

Zoekverantwoording

Onderzoeksvraag 1: effectiviteit proactieve zorgplanning

Wat zijn de (on)gunstige effecten van proactieve zorgplanning ten opzichte van geen proactieve zorgplanning bij patiënten die palliatieve zorg ontvangen?

Patients	Patiënten die palliatieve zorg ontvangen of zorgverleners die palliatieve zorg verlenen
Intervention	Proactieve zorgplanning
Comparator	Geen proactieve zorgplanning
Outcome	Patiënttevredenheid, kwaliteit van leven, kwaliteit van leven van mantelzorger, belasting van de patiënt (in tijd en ervaring), belasting van de mantelzorger (in tijd en ervaring), belasting van de zorgverlener (in tijd en ervaring), kosten, kwaliteit van sterven

Search strategy

On 6 January 2020 the scientific literature is searched in databases Medline and PsycINFO. The search strings are shown in this appendix. An update was performed in 16 January 2022.

The literature has been selected systematically based on the following predefined criteria:

- Design: comparative research, like RCT's, controlled clinical trials (CCT's) and case-control studies
- Language: English, Dutch, German and French
- Publication dates: from inception to 2022
- The outcomes are reported

Literature was excluded when no quantitative data was presented, when no comparative analyses were performed and when advance care planning was the outcome.

Search results

The selection criteria were applied on the references yielded from the search. 792 unique hits were screened on title and abstract (Table 1). Of these, 715 were excluded. Of the remaining 77 papers, the full-text was retrieved. Based on the full-text, an additional 66 papers were excluded. Additionally one study was identified by the working group that did come forward in the literature search. Table 2 provides an overview of the excluded studies with reasons.

Table 1. Overall search results of research question 1.

Database	Number of hits
Medline search 1	280
Medline search 2	395
PsycINFO	210
Total hits	885
n excluded (duplicates)	93
Total unique eligible hits	792

Table 2. Overview of excluded studies based on full-text evaluation of research question 1.

Reference	Reason for exclusion
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
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

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
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
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
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
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
Constantine, A., et al. (2021). "Palliative care in pulmonary hypertension associated with congenital heart disease: systematic review and expert opinion." <i>ESC Heart Failure</i> Jun;8(3):1901-1914.	wrong intervention and outcomes
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
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
DeCoursey, D. D., et al. (2019). "Advance Care Planning and Parent-Reported End-of-Life Outcomes in Children, Adolescents, and Young Adults With Complex Chronic Conditions." <i>Critical Care Medicine</i> 47(1):101-8.	Wrong population
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
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
Denvir, M. A., et al. (2016). "Phase 2 Randomised Controlled Trial and Feasibility Study of Future Care Planning in Patients with Advanced Heart Disease." <i>Scientific Reports</i> 6 (April): 24619.	included in a systematic review
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

Duenk, R. G., et al. (2017). "Proactive Palliative Care for Patients with COPD (PROLONG): A Pragmatic Cluster Controlled Trial." <i>International Journal of COPD</i> 12 (September): 2795–2806.	included in a systematic review
Dy, S.M., et al. (2021). "Integrating palliative care in ambulatory care of noncancer serious chronic illness." <i>Comparative Effectiveness Review</i> number 237.	report version of included review (Sloan)
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
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
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
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
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
Kernick, L., et al. (2018). "Does Advance Care Planning in Addition to Usual Care Reduce Hospitalisation for Patients with Advanced Heart Failure: A Systematic Review and Narrative Synthesis." <i>Palliative Medicine</i> . SAGE Publications Ltd.	better review available
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
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
Lim, C., et al. (2016). "Advance Care Planning for Haemodialysis Patients." <i>Cochrane Database of Systematic Reviews</i> . John Wiley and Sons Ltd.	better review available
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
Lyon, M.E., et al. (2014). "A Longitudinal, Randomized, Controlled Trial of Advance Care Planning for Teens with Cancer: Anxiety, Depression, Quality of Life, Advance Directives, Spirituality." <i>Journal of Adolescent Health</i> 54(6):710-17.	Wrong population
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
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
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
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
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
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
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
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
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
Schichtel, M., et al. (2019). "The effect of advance care planning on heart failure: a systematic review and meta-analysis." <i>Journal of General Internal Medicine</i> 35(3):874-84.	included studies with wrong intervention
Schneiter, 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." Australian Journal of Advanced Nursing 24(4): 29-36.	not on ACP as such
Sechaud, L., et al. (2014). "Advance care planning for institutionalised older people: An integrative review of the literature." International Journal of Older People Nursing 9(2): 159-168.	wrong outcomes
Simon, J., et al. (2008). "Facilitated advance care planning: What is the patient experience?" Journal of Palliative Care 24(4): 256-264.	no pdf
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." BMJ Open 7(2): e013415.	ACP use as outcome
Sprange, A., et al. (2019). "Advance Care Planning Preferences and Readiness in Cirrhosis: A Prospective Assessment of Patient Perceptions and Knowledge." Journal of Palliative Medicine 16: 16.	ACP as outcome
Strachan, P. H., et al. (2009). "Mind the gap: Opportunities for improving end-of-life care for patients with advanced heart failure." Canadian Journal of Cardiology 25(11): 635-640.	no intervention
Ufere, N. N., et al. (2019). "Barriers to Use of Palliative Care and Advance Care Planning Discussions for Patients With End-Stage Liver Disease." Clinical Gastroenterology & Hepatology 17(12): 2592-2599.	ACP as outcome
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." JMIR Human Factors 2(1): e2.	not on ACP as such
Van Scoy, L. J., et al. (2017). "Community Game Day: Using an End-of-Life Conversation Game to Encourage Advance Care Planning." Journal of Pain & Symptom Management 54(5): 680-691.	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." Palliative Medicine 32(8): 1305-1321.	no comparative study

