

OP86 THE CHALLENGE OF FINDING THE 'RIGHT' OUTCOME TO MEASURE THE EFFECTS OF ACP – PART IV

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Background There is little agreement about which outcomes are the most important outcomes to use in ACP trials. Previous studies have taken the first important steps to address this challenge by developing a consensus definition of ACP, a list of outcome measures for ACP studies and an organizing framework regarding outcomes that would define successful ACP in research. The extensive work they undertook included consulting multidisciplinary, international experts in Delphi panels. However, these expert panelist mainly consisted by healthcare professionals, lawyers, and researchers. Patients and family caregivers might rate the importance of outcomes for ACP differently. However, little is known about the most important and desired outcomes of ACP from patients' and family caregivers' perspective.

Methods/Design In this presentation, we will present the results of 1) a scoping review of the literature to identify desired outcomes of ACP from patients' and families' perspective, and 2) expert panels and/or interviews with patients, family caregivers, patient representatives, etc. to define in ranking in the outcomes according to their importance to achieve when engaging in the process ACP.

Conclusion The results of this study will provide an overview and ranking of outcomes that are considered as (most) important when engaging in ACP from patients' and family caregivers' perspectives. These results will add to the knowledge base regarding outcomes to measure successful ACP and might help researchers who are considering to perform evaluation studies of ACP interventions to reflect upon appropriate outcomes that are relevant to patients and family caregivers.

OP87 UNDERSTANDING ADVANCE CARE PLANNING FOR PEOPLE LIVING WITH DEMENTIA: A REVIEW OF REVIEWS

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Background Worldwide, every three seconds someone develops dementia. Dementia is a terminal condition. Therefore, communication about future care preferences (advance care planning, ACP) is important for people with dementia (PwD) and their network. This review of reviews aims to synthesize the evidence on ACP for PwD and their carers.

Methods PubMed, CINAHL Plus, SCOPUS, SocialCareOnline and Cochrane Library, were systematically searched for systematic reviews in July 2018. After tabulation of primary research, PubMed, CINAHL Plus and SCOPUS were searched for additional recent primary research articles in September. Methodological quality was assessed using AMSTAR-2 and the Joanna Briggs Institute instruments. Overarching themes were identified.

Results 19 reviews and 10 primary research articles met the inclusion criteria. Methodological quality was variable. Preliminary analysis suggests that ACP interventions led to increased ACP documentation, an increase in PwD dying in their preferred place and a decrease in hospitalisations. Qualitative data

showed that the ACP process can be experienced as stressful, but is also perceived as relevant by PwD and carers. Lack of knowledge about ACP and dementia were barriers to ACP use for all parties involved. Facilitators for ACP were; education to improve healthcare professionals' communication skills and legal and ethical knowledge; education for PwD and carers about the ACP process, the differences between palliative and terminal care and the dementia disease trajectory.

Conclusion ACP interventions have shown to be effective on health utilization outcomes, however education for all parties involved is key to optimize the ACP process for PwD and their carers.

OP88 ADVANCE CARE PLANNING AND SPOUSAL COUPLES AFFECTED BY DEMENTIA: A CONSTRUCTIVIST GROUNDED THEORY

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Background Global policy and clinical guidelines place emphasis on the implementation and use of advance care planning (ACP) to inform decision making about care and treatment at the end of life. For people with dementia, where its use is encouraged at the point of diagnosis, utilisation of ACP is relatively low, raising concerns about the challenges present in the context of the condition. This study explores the ways in which co-residing couples considered ACP in the light of a recent diagnosis of dementia.

Method Using face-to-face interviews as part of a constructivist grounded theory methodology the study sought to understand how people with dementia and their long-term co-residing partners consider and plan, or do not plan, for future medical and social care.

Results Sixteen participants were interviewed. They identified the importance of relationships in the process of planning alongside an absence of formal service support. As a result few engaged in ACP. Findings recognise the fundamental challenges faced by couples when considering end-of-life decisions whilst making efforts to 'live well'. Importantly, the paper identifies features of the ACP experience of a relational and biographical nature.

Conclusion The study challenges the relevance of current global policy and practice, concluding that what is evident is a process of 'emergent planning' through which couples build upon their knowledge of dementia, their networks and relationships, and a series of 'tipping points' in the process of considering future care options. The relational and collective nature of future planning is also emphasised.

OP89 USE OF ADVANCE CARE DIRECTIVES FOR INDIVIDUALS WITH DEMENTIA LIVING IN RESIDENTIAL ACCOMMODATION: A DESCRIPTIVE SURVEY

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Background End-of-life decision-making for individuals with dementia needs to be addressed because as dementia progresses, their capacity to make decisions about their health