke and coma</th>
<th>Scenario 3 Advanced cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Antibiotics</td>
<td>0</td>
<td>2 (3%)</td>
<td>7 (12%)</td>
<td>9 (15%)</td>
</tr>
<tr>
<td>a) CPR</td>
<td>1 (1%)</td>
<td>6 (10%)</td>
<td>6 (10%)</td>
<td>13 (22%)</td>
</tr>
<tr>
<td>a) Tube feeding</td>
<td>8 (13%)</td>
<td>7 (12%)</td>
<td>7 (12%)</td>
<td>22 (37%)</td>
</tr>
<tr>
<td>Total</td>
<td>9 (15%)</td>
<td>15 (25%)</td>
<td>23 (35%)</td>
<td></td>
</tr>
</tbody>
</table>

Uncertainty of carers’ estimates of PWD’s preferences for life sustaining treatment

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<th>Scenario 3 Advanced cancer</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Antibiotics</td>
<td>0</td>
<td>2 (3%)</td>
<td>6 (10%)</td>
<td>8 (14%)</td>
</tr>
<tr>
<td>a) CPR</td>
<td>2 (3%)</td>
<td>5 (8%)</td>
<td>4 (7%)</td>
<td>11 (19%)</td>
</tr>
<tr>
<td>a) Tube feeding</td>
<td>10 (16%)</td>
<td>3 (5%)</td>
<td>3 (5%)</td>
<td>16 (27%)</td>
</tr>
<tr>
<td>Total</td>
<td>12 (20%)</td>
<td>10 (17%)</td>
<td>13 (22%)</td>
<td></td>
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</table>
Personal context to decision making

- Nested qualitative interviews
- 6 dyads of high, medium and low levels of agreement
- Brief interview schedule

1. How have you made decisions about healthcare and/or treatment wishes in the past?
2. What changes to this decision making process (if any) do you see the diagnosis of dementia has made?
3. What healthcare and/or treatment decisions may you need to make in the future now that there is a diagnosis of dementia made (for you/your family member)?
Decisions relating to healthcare – emergent themes

**Historic**
- Untested decision making
- Belief in the principle of shared decision making
- Gender specific decision making
- Autonomy

**Effect of a diagnosis of dementia**
- Getting the diagnosis
- Transitions to decision making
- Stepping down
- Compromises and costs

**Future decision making**
- Future care
- Planning ahead for end of life
- Trust in others
Conclusions

• Policy and the evidence base
• Window of opportunity
• Hot potato
• Do we expect too much of family carers?
• Supporting people with dementia and their family carers in decision making over time (advance care planning?)