Search strings

MEDLINE (OVID)

Search 1

- 1 "advance care planning algemeen".ti. (0)
- 2 exp Advance Care Planning/ (8927)
- 3 (advance? adj2 care adj (plan or plans or planning)).tw. (2820)
- 4 (advance? adj2 care adj (plan or plans or planning)).kf. (1034)
- 5 (advance? adj2 (directive* or decision*)).tw. (4496)
- 6 (advance? adj2 (directive* or decision*)).kf. (625)
- 7 (living adj will*).tw. (1217)
- 8 (living adj will*).kf. (109)
- 9 Right to Die/ (4877)
- 10 ((right adj2 die) or (death adj3 dignit*)).tw. (1463)
- 11 ((right adj2 die) or (death adj3 dignit*)).kf. (228)
- 12 or/2-11 (16631)= advance care planning**
- 13 Palliative Care/ (52170)
- 14 palliative.tw. (58995)
- 15 palliative.kf. (8738)
- 16 or/13-15 (84091)= palliatieve setting**
- 17 12 and 16 (2896)
- 18 patient satisfaction/ or patient preference/ (86087)
- 19 personal satisfaction/ (17731)
- 20 "Quality of Life"/ (184006)
- 21 Workload/ (20560)

22 ((patient adj2 (preferenc* or satisfact*)) or (staff adj2 (preferen* or satisfact*)) or (quality adj2 life) or workload or (work adj load)).tw. (328920)

23 ((patient adj2 (preferenc* or satisfact*)) or (staff adj2 (preferen* or satisfact*)) or (quality adj2 life) or workload or (work adj load)).kf. (33555)

24 or/18-23 (473404)= outcome

25 17 and 24 (748)

26 (dutch or german or french or english).la. (27259647)= taal

27 25 and 26 (732)

28 "filter systematic reviews".ti. (0)

29 meta analysis.pt. (107612)

30 (meta-anal\$ or metaanal\$).tw,kf. (160375)

31 (quantitativ\$ adj10 (review\$ or overview\$)).tw. (8736)

32 (systematic\$ adj10 (review\$ or overview\$)).tw. (172601)

33 (methodologic\$ adj10 (review\$ or overview\$)).tw. (11279)

34 (quantitativ\$ adj10 (review\$ or overview\$)).kf. (63)

35 (systematic\$ adj10 (review\$ or overview\$)).kf. (16708)

36 (methodologic\$ adj10 (review\$ or overview\$)).kf. (68)

37 medline.tw. and review.pt. (77244)

38 (pooled adj3 analy*).tw. (18249)

39 (pooled adj3 analy*).kf. (236)

40 "cochrane\$".fc_jour. (15278)

41 or/29-40 (329309)= sr

42 27 and 41 (35)

43 "Filter observationele studies".ti. (0)

44 epidemiologic studies/ (8146)

45 exp case-control studies/ (1031781)

46 exp cohort studies/ (1919850)

47 cross-sectional studies/ (309351)

48 (case adj3 control).tw,kf. (126178)

49 (cohort adj5 (study or studies or analy\$)).tw,kf. (247254)

50 (follow-up adj5 (study or studies)).tw,kf. (86769)

51 (longitudinal or retrospective or prospective or (cross adj5 sectional)).tw,kf. (1479240)

52 (observational adj5 (study or studies)).tw,kf. (132866)

53 or/44-52 (3044536)

54 comparative study/ (1845942)

55 53 or 54 (4488768)= observat of comp

56 (27 and 55) not 41 (141)

57 "bij hartfalen".ti. (0)

58 exp Heart Failure/ (116661)

59 (heart adj2 failure*).tw. (157637)

60 (cardiac adj2 failure*).tw. (14693)

61 (myocardial adj2 failure*).tw. (3070)

62 (heart adj2 decompensat*).tw. (3825)

63 (heart adj2 failure*).kf. (26627)

64 (cardiac adj2 failure*).kf. (223)

65 (myocardial adj2 failure*).kf. (6)

66 (heart adj2 decompensat*).kf. (279)

67 or/58-66 (207200)

68 Amyotrophic Lateral Sclerosis/ (18081)

69 (ALS or (amyotrophic adj2 lateral adj2 sclerosis)).tw. (34695)

70 (ALS or (amyotrophic adj2 lateral adj2 sclerosis)).kf. (5398)

71 Pulmonary Disease, Chronic Obstructive/ (37413)

72 (copd or (chronic adj2 obstructive adj2 pulmonar* adj2 disease*)).tw. (59498)

73 (copd or (chronic adj2 obstructive adj2 pulmonar* adj2 disease*)).kf. (10894)

