

## Bijlage 5. Zoekverantwoording

### 5.1.1: Wat zijn de (on)gunstige effecten van proactieve zorgplanning bij patiënten met de ziekte van Parkinson?

#### PICO

<b>P</b>	Mensen met de ziekte van Parkinson
<b>I</b>	Proactieve zorgplanning
<b>C</b>	Geen proactieve zorgplanning
<b>O</b>	Tevredenheid van de patiënt, tevredenheid van de familieleden, kwaliteit van leven, kwaliteit van sterven, (ongewenste) opname, percentage reanimatie in eindstadium

#### Zoekstrategie

Database: Ovid MEDLINE(R) ALL <1946 to November 07, 2019>  
Search Strategy:

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1 "advanced 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)= advanced 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)  
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)  
**102 12 and 83 and 24 and 26 and 101 (33)= rct spec**  
**103 12 and 16 and 24 and 26 and 41 (35) = rct palliatief alg**  
104 102 or 103 (63)

**Database: Ovid MEDLINE(R) ALL <1946 to January 14, 2022>  
Search Strategy:**

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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)  
13 Palliative Care/ (59148)  
14 palliative.tw. (69329)  
15 palliative.kf. (13649)  
16 or/13-15 (96752)

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)  
25 17 and 24 (992)  
26 (dutch or german or french or english).la. (30508855)  
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)  
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)  
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)  
84 12 and 83 and 24 and 26 and 41 (18)  
85 12 and 16 and 24 and 26 and 41 (55)  
86 84 or 85 (61)  
87 12 and 83 and 24 and 26 and 55 (65)  
88 12 and 16 and 24 and 26 and 55 (211)  
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)  
 102 12 and 83 and 24 and 26 and 101 (42)  
 103 12 and 16 and 24 and 26 and 41 (55)  
 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)

Database: APA PsycInfo <1806 to January Week 2 2022>  
 Search Strategy:

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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**

## Overzicht van geëxcludeerde studies

Referentie	Reden voor exclusie
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 &amp; 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
Au, David H., Edmunds M. Udris, Ruth A. Engelberg, Paula H. Diehr, Christopher L. Bryson, Lynn F. Reinke, and J. Randall Curtis. 2012. "A Randomized Trial to Improve Communication about End-of-Life Care among Patients with COPD." <i>Chest</i> 141(3):726-35. doi: 10.1378/CHEST.11-0362.	wrong population
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 &amp; 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 &amp; 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

Brinkman-Stoppelenburg, Arianne, Judith A. C. Rietjens, and Agnes Van Der Heide. 2014. "The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review." <i>Palliative Medicine</i> 28(8):1000–1025.	wrong population
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
Curtis, J. Randall, Lois Downey, Anthony L. Back, Elizabeth L. Nielsen, Sudiptho Paul, Alexandria Z. Lahdya, Patsy D. Treece, Priscilla Armstrong, Ronald Peck, and Ruth A. Engelberg. 2018. "Effect of a Patient and Clinician Communication-Priming Intervention on Patient-Reported Goals-of-Care Discussions Between Patients With Serious Illness and Clinicians: A Randomized Clinical Trial." <i>JAMA Internal Medicine</i> 178(7):930–40. doi: 10.1001/JAMAINTERNMED.2018.2317.	wrong population
Dassel, K. B., et al. (2018). "The Influence of Hypothetical Death Scenarios on Multidimensional End-of-Life Care Preferences." <i>American Journal of Hospice &amp; Palliative Medicine</i> 35(1): 52-59.	healthy population, not on ACP intervention
DeCoursey, Danielle D., Melanie Silverman, Adeolu Oladunjoye, and Joanne Wolfe. 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. doi: 10.1097/CCM.0000000000003472.	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, Martin A., Sarah Cudmore, Gill Highet, Shirley Robertson, Lisa Donald, Jacqueline Stephen, Kristin Haga, Karen Hogg, Christopher J. Weir, Scott A. Murray, and Kirsty Boyd. 2016a. "Phase 2 Randomised Controlled Trial and Feasibility Study of Future Care Planning in Patients with Advanced Heart Disease." <i>Scientific Reports</i> 6. doi: 10.1038/SREP24619.	wrong population
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
Doorenbos, Ardith Z., Wayne C. Levy, J. Randall Curtis, and Cynthia M. Dougherty. 2016. "An Intervention to Enhance Goals-of-Care Communication Between Heart Failure Patients and Heart Failure Providers." <i>Journal of Pain and Symptom Management</i> 52(3):353–60. doi: 10.1016/J.JPAINSYMMAN.2016.03.018.	wrong population
Duenk, R. G., C. Verhagen, E. M. Bronkhorst, P. J. W. B. Van Mierlo, M. E. A. C. Broeders, S. M. Collard, P. N. R. Dekhuijzen, K. C. P. Vissers, Y. Heijdra, and Y. Engels. 2017. "Proactive Palliative Care for Patients with COPD (PROLONG): A Pragmatic Cluster Controlled Trial." <i>International Journal of COPD</i> 12:2795–2806. doi: 10.2147/COPD.S141974.	wrong population
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 &amp; 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 &amp; 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
Johnson, Stephanie B., Phyllis N. Butow, Melanie L. Bell, Karen Detering, Josephine M. Clayton, William Silvester, Belinda E. Kiely, Stephen Clarke, Lisa Vaccaro, Martin R. Stockler, Phillip Beale, Natalie Fitzgerald, and Martin H. N. Tattersall. 2018. "A Randomised Controlled Trial of an Advance Care Planning Intervention for Patients with Incurable Cancer." <i>British Journal of Cancer</i> 119(10):1182–90. doi: 10.1038/s41416-018-0303-7.	wrong population
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
Kirchhoff, Karin T., Bernard J. Hammes, Karen A. Kehl, Linda A. Briggs, and Roger L. Brown. 2012. "Effect of a Disease-Specific Advance Care Planning Intervention on End-of-Life Care." <i>Journal of the American Geriatrics Society</i> 60(5):946–50. doi: 10.1111/J.1532-5415.2012.03917.X.	wrong population
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 &amp; Frontotemporal Degeneration</i> 18(5-6): 388-396.	ACP as outcome, no comparative study
Lin, Cheng Pei, Catherine J. Evans, Jonathan Koffman, Jo Armes, Fliss E. M. Murtagh, and Richard Harding. 2019. "The Conceptual Models and Mechanisms of Action That Underpin Advance Care Planning for Cancer Patients: A Systematic Review of Randomised Controlled Trials." <i>Palliative Medicine</i> 33(1):5–23.	wrong population

