

Bijlage Exclusietabellen

Advance Care Planning

Referentie	Reden voor exclusie
Mitsumoto, H., et al. (2005). "Promoting excellence in end-of-life care in ALS." <i>Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders</i> 6(3): 145-154.	narrative overview, not on ACP as such
Murray, L. and P. N. Butow (2016). "Advance Care Planning in motor neuron disease: A systematic review." <i>Palliative & Supportive Care</i> 14(4): 411-432.	excluded palliative studies
Au, D. H., et al. (2012). "A randomized trial to improve communication about end-of-life care among patients with COPD." <i>Chest</i> 141(3): 726-735.	not on ACP as such
Denvir, M. A., et al. (2015). "Future care planning: a first step to palliative care for all patients with advanced heart disease." <i>Heart</i> 101(13): 1002-1007.	narrative overview
El-Jawahri, A., et al. (2016). "Randomized, Controlled Trial of an Advance Care Planning Video Decision Support Tool for Patients With Advanced Heart Failure." <i>Circulation</i> 134(1): 52-60.	ACP use as outcome
Malhotra, C., et al. (2018). "Associations between understanding of current treatment intent, communication with healthcare providers, preferences for invasive life-sustaining interventions and decisional conflict: results from a survey of patients with advanced heart failure in Singapore." <i>BMJ Open</i> 8(9): e021688	baseline data, no intervention
Nedjat-Haiem, F. R., et al. (2017). "Implementing an Advance Care Planning Intervention in Community Settings with Older Latinos: A Feasibility Study." <i>Journal of Palliative Medicine</i> 20(9): 984-993.	no palliative care patients, wrong intervention
Peretti-Watel, P., et al. (2008). "District nurses' attitudes toward patient consent: the case of mechanical ventilation on amyotrophic lateral sclerosis patients: results from a French national survey." <i>Journal of Critical Care</i> 23(3): 332-338.	no ACP intervention study
Reinke, L. F., et al. (2017). "The long term impact of an end-of-life communication intervention among veterans with COPD." <i>Heart & Lung</i> 46(1): 30-34.	ACP use as outcome
Sinclair, C., et al. (2017). "Advance Care Planning uptake among patients with severe lung disease: a randomised patient preference trial of a nurse-led, facilitated Advance Care Planning intervention." <i>BMJ Open</i> 7(2): e013415.	ACP use as outcome
Andreassen, P., et al. (2017). "The diverse impact of advance care planning: a long-term follow-up study on patients' and relatives' experiences." <i>BMJ supportive & palliative care</i> 7(3): 335-340.	no comparative study
Cosgriff, J. A., et al. (2007). "The association between treatment preferences and trajectories of care at the end-of-life." <i>Journal of General Internal Medicine</i> 22(11): 1566-1571.	ACP not assessed
Gordon, N. A., et al. (2017). "Let Us Talk About It: Heart Failure Patients' Preferences Toward Discussions about Prognosis, Advance Care Planning, and Spiritual Support." <i>Journal of Palliative Medicine</i> 20(1): 79-83.	ACP as outcome
Levi, B. H., et al. (2017). "Advance Care Planning for patients with amyotrophic lateral sclerosis." <i>Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration</i> 18(5-6): 388-396.	ACP as outcome, no comparative study
Strachan, P. H., et al. (2009). "Mind the gap: Opportunities for improving end-of-life care for patients with advanced heart failure." <i>Canadian Journal of Cardiology</i> 25(11): 635-640.	no intervention
Uhler, L. M., et al. (2015). "InformedTogether: Usability Evaluation of a Web-Based Decision Aid to Facilitate Shared Advance Care Planning for Severe Chronic Obstructive Pulmonary Disease." <i>JMIR Human Factors</i> 2(1): e2.	not on ACP as such
Andersen, P. M., et al. (2018). "Therapeutic decisions in ALS patients: cross-cultural differences and clinical implications." <i>Journal of Neurology</i> 265(7): 1600-1606.	not on ACP
Beringer, A. J. and E. J. Heckford (2014). "Was there a plan? End-of-life care for children with life-limiting conditions: a review of multi-service healthcare records." <i>Child: Care, Health & Development</i> 40(2): 176-183.	not on ACP as such
Bostwick, D., et al. (2017). "Comparing the Palliative Care Needs of Those With Cancer to Those With Common Non-Cancer Serious Illness." <i>Journal of Pain & Symptom Management</i> 53(6): 1079-1084.e1071.	not on ACP as such
Bradshaw, C. L., et al. (2019). "Medical Record Documentation of Goals-of-Care Discussions Among Older Veterans With Incident Kidney Failure." <i>American Journal of Kidney Diseases</i> 31: 31.	wrong outcomes, ACP unclear
Carlucci, A., et al. (2016). "End-of-Life Discussion, Patient Understanding and Determinants of Preferences in Very Severe COPD Patients: A Multicentric Study." <i>Copd: Journal of Chronic Obstructive Pulmonary Disease</i> 13(5): 632-638.	not on ACP
Chambaere, K., et al. (2015). "End-of-life decisions in individuals dying with dementia in Belgium." <i>Journal of the American Geriatrics Society</i> 63(2): 290-296.	not on ACP
Cheung, K. C., et al. (2018). "Advance Care Planning for patients with advanced neurology diseases." <i>Annals of Palliative Medicine</i> 7(3): 349-354.	no comparative study
Chung, R. Y., et al. (2017). "Knowledge, Attitudes, and Preferences of Advance Decisions, End-of-Life Care, and Place of Care and Death in Hong Kong. A Population-Based Telephone Survey of 1067 Adults." <i>Journal of the American Medical Directors Association</i> 18(4): 367.e319-367.e327.	healthy population, not on ACP intervention
Curtin, K. B., et al. (2017). "Pediatric Advance Care Planning (pACP) for teens with cancer and their families: Design of a dyadic, longitudinal RCCT." <i>Contemporary Clinical Trials</i> 62: 121-129.	study protocol