74 Constipation/ (13633)
 75 Intestinal Obstruction/ (29352)
 76 Hiccup/ (1087)
 77 Pruritus/ (11400)
 78 itching.tw. (8009)
 79 Mentally Disabled Persons/ (3531)
 80 (mental* adj disabled).tw. (515)
 81 (mental* adj disabled).kf. (15)
 82 or/68-81 (168768)
83 67 or 82 (371693)= relevante ziektes
84 12 and 83 and 24 and 26 and 41 (13)= SR spec
85 12 and 16 and 24 and 26 and 41 (35)= SR palliatief alg
 86 84 or 85 (39)
87 12 and 83 and 24 and 26 and 55 (59)= observat comp spec
88 12 and 16 and 24 and 26 and 55 (149)= observat comp palliatief alg
 89 87 or 88 (178)
 90 "medline rct filter".ti. (0)
 91 controlled-clinical-trial.pt. (93416)
 92 randomized-controlled-trial.pt. (494042)
 93 randomized controlled trial/ (494042)
 94 randomi?ed controlled trial?.tw. (164304)
 95 randomi?ed controlled trial?.kf. (9438)
 96 random-allocation.tw,kf. (1632)
 97 double-blind-method.tw,kf. (482)
 98 single-blind-method.tw,kf. (87)
 99 (random adj8 (selection? or sample?)).kf,tw. (44286)
 100 random*.tw,kf. (1088043)
101 or/91-100 (1294827)= rct
102 12 and 83 and 24 and 26 and 101 (33)= rct spec
103 12 and 16 and 24 and 26 and 101 (35)= rct palliatief alg
 104 102 or 103 (63)

Search 2

1 "advanced care planning algemeen".ti. (0)
 2 exp Advance Care Planning/ (10485)
 3 (advance? adj2 care adj (plan or plans or planning)).tw. (4134)
 4 (advance? adj2 care adj (plan or plans or planning)).kf. (1784)
 5 (advance? adj2 (directive* or decision*)).tw. (5189)
 6 (advance? adj2 (directive* or decision*)).kf. (949)
 7 (living adj will*).tw. (1300)
 8 (living adj will*).kf. (154)
 9 Right to Die/ (4951)
 10 ((right adj2 die) or (death adj3 dignit*)).tw. (1521)
 11 ((right adj2 die) or (death adj3 dignit*)).kf. (242)
12 or/2-11 (19027)= advance care planning
 13 Palliative Care/ (59148)
 14 palliative.tw. (69329)
 15 palliative.kf. (13649)
16 or/13-15 (96752)= palliatieve setting
 17 12 and 16 (3769)
 18 patient satisfaction/ or patient preference/ (96402)
 19 personal satisfaction/ (21821)
 20 "Quality of Life"/ (231216)
 21 Workload/ (23058)

22 ((patient adj2 (preferenc* or satisfact*)) or (staff adj2 (preferen* or satisfact*)) or (quality adj2 life or workload or (work adj load)).tw. (406440)

23 ((patient adj2 (preferenc* or satisfact*)) or (staff adj2 (preferen* or satisfact*)) or (quality adj2 life or workload or (work adj load)).kf. (52618)

24 or/18-23 (569856)= outcome

25 17 and 24 (992)

26 (dutch or german or french or english).la. (30508855)= taal

27 25 and 26 (972)

28 "filter systematic reviews".ti. (0)

29 meta analysis.pt. (150690)

30 (meta-anal\$ or metaanal\$).tw,kf. (224935)

31 (quantitativ\$ adj10 (review\$ or overview\$)).tw. (11338)

32 (systematic\$ adj10 (review\$ or overview\$)).tw. (255069)

33 (methodologic\$ adj10 (review\$ or overview\$)).tw. (13928)

34 (quantitativ\$ adj10 (review\$ or overview\$)).kf. (97)

35 (systematic\$ adj10 (review\$ or overview\$)).kf. (29315)

36 (methodologic\$ adj10 (review\$ or overview\$)).kf. (92)

37 medline.tw. and review.pt. (87615)

38 (pooled adj3 analy*).tw. (24514)

39 (pooled adj3 analy*).kf. (331)

40 "cochrane\$".fc_jour. (15745)

41 or/29-40 (443688)= sr

42 27 and 41 (55)

43 "Filter observationele studies".ti. (0)

44 epidemiologic studies/ (8967)

45 exp case-control studies/ (1272643)

46 exp cohort studies/ (2279737)

47 cross-sectional studies/ (407304)

48 (case adj3 control).tw,kf. (147906)

49 (cohort adj5 (study or studies or analy\$)).tw,kf. (337259)

50 (follow-up adj5 (study or studies)).tw,kf. (100002)

51 (longitudinal or retrospective or prospective or (cross adj5 sectional)).tw,kf. (1846472)

52 (observational adj5 (study or studies)).tw,kf. (182761)

53 or/44-52 (3636689)

54 comparative study/ (1906741)

55 53 or 54 (5112933)= observant of comp

56 (27 and 55) not 41 (200)

57 "bij hartfalen".ti. (0)

58 exp Heart Failure/ (134685)

59 (heart adj2 failure*).tw. (186061)

60 (cardiac adj2 failure*).tw. (15835)

61 (myocardial adj2 failure*).tw. (3450)

62 (heart adj2 decompensat*).tw. (4681)

63 (heart adj2 failure*).kf. (38970)

64 (cardiac adj2 failure*).kf. (302)

65 (myocardial adj2 failure*).kf. (10)

66 (heart adj2 decompensat*).kf. (425)

67 or/58-66 (241426)

68 Amyotrophic Lateral Sclerosis/ (21211)

69 (ALS or (amyotrophic adj2 lateral adj2 sclerosis)).tw. (46043)

70 (ALS or (amyotrophic adj2 lateral adj2 sclerosis)).kf. (8029)

71 Pulmonary Disease, Chronic Obstructive/ (45523)

72 (copd or (chronic adj2 obstructive adj2 pulmonar* adj2 disease*)).tw. (71016)

