ADVANCE CARE PLANNING IN DEMENTIA: ‘LIVING WELL’ WITH AN UNCERTAIN FUTURE

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Introduction There is compelling evidence that Advance Care Planning (ACP) remains a key factor in the delivery of appropriate end of life care and facilitates the timely transition to palliative care for people with dementia (van der Steen et al., 2014).

Aims To explore the experiences in the use of ACP amongst spousal couples affected by dementia.

Method The study utilised a constructivist grounded theory (CGT) methodology (Charmaz 2014). Sixteen participants (eight couples) living at home in the community were interviewed to gain insight into the process of planning for future and use of ACP.

Results All participants were aged 65 or above and the minimum length of time since diagnosis was 18 months. There was limited evidence that ACP was being undertaken by participants. A number of factors were identified to help explain why this was the case with a focus on the core social process of ‘postponement’. Important categories are noted: discordance between ACP and ‘living well’ with dementia; caregiver precedence in seeking to maintain an equilibrium in day to day life; maintaining couplehood.

Conclusions ACP remained a difficult proposition for spousal couples. Reluctance to engage in ACP for them is grounded in the realities of living as a couple with dementia, perceptions of the planning process and caregiver priorities. The findings will have implications for practice which may best facilitate actions enabling ACP to take place. The work also contributes to burgeoning discussion around the planning of future care in relation to the discourse of individual responsibility in end of life care.

REFERENCES