Dassel, K. B., et al. (2018). "The Influence of Hypothetical Death Scenarios on Multidimensional End-of-Life Care Preferences." <i>American Journal of Hospice & Palliative Medicine</i> 35(1): 52-59.	healthy population, not on ACP intervention
Ermers, D. J. M., et al. (2019). "Advance Care Planning for patients with cancer in the palliative phase in Dutch general practices." <i>Family Practice</i> 36(5): 587-593.	not on ACP as such
Fakhri, S., et al. (2016). "Factors Affecting Patients' Preferences for and Actual Discussions About End-of-Life Care." <i>Journal of Pain & Symptom Management</i> 52(3): 386-394.	ACP as outcome
Flieger, S. P., et al. (2019). "Quality Improvement Initiatives to Reduce Mortality: An Opportunity to Engage Palliative Care and Improve Advance Care Planning." <i>American Journal of Hospice & Palliative Medicine</i> 36(2): 97-104.	no comparative study
Gainza-Miranda, D., et al. (2019). "Breaking Barriers: Prospective Study of a Cohort of Advanced Chronic Obstructive Pulmonary Disease Patients To Describe Their Survival and End-of-Life Palliative Care Requirements." <i>Journal of Palliative Medicine</i> 22(3): 290-296.	ACP as outcome
Heffner, J. E. (2011). "Advance Care Planning in chronic obstructive pulmonary disease: barriers and opportunities." <i>Current Opinion in Pulmonary Medicine</i> 17(2): 103-109.	narrative review
Hoerger, M., et al. (2018). "Defining the Elements of Early Palliative Care That Are Associated With Patient-Reported Outcomes and the Delivery of End-of-Life Care." <i>Journal of Clinical Oncology</i> 36(11): 1096-1102.	not on ACP
Hughes, P. M., et al. (2010). "What progress has been made towards implementing national guidance on end of life care? A national survey of UK general practices." <i>Palliative Medicine</i> 24(1): 68-78.	not on ACP as such
Jabbarian, L. J., et al. (2019). "Assessing Emotional Functioning with Increased Power: Relative Validity of a Customized EORTC Short Form in the International ACTION Trial." <i>Value in Health</i> 22(1): 92-98.	not on ACP, questionnaire validation study
Janssen, D. J. A., et al. (2011). "A call for high-quality Advance Care Planning in outpatients with severe COPD or chronic heart failure." <i>Chest</i> 139(5): 1081-1088.	ACP as outcome
Kimmel, A. L., et al. (2015). "Family CEntered (FACE) advance care planning: Study design and methods for a patient-centered communication and decision-making intervention for patients with HIV/AIDS and their surrogate decision-makers." <i>Contemporary Clinical Trials</i> 43: 172-178.	study protocol
Kok, M., et al. (2018). "Feasibility of hospital-initiated non-facilitator assisted Advance Care Planning documentation for patients with palliative care needs." <i>BMC Palliative Care</i> 17(1): 79.	no comparative study
Kurita, K., et al. (2018). "Associations between Mild Cognitive Dysfunction and End-of-Life Outcomes in Patients with Advanced Cancer." <i>Journal of Palliative Medicine</i> 21(4): 536-540.	no intervention
Mitchell, G., et al. (2011). "Enhancing palliative care in rural Australia: the residential aged care setting." <i>Australian Journal of Primary Health</i> 17(1): 95-101.	pdf missing, seems to be not on ACP as such
Needle, J. S., et al. (2019). ""Can you tell me why you made that choice?": A qualitative study of the influences on treatment decisions in Advance Care Planning among adolescents and young adults undergoing bone marrow transplant." <i>Palliative Medicine</i> : 269216319883977.	not on palliative care, no comparative study
Nilsson, M. E., et al. (2009). "Mental health, treatment preferences, advance care planning, location, and quality of death in advanced cancer patients with dependent children." <i>Cancer</i> 115(2): 399-409.	ACP as outcome
Schneider, M. K., et al. (2019). "The earlier the better: the role of palliative care consultation on aggressive end of life care, hospice utilization, and Advance Care Planning documentation among gynecologic oncology patients."	wrong intervention
Seal, M. (2007). "Patient advocacy and Advance Care Planning in the acute hospital setting." <i>Australian Journal of Advanced Nursing</i> 24(4): 29-36.	not on ACP as such
Sprange, A., et al. (2019). "Advance Care Planning Preferences and Readiness in Cirrhosis: A Prospective Assessment of Patient Perceptions and Knowledge." <i>Journal of Palliative Medicine</i> 16: 16.	ACP as outcome
Ufere, N. N., et al. (2019). "Barriers to Use of Palliative Care and Advance Care Planning Discussions for Patients With End-Stage Liver Disease." <i>Clinical Gastroenterology & Hepatology</i> 17(12): 2592-2599.	ACP as outcome
Van Scoy, L. J., et al. (2017). "Community Game Day: Using an End-of-Life Conversation Game to Encourage Advance Care Planning." <i>Journal of Pain & Symptom Management</i> 54(5): 680-691.	ACP as outcome
Chow, J. and H. Senderovich (2018). "It's Time to Talk: Challenges in Providing Integrated Palliative Care in Advanced Congestive Heart Failure. A Narrative Review." <i>Current cardiology reviews</i> 14(2): 128-137.	not on ACP as such, narrative review
Delmaczynska, E. and R. Newham (2019). "To explore the prevalence and outcomes of Advance Care Planning for patients with left ventricular assist devices: A review." <i>Journal of Clinical Nursing</i> 28(9-10): 1365-1379.	no comparative study
Diagnosis, E. T. F. o., et al. (2012). "EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)--revised report of an EFNS task force." <i>European Journal of Neurology</i> 19(3): 360-375.	not on ACP
Lovell, A. and P. Yates (2014). "Advance Care Planning in palliative care: a systematic literature review of the contextual factors influencing its uptake 2008-2012." <i>Palliative Medicine</i> 28(8): 1026-1035.	ACP as outcome

