

Exploring the initiation and revision of ACP with and for people with dementia: a narrative study

Tharin Phenwan, Judith Sixsmith, Linda McSwiggan¹

¹ School of Health Sciences, University of Dundee

Abbreviated abstract: Advance Care Planning (ACP) is a process for individuals to create and document their personal values and preferences for care in case of future incapacitation or terminal illnesses. ACP is challenging to undertake with and for people with dementia (PwD) due to symptoms of forgetfulness and fluctuating mental capacity. The optimal timing to discuss ACP is unclear thus requires further exploration to ensure that PwD can discuss ACP at the appropriate time with the appropriate people

Related publications:

-Phenwan, T., Sixsmith, J., McSwiggan, L. and Buchanan, D. (2020) 'A narrative review of facilitating and inhibiting factors in advance care planning initiation in people with dementia', *Eur Geriatr Med*, 11(3), pp. 353-368. doi: 10.1007/s41999-020-00314-1

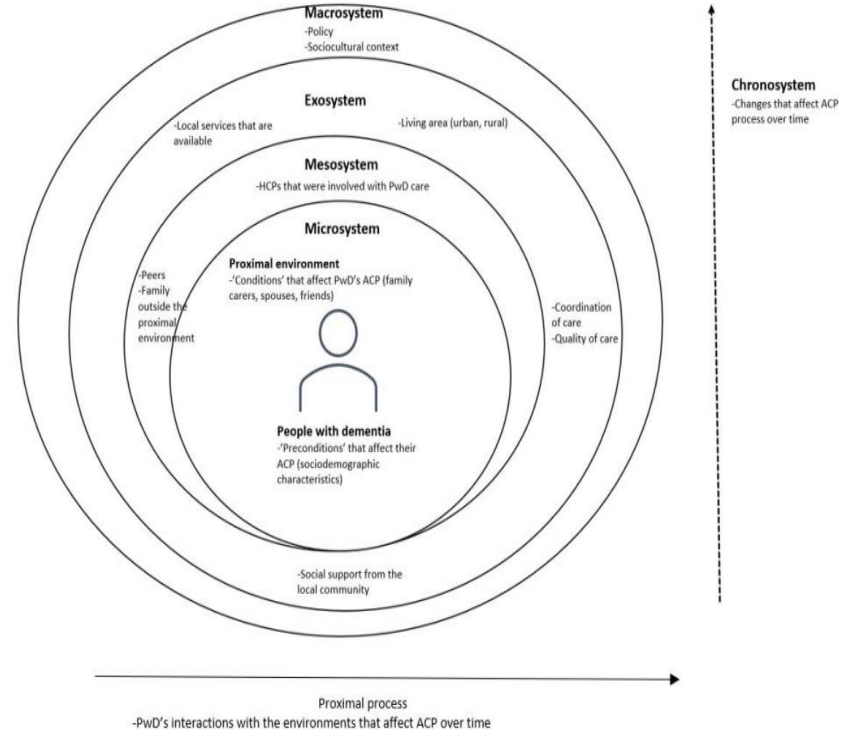
-Phenwan, T, Sixsmith, J, McSwiggan, L & Buchanan, D 2021, 'A Rapid Review of Internet Mediated Research Methods with People with Dementia: Practical, Technical and Ethical Considerations', *The Qualitative Report*, vol. 26, no. 11, 2, pp. 3318-3341. <https://doi.org/10.46743/2160-3715/2021.5089>

Previous work, challenge, and approach

- PwD's fluctuating mental capacity makes it challenging to discuss their ACP
- Family carers will have more input in ACP as the disease progresses which may result in PwD's needs not being met

Aims

- To explore PwD's changing needs as the disease progresses
- To examine the social contexts that influence a PwD's ACP process
- To identify if there is an optimal timing to discuss ACP



Techniques and Methods

- Narrative online and telephone interviews were conducted across Scotland between October 2020 – March 2021 with:
 - 13 PwD
 - 23 family carers
 - Participants were recruited via Join Dementia Research Platform
 - Narrative analysis was used
-
- Three narratives were generated:
 - I. Shifting expectations
 - II. Interdependency
 - III. Tipping points



Results and Conclusions

Shifting expectations

- PwD's needs shifted to co-constructed needs with their family as PwD's independence declined

Interdependency

- ACP was almost always co-created and revised with PwD's key persons –family or healthcare professionals–whom PwD had trusting relationships with

Tipping points

- The ACP tipping points were indicated before the diagnosis and throughout dementia trajectory

Conclusions

- Findings emphasised the discursive nature of ACP and the importance of regular revision of ACP
- ACP should be discussed with key persons who can provide relational support for PwD as their abilities and independence decline