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, Maureen E., Shana Jacobs, Linda Briggs, Yao Iris Cheng, and Jichuan Wang. 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. doi: 10.1016/j.jadohealth.2013.10.206.	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
Malhotra, Chetna, David Sim, Fazlur Rehman Jaufeerally, Meibo Hu, Nivedita Nadkarni, Clarice Shu Hwa Ng, Genevieve Wong, Boon Cheng Tan, Jing Fen Lim, Claire Ya Ting Chuang, and Eric A. Finkelstein. 2020. "Impact of a Formal Advance Care Planning Program on End-of-Life Care for Patients With Heart Failure: Results From a Randomized Controlled Trial." <i>Journal of Cardiac Failure</i> 26(7):594-98. doi: 10.1016/J.CARDFAIL.2020.01.015.	wrong population
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 &amp; 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 &amp; 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 &amp; 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
Nishikawa, Yuri, Natsuko Hiroshima, Hiroki Fukahori, Erika Ota, Atsushi Mizuno, Mitsunori Miyashita, Daisuke Yoneoka, and Joey S. W. Kwong. 2020. "Advance Care Planning for Adults with Heart Failure." <i>The Cochrane Database of Systematic Reviews</i> 2(2). doi: 10.1002/14651858.CD013022.PUB2.	wrong population
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
O'Donnell, Arden E., Kristen G. Schaefer, Lynne W. Stevenson, Kristen Devoe, Kayley Walsh, Mandeep R. Mehra, and Akshay S. Desai. 2018. "Social Worker-Aided Palliative Care Intervention in High-Risk Patients With Heart Failure (SWAP-HF): A Pilot Randomized Clinical Trial." <i>JAMA Cardiology</i> 3(6):516-19. doi: 10.1001/JAMACARDIO.2018.0589.	wrong population
Peltier, Wendy L., Faiz Gani, Jennifer Blissitt, Katherine Walczak, Kristi Opper, Arthur R. Derse, and Fabian M. Johnston. 2017a. "Initial Experience with 'Honoring Choices Wisconsin': Implementation of an Advance Care Planning Pilot in a Tertiary Care Setting." <i>Journal of Palliative Medicine</i> 20(9):998-1003. doi: 10.1089/jpm.2016.0530.	wrong population
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 &amp; Lung</i> 46(1): 30-34.	ACP use as outcome
Rogers, Joseph G., Chetan B. Patel, Robert J. Mentz, Bradi B. Granger, Karen E. Steinhilber, Mona Fiuzat, Patricia A. Adams, Adam Speck, Kimberly S. Johnson, Arun Krishnamoorthy, Hongqiu Yang, Kevin J. Anstrom, Gwen C. Dodson, Donald H. Taylor, Jerry L. Kirchner, Daniel B. Mark, Christopher M. O'Connor, and James A. Tulsky. 2017. "Palliative Care in Heart Failure: The PAL-HF Randomized, Controlled	wrong population



Clinical Trial." <i>Journal of the American College of Cardiology</i> 70(3):331–41. doi: 10.1016/J.JACC.2017.05.030.	
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
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
Sechoud, 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
Sidebottom, Abbey C., Ann Jorgenson, Hallie Richards, Justin Kirven, and Arthur Sillah. 2015. "Inpatient Palliative Care for Patients with Acute Heart Failure: Outcomes from a Randomized Trial." <i>Journal of Palliative Medicine</i> 18(2):134–42. doi: 10.1089/JPM.2014.0192.	wrong population
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
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
Skorstengaard, Marianne Hjorth, Anders Bonde Jensen, Pernille Andreassen, Trine Brogaard, Elisabeth Brendstrup, Anders Løkke, Susanne Agaard, Henrik Wiggers, and Mette Asbjørn Neergaard. 2020. "Advance Care Planning and Place of Death, Hospitalisation and Actual Place of Death in Lung, Heart and Cancer Disease: A Randomised Controlled Trial." <i>BMJ Supportive &amp; Palliative Care</i> 10(4):E37. doi: 10.1136/BMJSPCARE-2018-001677.	wrong population
Sloan, Danetta H., Susan M. Hannum, Lyndsay DeGroot, Sydney M. Dy, Julie Waldfoegel, Linda C. Chyr, Jaalah Ai Heughan, Allen Zhang, Renee F. Wilson, Christina T. Yuan, David S. Wu, Karen A. Robinson, and Valerie T. Cotter. 2021. "Advance Care Planning Shared Decision-Making Tools for Non-Cancer Chronic Serious Illness: A Mixed Method Systematic Review." <i>The American Journal of Hospice &amp; Palliative Care</i> 38(12):1526–35. doi: 10.1177/1049909121995416.	wrong population
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
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
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 &amp; Hepatology</i> 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." <i>JMIR Human Factors</i> 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." <i>Journal of Pain &amp; Symptom Management</i> 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." <i>Palliative Medicine</i> 32(8): 1305-1321.	no comparative study

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

### PICO

<b>P</b>	Mensen met de ziekte van Parkinson die palliatieve zorg ontvangen, hun naasten, of zorgverleners die palliatieve zorg verlenen
<b>I</b>	Proactieve zorgplanning
<b>C</b>	Niet van toepassing
<b>O</b>	Ervaringen en voorkeuren t.a.v. proactieve zorgplanning van patiënten, hun naasten en hun zorgverleners

### Zoekstrategie

Database: Ovid MEDLINE(R) ALL <1946 to March 18, 2022>

Search Strategy:

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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)=ACP
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)

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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)  
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**

## Overzicht van geëxcludeerde studies

Referentie	Reden voor exclusie
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. PMID: 30873713.	Wrong population
Carr, Karen, Felicity Hasson, Sonja McIlpatrick, and Julia Downing. 2021. "Factors Associated with Health Professionals Decision to Initiate Paediatric Advance Care Planning: A Systematic Integrative Review." <i>Palliative Medicine</i> 35(3):503–28. doi: 10.1177/0269216320983197.	Wrong population
Cottrell, Laura, Guillaume Economos, Catherine Evans, Eli Silber, Rachel Burman, Richard Nicholas, Bobbie Farsides, Stephen Ashford, and Jonathan Simon Koffman. 2020. "A Realist Review of Advance Care Planning for People with Multiple Sclerosis and Their Families." <i>PloS One</i> 15(10). doi: 10.1371/JOURNAL.PONE.0240815.	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	Wrong population

