THE CHALLENGE OF FINDING THE ‘RIGHT’ OUTCOME TO MEASURE THE EFFECTS OF ACP – PART IV

A De Vlemmick, J Stevens*, J Gillissen. Vrije Universiteit Brussel (VUB) and Ghent University, Brussels, Belgium

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 panelists mainly consisted of 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 scope 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 and desired outcomes of 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.

UNIVERSITY OF HERFORDSHIRE, HATFIELD, UK

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

1A Van Dael*, 2F Bunn, 3J Lynch, 1L Pyszolic, 1C Van den Block, 1O Goodman. 1VUB, Brussels, Belgium; 2University of Herfordshire, Hatfield, UK

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.

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


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...