McDermott, E. and L. E. Selman (2018). "Cultural Factors Influencing Advance Care Planning in Progressive, Incurable Disease: A Systematic Review With Narrative Synthesis." <i>Journal of Pain & Symptom Management</i> 56(4): 613-636.	ACP as outcome
Zwakman, M., et al. (2018). "Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness." <i>Palliative Medicine</i> 32(8): 1305-1321.	no comparative study
Andersen, P. M., et al. (2012). "EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)-Revised report of an EFNS task force." <i>European Journal of Neurology</i> 19(3): 360-375.	not on ACP, duplicate
Janssen, D. J., et al. (2012). "Advance Care Planning for patients with COPD: Past, present and future." <i>Patient Education and Counseling</i> 86(1): 19-24.	narrative review
Johnson, S. B., et al. (2018). "How well do current measures assess the impact of Advance Care Planning on concordance between patient preferences for end-of-life care and the care received: A methodological review." <i>Journal of Pain and Symptom Management</i> 55(2): 480-495.	methodological paper
O'Hanlon, C. E., et al. (2018). "A framework to guide economic analysis of advance care planning." <i>Journal of Palliative Medicine</i> 21(10): 1480-1485	narrative overview
Sechaud, L., et al. (2014). "Advance Care Planning for institutionalised older people: An integrative review of the literature." <i>International Journal of Older People Nursing</i> 9(2): 159-168.	wrong outcomes
Simon, J., et al. (2008). "Facilitated advance care planning: What is the patient experience?" <i>Journal of Palliative Care</i> 24(4): 256-264.	no pdf
Murray, L., et al. (2016). "Advance Care Planning in motor neuron disease: A qualitative study of caregiver perspectives." <i>Palliative Medicine</i> 30(5): 471-478.	no comparative analysis