73 (copd or (chronic adj2 obstructive adj2 pulmonar* adj2 disease*)).kf. (15950)

- 74 Constipation/ (15011)
75 Intestinal Obstruction/ (30697)
76 Hiccup/ (1162)
77 Pruritus/ (12782)
78 itching.tw. (9155)
79 Mentally Disabled Persons/ (3681)
80 (mental* adj disabled).tw. (535)
81 (mental* adj disabled).kf. (21)
82 or/68-81 (198426)
83 67 or 82 (434507)= relevante ziekte
84 12 and 83 and 24 and 26 and 41 (18)= SR spec
85 12 and 16 and 24 and 26 and 41 (55)= SR palliatief alg
86 84 or 85 (61)
87 12 and 83 and 24 and 26 and 55 (65)= observant comp spec
88 12 and 16 and 24 and 26 and 55 (211)=observant comp palliatief alg
89 87 or 88 (242)
90 "medline rct filter".ti. (0)
91 controlled-clinical-trial.pt. (94644)
92 randomized-controlled-trial.pt. (555855)
93 randomized controlled trial/ (555855)
94 randomi?ed controlled trial?.tw. (212463)
95 randomi?ed controlled trial?.kf. (15033)
96 random-allocation.tw,kf. (1874)
97 double-blind-method.tw,kf. (517)
98 single-blind-method.tw,kf. (93)
99 (random adj8 (selection? or sample?)).kf,tw. (49099)
100 random*.tw,kf. (1287040)
101 or/91-100 (1501254)= rct
102 12 and 83 and 24 and 26 and 101 (42)= rct spec
103 12 and 16 and 24 and 26 and 101 (55)= rct palliatief alg
104 102 or 103 (91)
105 12 and (16 or 83) and 26 (4191)
106 105 and 41 (189)
107 (105 and 101) not 41 (247)
108 (105 and 55) not (41 or 101) (812)
109 106 not 42 (134)
110 Sweating/ (7040)
111 sweat*.tw,kf. (25799)
112 110 or 111 (28242)
113 12 and 112 (1)

PSYCINFO

- 1 "advanced care planning algemeen".ti. (0)
2 advance directives/ (1826)
3 symptoms based treatment/ or terminally ill patients/ (5086)
4 (advance? adj2 care adj (plan or plans or planning)).tw. (1509)
5 (advance? adj2 care adj (plan or plans or planning)).id. (924)
6 (advance? adj2 (directive* or decision*)).tw. (2040)
7 (advance? adj2 (directive* or decision*)).id. (1061)
8 (living adj will*).tw. (408)
9 (living adj will*).id. (109)
10 "death and dying"/ (34254)
11 ((right adj2 die) or (death adj3 dignit*)).tw. (467)
12 ((right adj2 die) or (death adj3 dignit*)).id. (128)

13 or/2-12 (41058)
14 exp Palliative Care/ (15396)
15 palliative.tw. (13411)
16 palliative.id. (9634)
17 or/14-16 (18511)
18 13 and 17 (5712)
19 client satisfaction/ (5978)
20 client attitudes/ (18357)
21 life satisfaction/ or exp "quality of life"/ (57280)
22 work load/ (3276)
23 ((patient adj2 (preferenc* or satisfact*)) or (staff adj2 (preferen* or satisfact*)) or (quality adj2 life)
or workload or (work adj load)).tw. (96102)
24 ((patient adj2 (preferenc* or satisfact*)) or (staff adj2 (preferen* or satisfact*)) or (quality adj2 life)
or workload or (work adj load)).id. (46506)
25 or/19-24 (128861)
26 18 and 25 (935)
27 (dutch or german or french or english).la. (4874285)
28 26 and 27 (927)
29 "psycinfo filter rct".ti. (0)
30 randomi?ed controlled trial*.tw. (37215)
31 controlled clinical trial*.tw. (3319)
32 ((random adj allocation) or (double adj blind adj (method* or stud*))).tw. (2972)
33 single blind stud*.tw. (159)
34 or/30-33 (43093)
35 "sensitief filter trials prospective followup evaluations".ti. (0)
36 exp Posttreatment Followup/ or exp Followup Studies/ or followup.mp. (19221)
37 exp Prospective Studies/ or prospective.mp. (79666)
38 evaluations studies.mp. (27)
39 (control* or prospectiv* or volunteer* or evaluati*).tw. (1102939)
40 or/36-39 (1123069)
41 "filter systematic reviews psycinfo".ti. (0)
42 (meta-anal* or metaanal*).tw. (44672)
43 (quantitativ* adj5 (review* or overview*)).tw. (2865)
44 (quantitativ* adj5 (review* or overview*)).id. (73)
45 (systematic* adj5 (review* or overview*)).tw,id. (44298)
46 (methodolo* adj5 (review* or overview*)).tw,id. (7583)
47 ((medline or cochrane) adj5 (review* or overview*)).tw. (3305)
48 (literature adj5 (overview or review)).tw,id. (87246)
49 (synthes* adj3 (literature* or research or studies or data)).tw,id. (10741)
50 (pooled adj5 analys*).tw,id. (2693)
51 (data adj2 pool*).tw,id. (2610)
52 ((hand or manual* or database* or computer* or electronic*) adj2 search*).tw,id. (13275)
53 "literature review"/ or meta analysis/ (27845)
54 or/42-53 (171595)
55 28 and 54 (91)
56 55 (91)
57 limit 56 to all journals (85)
58 exp cardiovascular disorders/ (66660)
59 from 57 keep 1-72 (72)
60 (heart adj2 failure*).tw,id. (4265)
61 (cardiac adj2 failure*).tw,id. (183)
62 (myocardial adj2 failure*).tw,id. (45)
63 (heart adj2 decompensat*).tw,id. (39)
64 or/58-63 (68100)