planning: a systematic review. Scand J Prim Health Care. 2013 Dec;31(4):215-26. doi: 10.3109/02813432.2013.854590. PMID: 24299046; PMCID: PMC3860298.	
Delmaczynska E, Newham R. To explore the prevalence and outcomes of advance care planning for patients with left ventricular assist devices: A review. J Clin Nurs. 2019 May;28(9-10):1365-1379. doi: 10.1111/jocn.14748. Epub 2019 Jan 7. PMID: 30552798.	Wrong outcomes
Dening KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. Int Psychogeriatr. 2011 Dec;23(10):1535-51. doi: 10.1017/S1041610211001608. Epub 2011 Aug 26. PMID: 21867597.	Wrong population
Hall, Alex, Christine Rowland, and Gunn Grande. 2019. "How Should End-of-Life Advance Care Planning Discussions Be Implemented According to Patients and Informal Carers? A Qualitative Review of Reviews." Journal of Pain and Symptom Management 58(2):311–35. doi: 10.1016/J.JPAINSYMMAN.2019.04.013.	Wrong population
Johnson S, Butow P, Kerridge I, Tattersall M. Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers. Psychooncology. 2016 Apr;25(4):362-86. doi: 10.1002/pon.3926. Epub 2015 Sep 20. PMID: 26387480.	Wrong population
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. Palliat Med. 2017 May;31(5):394-405. doi: 10.1177/0269216316663507. Epub 2016 Aug 11. PMID: 27515975.	Wrong population
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. J Clin Nurs. 2015 Aug;24(15-16):2057-73. doi: 10.1111/jocn.12853. Epub 2015 May 4. PMID: 25940451.	Wrong population
Lotz JD, Jox RJ, Borasio GD, Führer M. Pediatric advance care planning: a systematic review. Pediatrics. 2013 Mar;131(3):e873-80. doi: 10.1542/peds.2012-2394. Epub 2013 Feb 11. PMID: 23400610.	Wrong population
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. J Am Med Dir Assoc. 2021 Feb;22(2):349.e1-349.e28. doi: 10.1016/j.jamda.2020.12.018. Epub 2021 Jan 7. PMID: 33421371.	Wrong population
McDermott, Ella, and Lucy Ellen Selman. 2018. "Cultural Factors Influencing Advance Care Planning in Progressive, Incurable Disease: A Systematic Review With Narrative Synthesis." Journal of Pain and Symptom Management 56(4):613–36. doi: 10.1016/J.JPAINSYMMAN.2018.07.006.	Wrong population
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. Clin Interv Aging. 2017 Mar 3;12:475-484. doi: 10.2147/CIA.S128937. PMID: 28424546; PMCID: PMC5344428.	Wrong population
Ora, Linda, Judy Mannix, Lucy Morgan, Linda Gregory, Lauretta Luck, and Lesley Wilkes. 2021. "Chronic Obstructive Pulmonary Disease and Advance Care Planning: A Synthesis of Qualitative Literature on Patients' Experiences." Chronic Illness 1742395321990109. doi: 10.1177/1742395321990109.	Wrong population
Owen L, Steel A. Advance care planning: what do patients want? Br J Hosp Med (Lond). 2019 May 2;80(5):263-267. doi: 10.12968/hmed.2019.80.5.263. PMID: 31059340.	Wrong population
Sanders JJ, Robinson MT, Block SD. Factors Impacting Advance Care Planning among African Americans: Results of a Systematic Integrated Review. J Palliat Med. 2016 Feb;19(2):202-27. doi: 10.1089/jpm.2015.0325. PMID: 26840857.	Wrong population
Schichtel, Markus, Bee Wee, John I. MacArtney, and Sarah Collins. 2019. "Clinician Barriers and Facilitators to Heart Failure Advance Care Plans: A Systematic Literature Review and Qualitative Evidence Synthesis." BMJ Supportive & Palliative Care bmjpspcare-2018-001747. doi: 10.1136/BMJSPCARE-2018-001747.	Wrong population
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. Palliat Med. 2019 Mar;33(3):274-290. doi: 10.1177/0269216318809571. Epub 2018 Nov 8. PMID: 30404576; PMCID: PMC6376607.	Wrong population
Silies, Katharina Theodora, Sascha Köpke, and Rieke Schnakenberg. 2021. "Informal Caregivers and Advance Care Planning: Systematic Review with Qualitative Meta-Synthesis." BMJ Supportive & Palliative Care. doi: 10.1136/BMJSPCARE-2021-003095.	Wrong population
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. PLoS One. 2018 Jun 20;13(6):e0198535. doi: 10.1371/journal.pone.0198535. PMID: 29924837; PMCID: PMC6010277.	Wrong population

Van der Haeghen, Birgit, Karen van Beek, Mieke de Pril, Inge Bossuyt, Johan Menten, and Peter Rober. 2019. "What Do Hospitalists Experience as Barriers and Helpful Factors for Having ACP Conversations? A Systematic Qualitative Evidence Synthesis." <i>Perspectives in Public Health</i> 139(2):97–105. doi: 10.1177/1757913918786524.	Wrong population
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. PMID: 24531163.	Wrong population
Wendrich-van Dael, Annelien, Frances Bunn, Jennifer Lynch, Lara Pivodic, Lieve van den Block, and Claire Goodman. 2020. "Advance Care Planning for People Living with Dementia: An Umbrella Review of Effectiveness and Experiences." <i>International Journal of Nursing Studies</i> 107. doi: 10.1016/J.IJNURSTU.2020.103576.	Wrong population
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. PMID: 29956558; PMCID: PMC6088519.	Wrong population

**5.2: Welk instrument identificeert palliatieve zorgbehoeften en wensen afgezet tegen een gouden standaard vragen- of scorelijst die veelvuldig in onderzoek gebruikt wordt (zoals de UPDRS, niet-motor symptom scale of PDQ).**

PICO

<b>P</b>	Mensen met de ziekte van Parkinson die palliatieve zorg krijgen en hun naasten
<b>I</b>	Instrumenten om in de palliatieve fase zorgbehoefte en wensen te signaleren
<b>C</b>	Geen instrument of een ander instrument
<b>O</b>	Diagnostische accuratesse (sensitiviteit, specificiteit, AUC), klinimetrische eigenschappen, patiënttevredenheid, tevredenheid van naasten

**Zoekstrategie**

Database: Ovid MEDLINE(R) ALL <1946 to January 12, 2022>  
Search Strategy:

- 
- 1 "parkinson screening palliatieve fase".ti. (0)
  - 2 "parkinson palliative care needs AvE".ti. (0)
  - 3 "richardson\$.fc\_auts. and "needs assessment".fc\_titl. and "2007".fc\_pubyr. (2)
  - 4 "homs\$.fc\_auts. and "symptom".fc\_titl. and "2006".fc\_pubyr. (1)
  - 5 "walsh \$.fc\_auts. and "diagnostic tools".fc\_titl. and "2015".fc\_pubyr. (1)
  - 6 "datla\$.fc\_auts. and "palliative ".fc\_titl. (1)
  - 7 "maas\$.fc\_auts. and "tools".fc\_titl. and "2013".fc\_pubyr. (1)
  - 8 "highet\$.fc\_auts. and "supportive".fc\_titl. and "2014".fc\_pubyr. (1)
  - 9 "velseboer\$.fc\_auts. and "validation".fc\_titl. (1)
  - 10 or/3-9 (8)
  - 11 "bruera\$.fc\_auts. and "edmonton".fc\_titl. (33)
  - 12 from 10 keep 1-8 (8)
  - 13 from 11 keep 2,4,6,8-9,14,17,24 (8)
  - 14 "colagiuri\$.fc\_auts. and "care needs".fc\_titl. (1)
  - 15 "hearn\$.fc\_auts. and "validation".fc\_titl. (10)
  - 16 from 13 keep 1-8 (8)
  - 17 from 15 keep 10 (1)
  - 18 "sleeman\$.fc\_auts. and "psychometric validation".fc\_titl. (1)
  - 19 14 or 17 or 18 (3)
  - 20 "27".fc\_vol. and "saleem\$.fc\_auts. and "symptom".fc\_titl. and "2013".fc\_pubyr. (1)
  - 21 "richfield\$.fc\_auts. and "assessing".fc\_titl. and "2014".fc\_pubyr. (0)
  - 22 "validation of a screening tool".fc\_titl. and "2015".fc\_pubyr. (2)
  - 23 "zhong\$.fc\_auts. and "validity".fc\_titl. and "2013".fc\_pubyr. (3)
  - 24 from 19 keep 1-3 (3)
  - 25 from 23 keep 2 (1)
  - 26 "hudson\$.fc\_auts. and "would people".fc\_titl. and "2006".fc\_pubyr. (1)
  - 27 22 or 25 or 26 (4)
  - 28 "P Parkinson".ti. (0)
  - 29 Parkinson Disease/ (74187)
  - 30 parkinson\*.tw,kw. (131514)
  - 31 29 or 30 (139203)=P parkinson**
  - 32 Palliative Care/ (59132)
  - 33 Terminal Care/ (30371)
  - 34 Terminally Ill/ (6723)
  - 35 Hospice Care/ (7278)
  - 36 (palliat\* or terminal\* or endstage or hospice\* or (end adj2 life) or (care adj3 dying) or ((advanced or late or last or end or final) adj2 (stage\* or phase\*))).tw,kw. (791228)
  - 37 "advanced disease\*".tw,kw. (22118)
  - 38 ("end-stage disease\*" or "end stage disease\*" or end-stage illness" or "end stage").tw,kw. (75050)
  - 39 (terminal\* adj6 care\*).tw,kw. (4370)
  - 40 (terminal\* adj6 (ill\* or disease)).tw,kw. (11731)
  - 41 terminal?stage\*.tw,kw. (20)
  - 42 (dying or (close adj6 death)).tw,kw. (38429)
  - 43 or/32-42 (862876)=palliatieve zorg**
  - 44 "Palliative care in Parkinson's disease".ti. (9)
  - 45 "richfield\$.fc\_auts. and "palliative".fc\_titl. (5)
  - 46 Parkinson Disease/nu (445)
  - 47 31 and 43 (6053)
  - 48 (clinical adj2 tool?).tw,kw. (15302)
  - 49 47 and 48 (6)
  - 50 (need? adj2 assess\*).tw,kw. (18130)
  - 51 31 and 50 (61)
  - 52 Needs Assessment/ (31982)
  - 53 "Health Services Needs and Demand"/ (54763)

