Barriers to advance care planning for people affected by dementia: time for a rethink?

Dr. Tony Ryan & Dr. Jane McKeown
School of Nursing & Midwifery, Faculty of Medicine, Dentistry & Health, The University of Sheffield, UK
Context of ACP and Dementia

• Rising prevalence and death from dementia

• Advance Care Planning (ACP) & Guidance

• Failure to achieve good quality end of life care for people affected by dementia (Ryan et al 2013; Dempsey et al 2015)

• ACP literature: Process and outcome (van der Steen et al 2014; Brinkman-Stoppelenburg et al 2014)
Study Aims

- To understand more fully the ways in which people with dementia and their long-term co-residing partners consider and plan, or do not plan, for the future in the light of a recent diagnosis.
- To begin to consider how people with dementia and their families might be assisted to discuss their future and to formulate plans where appropriate.
Methodology

• Constructivist grounded theory (CGT) (Charmaz 2014)

I. In-depth exploration

II. Agency and meaning

III. Comprehensive and systematic

IV. Social and psychological processes

• Recruitment and interviews with spousal couples + post analysis group discussion
<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Person with dementia or caregiver?</th>
<th>Length of time since diagnosis</th>
<th>Occupational status (prior to retirement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samuel</td>
<td>78</td>
<td>Person with dementia</td>
<td>18 months</td>
<td>Skilled manual</td>
</tr>
<tr>
<td>Margaret</td>
<td>73</td>
<td>Caregiver</td>
<td></td>
<td>Skilled non-manual</td>
</tr>
<tr>
<td>Eric</td>
<td>83</td>
<td>Person with dementia</td>
<td>5 years</td>
<td>Professional</td>
</tr>
<tr>
<td>Barbara</td>
<td>73</td>
<td>Caregiver</td>
<td></td>
<td>Skilled non-manual</td>
</tr>
<tr>
<td>William</td>
<td>85</td>
<td>Person with dementia</td>
<td>4 Years</td>
<td>Professional</td>
</tr>
<tr>
<td>Mary</td>
<td>83</td>
<td>Caregiver</td>
<td></td>
<td>Homemaker</td>
</tr>
<tr>
<td>Stephen</td>
<td>72</td>
<td>Person with dementia</td>
<td>3 years</td>
<td>Skilled manual</td>
</tr>
<tr>
<td>Jane</td>
<td>72</td>
<td>Caregiver</td>
<td></td>
<td>Non-skilled manual</td>
</tr>
<tr>
<td>Sylvia</td>
<td>75</td>
<td>Person with dementia</td>
<td>18 months</td>
<td>Skilled non-manual</td>
</tr>
<tr>
<td>Stan</td>
<td>75</td>
<td>Caregiver</td>
<td></td>
<td>Skilled manual</td>
</tr>
<tr>
<td>Elizabeth</td>
<td>80</td>
<td>Person with dementia</td>
<td>5 years</td>
<td>Self-employed</td>
</tr>
<tr>
<td>Tom</td>
<td>83</td>
<td>caregiver</td>
<td></td>
<td>Self-employed</td>
</tr>
<tr>
<td>Keith</td>
<td>78</td>
<td>Person with dementia</td>
<td>4 years</td>
<td>Skilled non-manual</td>
</tr>
<tr>
<td>Bridget</td>
<td>78</td>
<td>Caregiver</td>
<td></td>
<td>Non-skilled manual</td>
</tr>
<tr>
<td>Alfred</td>
<td>77</td>
<td>Person with dementia</td>
<td>6 years</td>
<td>Professional</td>
</tr>
<tr>
<td>Rose</td>
<td>75</td>
<td>Caregiver</td>
<td></td>
<td>Skilled non-manual</td>
</tr>
</tbody>
</table>
Feeling abandoned

Postponement:
- Maintaining equilibrium
- Ageing & caregiving
- Latent planning
- ACP and the discordance with a ‘Living well with Dementia’ discourse

‘The time is right’

‘They don’t have time to talk’
Feeling abandoned

Postponement:

- Maintaining equilibrium
- Ageing & caregiving
- Latent planning
- ACP and the discordance with a ‘Living well with Dementia’ discourse

‘The time is right’

‘They don’t have time to talk’
Maintaining equilibrium

‘Well we can’t agree on it (Advance Statement) and we’ll leave it at that! We haven’t done it yet. It will get done eventually’ (Tom, Caregiver of Elizabeth)
Ageing & caregiving

‘I think of all the work involved with it (ACP). Can I cope with that? I must be honest I don’t cope as well as I used to. I would have done it earlier when I could cope.’ (Mary, Caregiver)
Latent Planning

‘I will always be there for Sylvia. I wouldn’t want her to go anywhere else other than for me to look after her. It’s my one aim, my goal that we’re always together.’ (Stan, Caregiver for Sylvia)
‘Living well with dementia’

‘I just thought well I can’t do anything about it. The only thing I can do is make the most of it’

(Samuel, PWD)

‘That’s the one thing I am concerned about. I’ve got to stop thinking too far into the future... I am trying to get out of that frame of mind and think ‘oh well we’ll go into town tomorrow”

(Margaret, Caregiver)
‘Living well with dementia’
‘There’s enough happening at the moment, there’s enough going on and we are keeping ourselves active and busy that I don’t really want to go down that route of ‘well what if this, that or the other happens’ and get all depressed about it.’ (Bridget, Caregiver)
Feeling abandoned

Postponement:
- Maintaining equilibrium
- Ageing & caregiving
- Latent planning
- ACP and the discordance with a ‘Living well with Dementia’ discourse

‘The time is right’

‘They don’t have time to talk’
The Time is Right: ‘Tipping Points’

- Work and life biography
- Family resources and practices
- Relationality in future planning
- Further losses and carer ill health: the end of ‘living well’?
- Time for reflection on living with dementia
‘The time is right’

William: This to my mind is a good time because you’ve had plenty of time to swallow the idea, in my case that I’d got Alzheimer’s. There’s been plenty of time for me to understand.

Mary: I would have done it earlier..

William: We had less understanding of the problems then
Discussion and Implications:

• Qualitative study identified potential sources of delay in families undertaking ACP
• The irony of choice at the end of life
• Relationality, nursing and couplehood work
• Time for a rethink?

Charmaz K (2014) Constructing Grounded Theory (2nd Ed.) Sage: California


Ryan T et al (2103) Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. *BMC Palliative Care*, 12(11)


Acknowledgements

- Yorkshire & Humber NIHR CLAHRC
- Participating couples
- Alzheimer’s Society
- Dr Jane McKeown
- Ms Kate Chadwick