65 amyotrophic lateral sclerosis/ (4174)
66 (ALS or (amyotrophic adj2 lateral adj2 sclerosis)).tw,id. (17159)
67 exp chronic obstructive pulmonary disease/ (1594)
68 (copd or (chronic adj2 obstructive adj2 pulmonar* adj2 disease*)).tw,id. (2764)
69 constipation/ (465)
70 exp gastrointestinal disorders/ (9142)
71 Hiccup.mp. (97)
72 pruritus/ (293)
73 itching.tw,id. (386)
74 sweating/ (270)
75 sweat*.tw,id. (2493)
76 exp intellectual development disorder/ (46771)
77 (mental* adj disabled).tw,id. (668)
78 or/65-77 (79466)
79 64 or 78 (146229)
80 13 and 25 and 27 and 79 (305)
81 80 and 54 (82)=SR
82 55 or 81 (100) SR
83 (80 and 34) not 54 (11)=rct
84 (80 and 40) not (34 or 54) (63)=observat
85 limit 80 to ("0430 followup study" or "0450 longitudinal study" or "0451 prospective study" or "0453
retrospective study" or 1600 qualitative study or 2100 treatment outcome) (79)
86 85 not (54 or 34 or 40) (36)= extra studietypen

Onderzoeksvraag 2: waarden en voorkeuren van patiënten, naasten en zorgverleners

Wat zijn de waarden en voorkeuren van patiënten, naasten en zorgverleners ten aanzien van proactieve zorgplanning?

Patients	Patiënten die palliatieve zorg ontvangen, hun naasten, of zorgverleners die palliatieve zorg verlenen
Intervention	Proactieve zorgplanning
Comparator	n.v.t.
Outcome	Ervaringen en voorkeuren t.a.v. proactieve zorgplanning van patiënten, hun naasten en hun zorgverleners

Search strategy

On 22 March 2022 the scientific literature is searched in databases Medline and Cinahl. The search strings are shown in this appendix.

The literature has been selected systematically based on the following predefined criteria:

- Design: systematic reviews of quantitative, qualitative and/or mixed methods studies
- Language: English and Dutch
- Publication dates: from 2017 to 2022
- The outcomes are reported

Literature was excluded when the methods used were not systematic, when the outcomes were not relevant or when there was too much overlap regarding subject and/or included studies between the systematic reviews.

Search results

The selection criteria were applied on the references yielded from the search. 438 unique hits were screened on title and abstract. Of these, 412 were excluded. Of the remaining 26 papers, the full-text was retrieved. Based on the full-text, an additional 17 papers were excluded. Table 3 provides an overview of the excluded studies with reasons.

Table 3. Overview of excluded studies based on full-text evaluation of research question 2.

Reference	Reason for exclusion
Batchelor F, Hwang K, Haralambous B, Fearn M, Mackell P, Nolte L, Detering K. Facilitators and barriers to advance care planning implementation in Australian aged care settings: A systematic review and thematic analysis. <i>Australas J Ageing</i> . 2019 Sep;38(3):173-181. doi: 10.1111/ajag.12639. Epub 2019 Mar 14.	Population included in other review
Carr K, Hasson F, McIlpatrick S, Downing J. Factors associated with health professionals decision to initiate paediatric advance care planning: A systematic integrative review. <i>Palliat Med</i> . 2021 Mar;35(3):503-528. doi: 10.1177/0269216320983197. Epub 2020 Dec 29.	Wrong population
De Vleminck A, Houttekier D, Pardon K, Deschepper R, Van Audenhove C, Vander Stichele R, Deliens L. Barriers and facilitators for general practitioners to engage in advance care planning: a systematic review. <i>Scand J Prim Health Care</i> . 2013 Dec;31(4):215-26. doi: 10.3109/02813432.2013.854590.	Population included in more recent review
Delmaczynska E, Newham R. To explore the prevalence and outcomes of advance care planning for patients with left ventricular assist devices: A review. <i>J Clin Nurs</i> . 2019 May;28(9-10):1365-1379. doi: 10.1111/jocn.14748. Epub 2019 Jan 7.	Reported outcomes not relevant
Dening KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. <i>Int Psychogeriatr</i> . 2011 Dec;23(10):1535-51. doi: 10.1017/S1041610211001608. Epub 2011 Aug 26.	Study included in Hall 2019
Johnson S, Butow P, Kerridge I, Tattersall M. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients,	Study included in Hall 2019