54 Outcome Assessment, Health Care/ (79102)  
55 (outcome adj3 assessment).tw,kw. (9274)  
56 exp patient outcome assessment/ (17104)  
57 (need? adj3 assess\*).tw,kw. (27126)  
58 exp disease progression/ (199004)  
59 (disease adj3 progre\*).tw,kw. (169977)  
60 "Severity of Illness Index"/ (264336)  
61 (severity adj3 (disease or illness)).tw,kw. (87141)  
62 HRQoL.ti,kw. (1041)  
**63 or/50,52-62 (840676)= outcome**  
64 43 and 63 (43249)  
**65 31 and 64 (985)=parkinson + palliatieve zorg + outcome**  
66 46 and 65 (13)  
67 nu.fs. (137294)  
68 31 and 67 (537)  
69 68 and 65 (14)  
70 66 or 69 (14)  
71 45 and 70 (1)  
72 from 44 keep 1-9 (9)  
73 from 45 keep 3 (1)  
74 from 70 keep 1-14 (14)  
75 "filter medline systematic reviews".ti. (0)  
76 meta analysis.pt. (150503)  
77 (meta-anal\$ or metaanal\$).tw,kf. (224728)  
78 (systematic\$ adj10 (review\$ or overview\$)).tw,kf. (256797)  
79 (quantitativ\$ adj10 (review\$ or overview\$)).tw,kf. (11388)  
80 (methodologic\$ adj10 (review\$ or overview\$)).tw,kf. (13966)  
81 medline.tw. and review.pt. (87568)  
82 (pooled adj3 analy\*).tw,kf. (24565)  
83 "cochrane\$.fc\_jour. (15740)  
**84 or/76-83 (443333)=SR**  
85 "medline filter rct".ti. (0)  
86 controlled-clinical-trial.pt. (94637)  
87 randomized-controlled-trial.pt. (555633)  
88 randomized controlled trial/ (555633)  
89 randomi?ed controlled trial?.tw. (212306)  
90 randomi?ed controlled trial?.kf. (15009)  
91 random-allocation.tw,kf. (1872)  
92 double-blind-method.tw,kf. (517)  
93 single-blind-method.tw,kf. (93)  
94 (random adj8 (selection? or sample?)).kf,tw. (49086)  
95 random\*.tw,kf. (1286444)  
**96 or/86-95 (1500630)=rct**  
97 "medline filter observationele studies".ti. (0)  
98 epidemiologic studies/ (8963)  
99 exp case-control studies/ (1271706)  
100 exp cohort studies/ (2278381)  
101 cross-sectional studies/ (406934)  
102 (case adj3 control).tw,kf. (147857)  
103 (cohort adj5 (study or studies or analy\$)).tw,kf. (336976)  
104 (follow-up adj5 (study or studies)).tw,kf. (99961)  
105 (longitudinal or retrospective or prospective or (cross adj5 sectional)).tw,kf. (1845398)  
106 (observational adj5 (study or studies)).tw,kf. (182626)  
**107 or/98-106 (3634858)=observat**  
**108 65 and 84 (23)= parkinson + palliatieve zorg + outcome + SR**  
**109 (65 and 96) not 84 (58)= parkinson + palliatieve zorg + outcome + rct**  
**110 (65 and 107) not (84 or 96) (214)= parkinson + palliatieve zorg + outcome + observat**  
111 \*Needs Assessment/ (9539)  
112 \*Health Services Needs and Demand"/ (23193)  
113 \*Outcome Assessment, Health Care/ (32175)  
114 (outcome adj3 assessment).ti,kw. (1424)  
115 (Palliative adj3 outcome adj3 score).tw,kw. (18)  
116 (POS or IPOS\* or Edmonton).tw,kw. (8261)  
117 (ESAS or PACA or (needs adj2 assessment adj2 tool?)).tw,kw. (4347)  
**118 or/111-117 (77140)=needs assessment**  
**119 110 and 118 (7)= parkinson + palliatieve zorg + outcome + observat + needs assessment**  
**120 65 and 118 (22)= parkinson + palliatieve zorg + outcome + needs assessment**

Embase search

Database: Embase <1974 to 2022 January 12>

Search Strategy:

-----  
1 "parkinson screening palliatieve fase".ti. (0)  
2 "parkinson palliative care needs AvE".ti. (0)  
3 "richardson\$.fc\_auts. and "needs assessment".fc\_titl. and "2007".fc\_pubyr. (2)  
4 "homsis\$.fc\_auts. and "symptom".fc\_titl. and "2006".fc\_pubyr. (1)

