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

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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



Pseudonym	Age	Person with dementia or caregiver?	Length of time since diagnosis	Occupational status (prior to retirement)
Samuel	78	Person with dementia	18 months	Skilled manual
Margaret	73	Caregiver		Skilled non-manual
Eric	83	Person with dementia	5 years	Professional
Barbara	73	Caregiver		Skilled non-manual
William	85	Person with dementia	4 Years	Professional
Mary	83	Caregiver		Homemaker
Stephen	72	Person with dementia	3 years	Skilled manual
Jane	72	Caregiver		Non-skilled manual
Sylvia	75	Person with dementia	18 months	Skilled non-manual
Stan	75	Caregiver		Skilled manual
Elizabeth	80	Person with dementia	5 years	Self-employed
Tom	83	caregiver		Self-employed
Keith	78	Person with dementia	4 years	Skilled non-manual
Bridget	78	Caregiver		Non-skilled manual
Alfred	77	Person with dementia	6 years	Professional
Rose	75	Caregiver		Skilled non-manual



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'



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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)



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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?

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