families, and healthcare providers. <i>Psychooncology</i> . 2016 Apr;25(4):362-86. doi: 10.1002/pon.3926. Epub 2015 Sep 20.	
Ke LS, Huang X, Hu WY, O'Connor M, Lee S. Experiences and perspectives of older people regarding advance care planning: A meta-synthesis of qualitative studies. <i>Palliat Med</i> . 2017 May;31(5):394-405. doi: 10.1177/0269216316663507. Epub 2016 Aug 11.	Study included in Hall 2019
Ke LS, Huang X, O'Connor M, Lee S. Nurses' views regarding implementing advance care planning for older people: a systematic review and synthesis of qualitative studies. <i>J Clin Nurs</i> . 2015 Aug;24(15-16):2057-73. doi: 10.1111/jocn.12853. Epub 2015 May 4.	Population included in more recent review
Lotz JD, Jox RJ, Borasio GD, Führer M. Pediatric advance care planning: a systematic review. <i>Pediatrics</i> . 2013 Mar;131(3):e873-80. doi: 10.1542/peds.2012-2394. Epub 2013 Feb 11.	Population included in more recent review
Martina D, Lin CP, Kristanti MS, Bramer WM, Mori M, Korfage IJ, van der Heide A, van der Rijt CCD, Rietjens JAC. Advance Care Planning in Asia: A Systematic Narrative Review of Healthcare Professionals' Knowledge, Attitude, and Experience. <i>J Am Med Dir Assoc</i> . 2021 Feb;22(2):349.e1-349.e28. doi: 10.1016/j.jamda.2020.12.018. Epub 2021 Jan 7.	Not relevant for Dutch situation
Mignani V, Ingravallo F, Mariani E, Chattat R. Perspectives of older people living in long-term care facilities and of their family members toward advance care planning discussions: a systematic review and thematic synthesis. <i>Clin Interv Aging</i> . 2017 Mar 3;12:475-484. doi: 10.2147/CIA.S128937.	Study included in Hall 2019
Owen L, Steel A. Advance care planning: what do patients want? <i>Br J Hosp Med (Lond)</i> . 2019 May 2;80(5):263-267. doi: 10.12968/hmed.2019.80.5.263.	Low quality study
Sanders JJ, Robinson MT, Block SD. Factors Impacting Advance Care Planning among African Americans: Results of a Systematic Integrated Review. <i>J Palliat Med</i> . 2016 Feb;19(2):202-27. doi: 10.1089/jpm.2015.0325.	Study included in Hall 2019
Sellars M, Chung O, Nolte L, Tong A, Pond D, Fetherstonhaugh D, McInerney F, Sinclair C, Detering KM. Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies. <i>Palliat Med</i> . 2019 Mar;33(3):274-290. doi: 10.1177/0269216318809571. Epub 2018 Nov 8.	Population included in more recent review
Tilburgs B, Vernooij-Dassen M, Koopmans R, van Gennip H, Engels Y, Perry M. Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review. <i>PLoS One</i> . 2018 Jun 20;13(6):e0198535. doi: 10.1371/journal.pone.0198535.	Study included in Hall 2019
van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, Onwuteaka-Philipsen BD, Deliens L, de Boer ME, Van den Block L, van Uden N, Hertogh CM, de Vet HC. Factors associated with initiation of advance care planning in dementia: a systematic review. <i>J Alzheimers Dis</i> . 2014;40(3):743-57. doi: 10.3233/JAD-131967.	Study included in Hall 2019
Zwakman M, Jabbarian LJ, van Delden J, van der Heide A, Korfage IJ, Pollock K, Rietjens J, Seymour J, Kars MC. Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness. <i>Palliat Med</i> . 2018 Sep;32(8):1305-1321. doi: 10.1177/0269216318784474. Epub 2018 Jun 29.	Study included in Hall 2019

Search strings

MEDLINE

- 1 "Patient and family caregiver communication after advance care planning: a qualitative analysis".fc_titl. (0)
- 2 "Patient and family caregiver communication after advance care planning: a qualitative analysis".fc_titl. (0)
- 3 "Patient and family caregiver communication after advance care planning".fc_titl. (0)
- 4 "cheung\$".fc_auts. and "barriers".fc_titl. (32)
- 5 from 4 keep 6 (1)

6 "advance care planning".fc_titl. (1950)
 7 qualitative research/ (72284)
 8 6 and 7 (177)
 9 proactiv*.tw. (20270)
 10 proactiv*.kw. (829)
 11 9 or 10 (20373)
 12 8 and 11 (7)
 13 view?.tw,kw. (393132)
 14 8 and 13 (35)
 15 "Perception"/ (40943)
 16 "professional perspective".kw. (7)
 17 13 or 15 or 16 (431930)
 18 8 and 17 (43)
 19 12 or 18 (47)
 20 "voss\$.fc_auts. and "2021".fc_pubyr. (575)
 21 acp.tw. (10416)
 22 20 and 21 (2)
 23 from 22 keep 2 (1)
 24 "onderdeel ACP conform cochrane".ti. (0)
 25 exp Advance Care Planning/ (10590)
 26 (advance* care adj plan*).tw. (4196)
 27 (advance* care adj plan*).kw. (3)
 28 (advance* adj (medical plan* or statement*)).tw. (61)
 29 (advance* adj (medical plan* or statement*)).kw. (1)
 30 acp.tw. (10416)
 31 acp.kw. (89)
 32 Statement of wishes.tw. (3)
 33 Terminal Care/ (30557)
 34 terminal care.tw. (1564)
 35 ((end of life or EOL) adj5 (care or discuss* or decision* or plan* or preference*)).tw. (17510)
 36 Treatment Refusal/ (12075)
 37 exp Withholding Treatment/ (16075)
 38 (treatment adj3 (refus* or withhold* or withdraw*)).tw. (13269)
 39 Living Wills/ (1678)
 40 living will*.tw. (1302)
 41 ((shared or sharing) adj2 decision*).tw. (11694)
 42 SDM.tw. (3375)
 43 **or/25-42 (101462)= pzp**
 44 7 and 43 (2686)
 45 "filter systematic reviews".ti. (0)
 46 meta analysis.pt. (155255)
 47 (meta-anal\$ or metaanal\$).tw,kf. (230739)
 48 (quantitativ\$ adj10 (review\$ or overview\$)).tw,kf. (11612)
 49 (systematic\$ adj10 (review\$ or overview\$)).tw,kf. (264790)
 50 (methodologic\$ adj10 (review\$ or overview\$)).tw,kf. (14216)
 51 medline.tw. and review.pt. (88954)
 52 (pooled adj3 analy*).tw,kf. (25084)
 53 "cochrane\$.fc_jour. (15814)
 54 **or/46-53 (454020)= SR**
 55 44 and 54 (137)
 56 "thematic synthesis".kw. (105)
 57 17 and 55 (20)
 58 Program Development/ (30185)
 59 Health Plan Implementation/ (6628)