5 "walsch\$" .fc\_ auts. and "diagnostic tools".fc\_ titl. and "2015".fc\_ pubyr. (1)  
6 "datla\$" .fc\_ auts. and "palliative" .fc\_ titl. (2)  
7 "maas\$" .fc\_ auts. and "tools".fc\_ titl. and "2013".fc\_ pubyr. (1)  
8 "highe\$" .fc\_ auts. and "supportive".fc\_ titl. and "2014".fc\_ pubyr. (1)  
9 "velseboer\$" .fc\_ auts. and "validation".fc\_ titl. (1)  
10 or/3-9 (9)  
11 "bruera\$" .fc\_ auts. and "edmonton".fc\_ titl. (42)  
12 from 10 keep 1-8 (8)  
13 from 11 keep 2,4,6,8-9,14,17,24 (8)  
14 "colagiuri\$" .fc\_ auts. and "care needs".fc\_ titl. (1)  
15 "hearn\$" .fc\_ auts. and "validation".fc\_ titl. (12)  
16 from 13 keep 1-8 (8)  
17 from 15 keep 10 (1)  
18 "sleeman\$" .fc\_ auts. and "psychometric validation".fc\_ titl. (1)  
19 14 or 17 or 18 (3)  
20 "27".fc\_ vol. and "saleem\$" .fc\_ auts. and "symptom".fc\_ titl. and "2013".fc\_ pubyr. (1)  
21 "richfield\$" .fc\_ auts. and "assessing".fc\_ titl. and "2014".fc\_ pubyr. (1)  
22 "validation of a screening tool".fc\_ titl. and "2015".fc\_ pubyr. (2)  
23 "zhong\$" .fc\_ auts. and "validity".fc\_ titl. and "2013".fc\_ pubyr. (3)  
24 from 19 keep 1-3 (3)  
25 from 23 keep 2 (1)  
26 "hudson\$" .fc\_ auts. and "would people".fc\_ titl. and "2006".fc\_ pubyr. (1)  
27 22 or 25 or 26 (4)  
28 "P Parkinson".ti. (0)  
29 Parkinson Disease/ (169679)  
30 parkinson\*.tw,kw. (187702)  
31 29 or 30 (219412)  
32 Palliative Care/ (81960)  
33 Terminal Care/ (38438)  
34 Terminally Ill/ (8293)  
35 Hospice Care/ (11631)  
36 (palliat\* or terminal\* or endstage or hospice\* or (end adj2 life) or (care adj3 dying) or ((advanced or late or last or end or final) adj2 (stage\* or phase\*))).tw,kw. (997537)  
37 "advanced disease\*".tw,kw. (37039)  
38 ("end-stage disease\*" or "end stage disease\*" or end-stage illness" or "end stage").tw,kw. (113536)  
39 (terminal\* adj6 care\*).tw,kw. (5757)  
40 (terminal\* adj6 (ill\* or disease)).tw,kw. (15631)  
41 terminal?stage\*.tw,kw. (47)  
42 (dying or (close adj6 death)).tw,kw. (49419)  
43 or/32-42 (1094293)  
44 31 and 43 (9960)  
45 10 or 27 (13)  
46 "vb refs".ti. (0)  
47 "zorgbehoefte meetopties".ti. (0)  
48 Needs Assessment/ (25959)  
49 "Health Services Needs and Demand"/ (140295)  
50 Outcome Assessment, Health Care/ (465126)  
51 (outcome adj3 assessment).tw,kw. (13179)  
52 exp patient outcome assessment/ (641672)  
53 (need? adj3 assess\*).tw,kw. (39011)  
54 exp disease progression/ (147110)  
55 (disease adj3 progre\*).tw,kw. (288436)  
56 "Severity of Illness Index"/ (19919)  
57 (severity adj3 (disease or illnes\*)).tw,kw. (134271)  
58 HRQoL.ti,kw. (2461)  
59 or/48-58 (1365884)  
60 ((Palliative adj2 outcome adj2 score?) or (IPOS adj2 neuro\*) or (Edmonton adj2 Symptom adj2 Assessment adj2 Scale\*) or ESAS or PACA or (needs adj2 assessment adj2 tool?)).tw,kw. (7683)  
61 Mass Screening/ (58309)  
62 screening.tw,kw. (831578)  
63 60 or 61 or 62 (858974)  
64 44 and 63 (230)  
65 (screening adj2 (tool or instrum\* or scal\* or assess\* or interv\*)).tw,kw. (64169)  
66 60 or 61 or 65 (126482)  
67 31 and 66 (987)  
68 "validity".kw. (12746)  
69 "Clinical indicators".kw. (129)  
70 (patient adj3 screening).tw,kw. (6512)  
71 (palliative adj4 scor\*).tw,kw. (636)  
72 (symptom\* adj4 assess\*).tw,kw. (62486)  
73 60 or 61 or 65 or 68 or 69 or 70 or 71 or 72 (204312)  
74 31 and 59 and 73 (496)  
**75 (dutch or english).la. (32302547)=talen**  
76 comparative study/ (931361)  
77 "richfield\$" .fc\_ auts. and "palliative".fc\_ titl. (8)  
78 from 77 keep 3 (1)



79 10 or 16 or 19 or 27 (24)  
80 Parkinson disease/ (169679)  
81 parkinso\*n.ti.kw. (19376)  
**82 80 or 81 (174730)=parkinson**  
83 exp palliative therapy/ (123898)  
**84 43 or 83 (1107768)=palliatieve zorg**  
85 59 and 82 and 84 (1301)  
86 symptom assessment/ (9928)  
87 edmonton symptom assessment system/ or neurologic disease assessment/ (6160)  
88 73 or 86 or 87 (215571)  
89 82 and 84 and 88 (120)  
90 75 and 89 (114)  
91 "Palliative care Outcome scale"/ (36)  
92 \*\*unmet medical need"/ (205)  
**93 88 or 91 or 92 (215798)= assessment schaal**  
94 75 and 82 and 84 and 93 (118)  
95 "filter observationele studies emb sign".ti. (0)  
96 Clinical study/ (156992)  
97 Case control study/ (182317)  
98 family study/ (25366)  
99 Longitudinal study/ (165791)  
100 Retrospective study/ (1184121)  
101 Prospective study/ (737730)  
102 Randomized controlled trials/ (217982)  
103 101 not 102 (729211)  
104 Cohort analysis/ (793699)  
105 (Cohort adj (study or studies)).tw,kw. (373660)  
106 (Case control adj (study or studies)).tw,kw. (150263)  
107 (follow up adj (study or studies)).tw,kw. (68059)  
108 (observational adj (study or studies)).tw,kw. (206907)  
109 (epidemiologic\$ adj (study or studies)).tw,kw. (114031)  
110 (cross sectional adj (study or studies)).tw,kw. (273806)  
111 96 or 97 or 98 or 99 or 100 or 103 or 104 or 105 or 106 or 107 or 108 or 109 or 110 (3280103)  
112 "rct filter embase".ti. (0)  
113 randomization/ (92744)  
114 exp randomized controlled trial/ (692050)  
115 exp controlled clinical trial/ (880954)  
116 Major Clinical Study/ (4343414)  
117 random\$.tw,kw. (1747029)  
118 double blind procedure/ (191298)  
119 or/113-118 (5847212)  
120 "emb SR filter".ti. (0)  
121 meta analysis/ (234267)  
122 "systematic review"/ (327575)  
123 (meta-analy\$ or metaanaly\$).tw,kw. (289479)  
124 (systematic\$ adj4 (review\$ or overview\$)).tw,kw. (307584)  
125 (quantitativ\$ adj5 (review? or overview?)).tw,kw. (6444)  
126 (methodologic adj5 (overview? or review?)).tw,kw. (408)  
127 (review\$ adj3 (database? or medline or embase or cinahl)).tw,kw. (33623)  
128 (pooled adj3 analy\$).tw,kw. (37010)  
129 (extensive adj3 review\$ adj3 literature).tw,kw. (4276)  
130 (meta or synthesis or (literature adj8 database?) or extraction).tw,kw. (1609482)  
131 review.pt. (2839469)  
132 130 and 131 (193963)  
133 or/121-129,132 (694541)  
134 94 and 133 (6)  
135 "conference abstract"/ (1426767)  
136 134 not 135 (3)  
137 (94 and 119) not 133 (51)  
138 (94 and 111) not (133 or 119) (7)  
**139 66 and 82 and 84 (37)=screening + parkinson + palliatieve zorg**  
140 exp symptomatology/ (1064627)  
141 from 134 keep 1-6 (6)  
142 from 137 keep 1-51 (51)  
143 from 138 keep 1-7 (7)  
144 from 139 keep 1-37 (37)  
145 75 and 82 and 84 and (93 or 140) (642)  
**146 75 and 82 and 84 and (93 or 140) and 133 (33)=talen + parkinson + assessment breed + SR compleet**  
**147 (75 and 82 and 84 and (93 or 140) and 119) not 133 (171)= talen + parkinson + assessment breed + rct compleet**  
148 147 and 76 (7)  
149 "sensitivity and specificity"/ (417310)  
150 from 146 keep 1-33 (33)  
151 receiver operating characteristic/ (159658)  
152 diagnostic accuracy/ or exp general pathological parameters/ (645311)  
153 exp diagnostic error/ (110434)  
**154 149 or 151 or 152 or 153 (1104746)=uitkomstmaten**