Cognitieve functiestoornissen en gedragsverandering

Referentie	Reden voor exclusie
Aho-Ozhan, H., et al. (2016). "Changes in cognitive profile during the course of 6 months in ALS." <i>Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration</i> 17 (Supplement 1): 264-265.	Conference abstract
Aho-Ozhan, H. E. A., et al. (2017). "Language is the cognitive function, which is most vulnerable to change in ALS." <i>Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration</i> 18 (Supplement 2): 70.	Conference abstract
Poletti, B., et al. (2017). "Longitudinal assessment in ALS using the Edinburgh Cognitive and Behavioural ALS Screen (ECAS)." <i>Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration</i> 18 (Supplement 2): 71-72.	Conference abstract

Intimiteit en seksualiteit

Referentie	Reden voor exclusie
Atkins, L., et al. (2010) "Marital relationship in amyotrophic lateral sclerosis" <i>Amyotrophic Lateral Sclerosis</i> 11(4):344-50	No prevalence reported
Goldstein, L., et al. (2006) "Longitudinal predictors of psychological distress and self-esteem in people with ALS" <i>Neurology</i> 67(9):1652-1658	No prevalence reported
Goldstein, L.H., et al. (1998) "The psychological impact of MND on patients and carers" <i>J Neurological Sciences</i> 160 Suppl 1:S114-21	No prevalence reported
Hyunjin, O., et al. (2013) "Wives Becoming Caregivers" <i>J Hospice & Palliative Nursing</i> 15(4):244-250	Article not available
Marconi, A., et al. (2012) "Aggressiveness, sexuality, and obsessiveness in late stages of ALS patients and their effects on caregivers" <i>Amyotrophic Lateral Sclerosis</i> 13(5):452-8	No prevalence reported
Marsden, R., et al. (2010) "Discussing sexuality with patients in a motor neurone disease clinic" <i>Nursing Standard</i> 25(15-17):40-46	No prevalence reported
O'Connor, E.J., et al. (2008) "The impact of neurological illness on marital relationship" <i>J Sex & Marital Therapy</i> 34(2):115-132	No prevalence reported
Poletti, B., et al. (2019) "Sexuality and intimacy in ALS: Systematic literature review and future perspectives" <i>J Neurology, Neurosurgery & Psychiatry</i> 90(6):712-719	Details of individuals studies not sufficiently reported
Watermeyer, T.J., et al. (2015) "Impact of disease, cognitive and behavioral factors on caregiver outcome in amyotrophic lateral sclerosis" <i>Amyotrophic Lateral sclerosis & Frontotemporal Degeneration</i> 16(5-6):316-23	No prevalence reported