60 communication barriers/ (7064)
61 Health Planning/ (21892)
62 exp Nursing Care/ (139672)
63 58 or 59 or 60 or 61 or 62 (202323)
64 43 and 54 and 63 (89)
65 (grounded adj2 theor*).tw,kw. (14258)
66 (thematic adj2 analy*).tw,kw. (34794)
67 kwalitatief*.tw,kw. (330843)
68 7 or 65 or 66 or 67 (362865)
69 64 and 68 (27)
70 Focus Groups/ (33976)
71 interview/ (30203)
72 7 or 65 or 66 or 67 or 70 or 71 (407044)= kwalitatieve studies
73 43 and 72 (7111)
74 (dutch or english).la. (29125647)= taal
75 Needs Assessment/ (32104)
76 (needs adj2 assess*).tw,kw. (10784)
77 9 or 10 or 13 or 15 or 16 or 75 or 76 (489261)= proactief of behoefte of perceptie of needs
78 73 and 74 and 77 (1264)
79 78 (1264)
80 limit 79 to yr="2017 -Current" (630)
81 exp Advance Care Planning/px (624)
82 px.fs. (1143664)
83 81 or 82 (1143664)
84 80 and 83 (258)
85 43 and 72 and 74 (6868)= ACP + kwalitatief + talen
86 54 and 85 (565)= ACP + kwalitatief + talen + SR
87 86 (565)
88 limit 87 to yr="2017 -Current" (373)
89 77 and 88 (64)= ACP + kwalitatief + talen + SR + vanaf 2017
90 exp *Advance Care Planning/ (7130)
91 (advance* care adj plan*).ti,kw. (2079)
92 (advance* care adj plan*).ti,kw. (2079)
93 (advance* adj (medical plan* or statement*)).ti,kw. (32)
94 (advance* adj (medical plan* or statement*)).ti,kw. (32)
95 acp.ti. (1941)
96 ((end of life or EOL) adj5 (care or discuss* or decision* or plan* or preference*)).ti,kw. (7881)
97 31 or 90 or 91 or 92 or 93 or 94 or 95 or 96 (16523)
98 "ACP focus".ti. (0)
99 72 and 74 and 97 (1769)=kwal + talen + ACP focus
100 54 and 99 (151)= kwal + talen + ACP focus +SR
101 77 and 99 (334)= proactief of behoefte of perceptie of needs + kwal + talen + ACP focus
102 101 (334)
103 limit 102 to yr="2017 -Current" (177)= proactief of behoefte of perceptie of needs + kwal + talen + ACP focus vanaf 2017

CINAHL

1 (MH "Advance Care Planning") (4433)
2 TX advance* care N1 plan* (5931)
3 TX advance* N1 (medical plan* or statement*) (283)
4 TX acp (7794)
5 TX Statement of wishes (75)
6 (MH "Terminal Care") (19207)
7 TX terminal care (20075)

8 TX ((end of life or EOL) N5 (care or discuss* or decision* or plan* or preference*)) (19688)
 9 (MH "Treatment Refusal") (5407)
 10 (MH "Euthanasia, Passive") (4927)
 11 TX (treatment N3 (refus* or withhold* or withdraw*)) (9461)
 12 (MH "Living Wills") (1013)
 13 TX living will* (2604)
 14 TX ((shared or sharing) N2 decision*) (9006)
 15 TX SDM (1929)
 16 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
 OR S14 OR S15 (64454)= **proactieve zorgplanning**
 17 (MH "Qualitative Studies+") (167112)
 18 (MH "Interviews+") (238837)
 19 (MH "Focus Groups") (47929)
 20 S17 OR S18 OR S19 (322484)= **kwalitatief**
 21 S16 AND S20 (7199)= **proactieve zorgplanning + kwalitatief**
 22 TI proactiv* OR AB proactive (9051)
 23 (MH "Perception+") (89197)
 24 TI ((view or perception*)) OR AB ((view or perception*)) (241045)
 25 TI application* OR AB application* (160151)
 26 S22 OR S23 OR S24 OR S25 (463277)= **waarden en voorkeuren**
 27 S21 AND S26 (1946)= **proactieve zorgplanning + kwalitatief + waarden en voorkeuren**
 28 S21 AND S26 (1415)
 29 S21 AND S26 (1876)
 30 S21 AND S26 (840)
 31 (MH "Needs Assessment") (20211)
 32 AB needs N1 assessment OR TI needs (76816)
 33 S31 OR S32 (88627)= **behoefte**
 34 S30 AND S33 (50)= = **proactieve zorgplanning + kwalitatief + waarden, voorkeuren en
 behoeften**
 35 (MH "Systematic Review") OR (MH "Meta Analysis") (136638)
 36 S30 AND S35 (16)= = **proactieve zorgplanning + kwalitatief + waarden en voorkeuren + SR**
 37 S21 AND S26 (818) = **proactieve zorgplanning + kwalitatief + waarden en voorkeuren**
 38 (MH "Terminal Care+/PF") (4131)
 39 S37 AND S38 (39) = **proactieve zorgplanning + kwalitatief + waarden en voorkeuren +
 terminale zorg**

Onderzoeksvraag 3: surprise question, dubbele surprise question en SPICT

Wat is de diagnostische accuratesse dan wel wat zijn de klinimetrische eigenschappen van de surprise question, de dubbele surprise question of de SPICT?