155 147 and 154 (14)  
 156 satisfaction/ or patient satisfaction/ (217667)  
**157 154 or 156 (1319142)= uitkomstmaten extra**  
**158 147 and 157 (16)= talen + parkinson + assessment breed + rct compleet en extra uitkomstmaten**  
 159 (94 and 111) not (158 or 146) (29)  
 160 exp qualitative research/ (95746)  
 161 from 158 keep 1-16 (16)  
 162 from 159 keep 1-29 (29)  
 163 major clinical study/ (4343414)  
 164 94 and 160 (3)  
 165 145 and 160 (4)  
 166 (145 and 119) not 146 (171)  
 167 166 and 163 (150)  
**168 166 and 163 and 75 (150)= talen + parkinson + assessment breed + rct compleet met major clinical study**  
**168 166 and 163 and 75 (150)=rct**  
**169 (145 and 111) not (168 or 133) (48)=observat**

## Overzicht van geëxcludeerde studies

Reference	Reason for exclusion
Holden, S.K., et al. (2019). "Measuring quality of life in palliative care for Parkinson's disease: A clinimetric comparison." <i>Parkinsonism &amp; Related disorders</i> 65(0):172-177	Wrong population
Kwok, J.Y.Y., et al. (2021). "Symptom burden and unmet support needs of patients with Parkinson's disease: A cross-sectional study in Asia-Pacific regions." <i>Journal of the American Medical Directors Association</i> 22(6):1255-1264	Wrong outcomes
Lithin, Z., et al. (2020). "Palliative care needs and care giver burden in neurodegenerative diseases: A cross sectional study." <i>Annals of Indian Academy of Neurology</i> 23(3):313-317	Wrong outcomes
Miyasaki, J.M., et al. (2012). "Palliative care for advanced Parkinson disease: An interdisciplinary clinic and new scale, the ESAS-PD." <i>Parkinsonism &amp; Related Disorders</i> 18(10):S6-9	Wrong outcomes
Saleem, T.Z., et al. (2013). "Symptom prevalence, severity and palliative care needs assessment using the Palliative Outcome Scale: A cross-sectional study of patients with Parkinson's disease and related neurological conditions." <i>Palliative Medicine</i> 27(8):722-731	Wrong outcomes
Sebring, K., et al. (2018). "Assessing the validity of proxy caregiver reporting for potential palliative outcome measures in Parkinson's disease." <i>Palliative Medicine</i> 32(9):1522-1528	Wrong outcomes
Guimaraes, I., et al. (2017). "The psychometric properties of the Voice Handicap Index in People with Parkinson's Disease." <i>Journal of Voice</i> 31(0):e13-258	Wrong instrument
Higginson, I.J., et al. (2012). "Symptoms and quality of life in late stage Parkinson syndromes: A longitudinal community study of predictive factors." <i>PLoS ONE</i> 7(0)	Wrong outcomes
Lee, M.A., et al. (2006). "Individualized assessment of quality of life in idiopathic Parkinson's disease." <i>Movement Disorders</i> 21(0):1929-1934	Wrong outcomes
Chaudhuri, K.R., et al. (2002). "The Parkinson's disease sleep scale: A new instrument for assessing sleep and nocturnal disability in Parkinson's disease." <i>Journal of Neurology Neurosurgery and Psychiatry</i> 73(0):629-635	Wrong instrument
Han, C., et al. (2020). "Early morning off in patients with Parkinson's disease: A Chinese nationwide study and a 7-question screening scale." <i>Translational Neurodegeneration</i> 9(29)	Wrong instrument
Lee, M.A., et al. (2007). "Measuring symptom load in Idiopathic Parkinson's disease." <i>Parkinsonism and Related Disorders</i> 13(0):284-289	Wrong outcomes
Miyasaki, J., et al. (2012). "Correlation between the modified edmonton symptom assessment scale (ESAS-PD), the health utility index and quality of life 15d scale." <i>Palliative Medicine</i> 26(0):592-593	Conference abstract
Richfield, E.W., et al. (2014). "Assessing palliative care in Parkinson's disease-development of the NAT:Parkinson's disease." <i>Palliative Medicine</i> 28(0):641	Conference abstract
Santangelo, G., et al. (2014). "Validation of the Italian version of Parkinson's disease-cognitive rating scale (PD-CRS)." <i>Neurological Sciences</i> 35(0):537-544	Wrong instrument
Simons, J.A., et al. (2016). "Reliability of a newly developed protocol for fiberoptic endoscopic evaluation of swallowing in Parkinson's patients (PARK-FEES)." <i>Movement Disorders</i> 31(0):S517-S518	Wrong instrument
Rader, V., et al. (2020). "The gut dysmotility questionnaire (GDQ) for Parkinson's disease: Current development." <i>Movement Disorders</i> 35(0):S581	Wrong instrument
Lennaerts-Kats, H., et al. (2020). "RADPAC-PD: A tool to support healthcare professionals in timely identifying palliative care needs of people with Parkinson's disease." <i>PLoS ONE</i> 15(4):e0230611	Wrong instrument

Richfield, E.W. & Johnson, M.J. (2020). "Palliative care in Parkinson's disease: review of needs assessment tools." <i>Annals of Palliative Medicine</i> 9(0):S6-S15	Narrative review, used for reference scanning
Ratti, P.L., et al. (2019). "A new prospective, home-based monitoring of motor symptoms in Parkinson's disease." <i>Journal of Parkinson's Disease</i> 9(0):803-809	Wrong instrument
Herlofson, K. & Larsen, J.P. (2002). "Measuring fatigue in patients with Parkinson's disease – the Fatigue Severity Scale." <i>European Journal of Neurology</i> 9(6):595-600	Wrong instrument

### 5.3: Wat zijn de (on)gunstige effecten van interventies ter behandeling van klachten in de stervensfase bij mensen met de ziekte van Parkinson?