Patients	Patiënten die mogelijk palliatieve zorg nodig hebben
Intervention	Surprise question, dubbele surprise question en/of de SPICT
Comparator	Geen instrument of een ander instrument
Outcome	Diagnostische accuratesse (sensitiviteit, specificiteit, AUC), klinimetrische eigenschappen

Search strategy

On 5 April 2022 the scientific literature is searched in database Medline. The search string is shown in this appendix. Also, the website of the SPICT was searched for relevant references.

The literature has been selected systematically based on the following predefined criteria:

- Design: systematic reviews, randomized controlled trials or observational research
- Language: English and Dutch
- Publication dates: from inception to 2022
- The outcomes are reported

Literature was excluded when the diagnostic accuracy and/or clinimetric properties were not reported or when it was a validation of the translation of the instrument.

Search results

The selection criteria were applied on the references yielded from the search. 33 unique hits were screened on title and abstract (Table 4). Of these, 22 were excluded. Of the remaining 11 papers, the full text was retrieved. Based on the full text, an additional 3 papers were excluded. Table 5 provides an overview of the excluded studies with reasons.

Table 4. Overall search results of research question 3.

Database	Number of hits
Medline	177
Total hits	177
n excluded (language, duplicates)	144
Total unique eligible hits	33

Table 5. Overview of excluded studies based on full-text evaluation of research question 3.

Reference	Reason for exclusion
Afshar K, Wiese B, Schneider N, Müller-Mundt G. Systematic identification of critically ill and dying patients in primary care using the German version of the Supportive and Palliative Care Indicators Tool (SPICT-DE). Ger Med Sci. 2020 Feb 3;18:Doc02.	No relevant outcomes
Hight G, Crawford D, Murray SA, Boyd K. Development and evaluation of the Supportive and Palliative Care Indicators Tool (SPICT): a mixed-methods study. BMJ Support Palliat Care. 2014 Sep;4(3):285-90.	No relevant outcomes
Weijers F, Veldhoven C, Verhagen C, Vissers K, Engels Y. Adding a second surprise question triggers general practitioners to increase the thoroughness of palliative care planning: results of a pilot RCT with cage vignettes. BMC Palliat Care. 2018 Apr 19;17(1):64.	No relevant outcomes
White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. BMC Med. 2017 Aug 2;15(1):139. doi: 10.1186/s12916-017-0907-4. PMID: 28764757; PMCID: PMC5540432.	Better systematic review available

Search string

MEDLINE

- 1 "vraag advanced care april 2022".ti. (0)
- 2 "surprise question".ti. (71)
- 3 "surprise question".kw. (32)
- 4 2 or 3 (80)
- 5 from 4 keep 5-6,8,10-12,14,19-20 (9)
- 6 from 4 keep 24 (1)
- 7 5 or 6 (10)
- 8 "double surprise question".ti. (2)
- 9 "double surprise question".kw. (0)
- 10 "not surprised if dead and not surprised if alive".tw. (1)
- 11 "Screening with the double surprise question to predict ".fc_titl. (1)
- 12 "Adding a second surprise question triggers general practitioners ".fc_titl. (1)
- 13 "Timely identification of patients in need of palliative care using ".fc_titl. (1)
- 14 11 or 12 or 13 (3)
- 15 "SPICT".fc_titl. (14)
- 16 "Development and evaluation of the Supportive and Palliative Care Indicators Tool ".fc_titl. (1)
- 17 "Recognising and managing key transitions in end of life care".fc_titl. (1)
- 18 16 or 17 (2)
- 19 (clinical adj3 (tool* or judg* or decisio* or evaluat*)).tw,kw. (226933)
- 20 *"Terminal Care"/ (22957)
- 21 Patient Selection/ (68910)
- 22 Terminally Ill/ (6745)
- 23 20 or 22 (28460)
- 24 21 and 23 (256)
- 25 19 and 24 (2)
- 26 *"Terminal Care"/mt (2721)
- 27 26 and (21 or 19) (78)
- 28 27 (78)
- 29 limit 28 to yr="2005 -Current" (38)
- 30 Palliative Care/ (59889)
- 31 Hospice Care/ (7404)
- 32 exp Terminal Care/ (55062)
- 33 ((palliative or hospice or terminal) adj3 care).ti,kw. (21236)
- 34 Prognosis/ (570271)
- 35 Psychometrics/ (83882)
- 36 progno*.ti,kw. (218083)
- 37 21 or 34 or 36 (699217)
- 38 psychometr*.ti,kw. (20759)
- 39 35 or 38 (89425)
- 40 30 or 31 or 32 or 33 (106614)
- 41 **37 and 39 and 40 (17)= care tools**
- 42 *"Advance Care Planning"/ (2841)
- 43 37 and 42 (136)
- 44 tool?.tw,kw. (851836)
- 45 prognostication.tw,kw. (10522)
- 46 44 or 45 (860999)
- 47 **43 and 46 (16)= tools prognostification**