<b>P</b>	Mensen met de ziekte van Parkinson in de palliatieve fase
<b>I</b>	Alle mogelijke interventies
<b>C</b>	Geen behandeling/placebo of andere interventie
<b>O</b>	Effectiviteit/afname van klachten, bijwerkingen, kwaliteit van leven

<b>P</b>	Mensen met de ziekte van Parkinson in de stervensfase
<b>I</b>	Alle mogelijke interventies
<b>C</b>	Geen behandeling/placebo of andere interventie
<b>O</b>	Effectiviteit/afname van klachten, bijwerkingen, kwaliteit van sterven

#### Zoekstrategie

Zoekstrategie in medline

Database: Ovid MEDLINE(R) ALL <1946 to June 24, 2022>

Search Strategy:

-----

- 1 "parkinson screening palliatieve fase".ti. (0)
- 2 "parkinson palliative care needs AvE".ti. (0)
- 3 "richardson\$.fc\_au. and "needs assessment".fc\_titl. and "2007".fc\_pubyr. (2)
- 4 "homsis\$.fc\_au. and "symptom".fc\_titl. and "2006".fc\_pubyr. (1)
- 5 "walsh \$.fc\_au. and "diagnostic tools".fc\_titl. and "2015".fc\_pubyr. (1)
- 6 "datla\$.fc\_au. and "palliative ".fc\_titl. (1)
- 7 "maas\$.fc\_au. and "tools".fc\_titl. and "2013".fc\_pubyr. (1)
- 8 "highet\$.fc\_au. and "supportive".fc\_titl. and "2014".fc\_pubyr. (1)
- 9 "velseboer\$.fc\_au. and "validation".fc\_titl. (1)
- 10 or/3-9 (8)
- 11 "bruera\$.fc\_au. and "edmonton".fc\_titl. (34)
- 12 from 10 keep 1-8 (8)
- 13 from 11 keep 2,4,6,8-9,14,17,24 (8)
- 14 "colagiuri\$.fc\_au. and "care needs".fc\_titl. (1)
- 15 "hearn\$.fc\_au. and "validation".fc\_titl. (11)
- 16 from 13 keep 1-8 (8)
- 17 from 15 keep 10 (1)
- 18 "sleeman\$.fc\_au. and "psychometric validation".fc\_titl. (1)
- 19 14 or 17 or 18 (3)
- 20 "27".fc\_vol. and "saleem\$.fc\_au. and "symptom".fc\_titl. and "2013".fc\_pubyr. (1)
- 21 "richfield\$.fc\_au. and "assessing".fc\_titl. and "2014".fc\_pubyr. (0)
- 22 "validation of a screening tool".fc\_titl. and "2015".fc\_pubyr. (2)
- 23 "zhong\$.fc\_au. and "validity".fc\_titl. and "2013".fc\_pubyr. (3)
- 24 from 19 keep 1-3 (3)
- 25 from 23 keep 2 (1)
- 26 "hudson\$.fc\_au. and "would people".fc\_titl. and "2006".fc\_pubyr. (1)
- 27 22 or 25 or 26 (4)
- 28 "P Parkinson".ti. (0)
- 29 Parkinson Disease/ (77304)
- 30 parkinson\*.tw,kw. (135723)
- 31 **29 or 30 (143459)= P**
- 32 Palliative Care/ (60649)
- 33 Terminal Care/ (30949)
- 34 Terminally Ill/ (6770)
- 35 Hospice Care/ (7556)
- 36 (palliat\* or terminal\* or endstage or hospice\* or (end adj2 life) or (care adj3 dying) or ((advanced or late or last or end or final) adj2 (stage\* or phase\*))).tw,kw. (807276)
- 37 "advanced disease\*".tw,kw. (22723)
- 38 ("end-stage disease\*" or "end stage disease\*" or "end-stage illness" or "end stage").tw,kw. (77292)
- 39 (terminal\* adj6 care\*).tw,kw. (4441)
- 40 (terminal\* adj6 (ill\* or disease)).tw,kw. (11924)
- 41 terminal?stage\*.tw,kw. (21)
- 42 (dying or (close adj6 death)).tw,kw. (39296)

43 or/32-42 (880139)  
44 "Palliative care in Parkinson's disease".ti. (9)  
45 "richfield\$.fc\_auts. and "palliative".fc\_titl. (5)  
46 Parkinson Disease/nu (445)  
47 31 and 43 (6223)  
48 (clinical adj2 tool?).tw,kw. (15933)  
49 47 and 48 (6)  
50 (need? adj2 assess\*).tw,kw. (18791)  
51 31 and 50 (63)  
52 Needs Assessment/ (32184)  
53 "Health Services Needs and Demand"/ (54960)  
54 Outcome Assessment, Health Care/ (80517)  
55 (outcome adj3 assessment).tw,kw. (9592)  
56 exp patient outcome assessment/ (18614)  
57 (need? adj3 assess\*).tw,kw. (28075)  
58 exp disease progression/ (202954)  
59 (disease adj3 progre\*).tw,kw. (176640)  
60 "Severity of Illness Index"/ (267777)  
61 (severity adj3 (disease or illnes\*)).tw,kw. (91137)  
62 HRQoL.ti,kw. (1109)  
63 or/50,52-62 (860533)  
64 43 and 63 (44478)  
65 31 and 64 (1020)  
66 46 and 65 (13)  
67 nu.fs. (137394)  
68 31 and 67 (537)  
69 68 and 65 (14)  
70 66 or 69 (14)  
71 45 and 70 (1)  
72 from 44 keep 1-9 (9)  
73 from 45 keep 3 (1)  
74 from 70 keep 1-14 (14)  
75 "filter medline systematic reviews".ti. (0)  
76 meta analysis.pt. (162920)  
77 (meta-anal\$ or metaanal\$).tw,kf. (240008)  
78 (systematic\$ adj10 (review\$ or overview\$)).tw,kf. (277360)  
79 (quantitativ\$ adj10 (review\$ or overview\$)).tw,kf. (12003)  
80 (methodologic\$ adj10 (review\$ or overview\$)).tw,kf. (14618)  
81 medline.tw. and review.pt. (91375)  
82 (pooled adj3 analy\*).tw,kf. (25934)  
83 "cochrane\$.fc\_jour. (15899)  
84 or/76-83 (470691)  
85 "medline filter rct".ti. (0)  
86 controlled-clinical-trial.pt. (94918)  
87 randomized-controlled-trial.pt. (571576)  
88 randomized controlled trial/ (571576)  
89 randomi?ed controlled trial?.tw. (223181)  
90 randomi?ed controlled trial?.kf. (16305)  
91 random-allocation.tw,kf. (1921)  
92 double-blind-method.tw,kf. (535)  
93 single-blind-method.tw,kf. (94)  
94 (random adj8 (selection? or sample?)).kf,tw. (50127)  
95 random\*.tw,kf. (1331388)  
96 or/86-95 (1546463)  
97 "medline filter observationele studies".ti. (0)  
98 epidemiologic studies/ (9124)  
99 exp case-control studies/ (1332398)  
100 exp cohort studies/ (2364720)  
101 cross-sectional studies/ (431047)  
102 (case adj3 control).tw,kf. (152471)  
103 (cohort adj5 (study or studies or analy\$)).tw,kf. (358558)  
104 (follow-up adj5 (study or studies)).tw,kf. (102898)  
105 (longitudinal or retrospective or prospective or (cross adj5 sectional)).tw,kf. (1929744)  
106 (observational adj5 (study or studies)).tw,kf. (194172)  
107 or/98-106 (3762240)  
108 65 and 84 (24)

- 109 (65 and 96) not 84 (62)  
 110 (65 and 107) not (84 or 96) (222)  
 111 \*Needs Assessment/ (9571)  
 112 \*\*Health Services Needs and Demand"/ (23265)  
 113 \*Outcome Assessment, Health Care/ (32494)  
 114 (outcome adj3 assessment).ti,kw. (1468)  
 115 (Palliative adj3 outcome adj3 score).tw,kw. (18)  
 116 (POS or IPOS\* or Edmonton).tw,kw. (8614)  
 117 (ESAS or PACA or (needs adj2 assessment adj2 tool?)).tw,kw. (4529)  
 118 or/111-117 (78103)  
 119 110 and 118 (7)  
 120 65 and 118 (22)  
 121 33 or 34 or 39 or 40 or 41 or 42 (75816)  
**122 31 and 121 (430)= P + terminale fase**  
 123 (dutch or english).la. (29565788)  
 124 (dt or rt or rh or su or th).fs. (6617624)  
 125 96 or 107 (4893839)  
**126 122 and 123 and 125 (57)= P + terminale fase + talen + rct of observationele studies=behandeling rct of observat**  
 127 122 and 123 and 124 (92)= P + terminale fase + talen + behandeling  
**128 127 not 125 (72)= behandeling overige studietypen**  
 129 comparative study/ (1911224)  
 130 from 126 keep 1-57 (57)  
 131 from 128 keep 1-72 (72)  
**132 122 and 123 and 129 (21)**

Embase

Database: Embase <1974 to 2022 June 24>

Search Strategy:

- 
- 1 "parkinson screening palliative fase".ti. (0)  
 2 "parkinson palliative care needs AvE".ti. (0)  
 3 "richardson\$.fc\_auts. and "needs assessment".fc\_titl. and "2007".fc\_pubyr. (2)  
 4 "homsis\$.fc\_auts. and "symptom".fc\_titl. and "2006".fc\_pubyr. (1)  
 5 "walsh \$.fc\_auts. and "diagnostic tools".fc\_titl. and "2015".fc\_pubyr. (1)  
 6 "datla\$.fc\_auts. and "palliative ".fc\_titl. (2)  
 7 "maas\$.fc\_auts. and "tools".fc\_titl. and "2013".fc\_pubyr. (1)  
 8 "highet\$.fc\_auts. and "supportive".fc\_titl. and "2014".fc\_pubyr. (1)  
 9 "velseboer\$.fc\_auts. and "validation".fc\_titl. (1)  
 10 or/3-9 (9)  
 11 "bruera\$.fc\_auts. and "edmonton".fc\_titl. (43)  
 12 from 10 keep 1-8 (8)  
 13 from 11 keep 2,4,6,8-9,14,17,24 (8)  
 14 "colagiuri\$.fc\_auts. and "care needs".fc\_titl. (1)  
 15 "hearn\$.fc\_auts. and "validation".fc\_titl. (12)  
 16 from 13 keep 1-8 (8)  
 17 from 15 keep 10 (1)  
 18 "sleeman\$.fc\_auts. and "psychometric validation".fc\_titl. (1)  
 19 14 or 17 or 18 (3)  
 20 "27".fc\_vol. and "saleem\$.fc\_auts. and "symptom".fc\_titl. and "2013".fc\_pubyr. (1)  
 21 "richfield\$.fc\_auts. and "assessing".fc\_titl. and "2014".fc\_pubyr. (1)  
 22 "validation of a screening tool".fc\_titl. and "2015".fc\_pubyr. (2)  
 23 "zhong\$.fc\_auts. and "validity".fc\_titl. and "2013".fc\_pubyr. (3)  
 24 from 19 keep 1-3 (3)  
 25 from 23 keep 2 (1)  
 26 "hudson\$.fc\_auts. and "would people".fc\_titl. and "2006".fc\_pubyr. (1)  
 27 22 or 25 or 26 (4)  
 28 "P Parkinson".ti. (0)  
 29 Parkinson Disease/ (174890)  
 30 parkinson\*.tw,kw. (193455)  
 31 29 or 30 (226100)  
 32 Palliative Care/ (85241)  
 33 Terminal Care/ (39353)  
 34 Terminally Ill/ (8378)  
 35 Hospice Care/ (12070)  
 36 (palliat\* or terminal\* or endstage or hospice\* or (end adj2 life) or (care adj3 dying) or ((advanced or late or last or end or final) adj2 (stage\* or phase\*))).tw,kw. (1020620)

37 "advanced disease\*".tw,kw. (38048)  
38 ("end-stage disease\*" or "end stage disease\* or end-stage illness" or "end stage").tw,kw. (117247)  
39 (terminal\* adj6 care\*).tw,kw. (5858)  
40 (terminal\* adj6 (ill\* or disease)).tw,kw. (15910)  
41 terminal?stage\*.tw,kw. (50)  
42 (dying or (close adj6 death)).tw,kw. (50684)  
43 or/32-42 (1120147)  
44 31 and 43 (10242)  
45 10 or 27 (13)  
46 "vb refs".ti. (0)  
47 "zorgbehoeften meetopties".ti. (0)  
48 Needs Assessment/ (26274)  
49 "Health Services Needs and Demand"/ (143523)  
50 Outcome Assessment, Health Care/ (530518)  
51 (outcome adj3 assessment).tw,kw. (13632)  
52 exp patient outcome assessment/ (707401)  
53 (need? adj3 assess\*).tw,kw. (40360)  
54 exp disease progression/ (157484)  
55 (disease adj3 progre\*).tw,kw. (299253)  
56 "Severity of Illness Index"/ (20482)  
57 (severity adj3 (disease or illness)).tw,kw. (140272)  
58 HRQoL.ti,kw. (2579)  
59 or/48-58 (1457497)  
60 ((Palliative adj2 outcome adj2 score?) or (IPOS adj2 neuro\*) or (Edmonton adj2 Symptom adj2 Assessment adj2 Scale\*)  
or ESAS or PACA or (needs adj2 assessment adj2 tool?)).tw,kw. (7947)  
61 Mass Screening/ (59571)  
62 screening.tw,kw. (861766)  
63 60 or 61 or 62 (889590)  
64 44 and 63 (238)  
65 (screening adj2 (tool or instrum\* or scal\* or assess\* or interv\*)).tw,kw. (66653)  
66 60 or 61 or 65 (130328)  
67 31 and 66 (1013)  
68 "validity".kw. (13290)  
69 "Clinical indicators".kw. (137)  
70 (patient adj3 screening).tw,kw. (6787)  
71 (palliative adj4 scor\*).tw,kw. (660)  
72 (symptom\* adj4 assess\*).tw,kw. (64720)  
73 60 or 61 or 65 or 68 or 69 or 70 or 71 or 72 (211048)  
74 31 and 59 and 73 (525)  
75 (dutch or english).la. (33157375)  
76 comparative study/ (955182)  
77 "richfield\$.fc\_auts. and "palliative".fc\_titl. (8)  
78 from 77 keep 3 (1)  
79 10 or 16 or 19 or 27 (24)  
80 Parkinson disease/ (174890)  
81 parkinso\*n.ti,kw. (19790)  
82 80 or 81 (180024)  
83 exp palliative therapy/ (128014)  
84 43 or 83 (1134060)  
85 59 and 82 and 84 (1364)  
86 symptom assessment/ (10697)  
87 edmonton symptom assessment system/ or neurologic disease assessment/ (6660)  
88 73 or 86 or 87 (223304)  
89 82 and 84 and 88 (127)  
90 75 and 89 (121)  
91 "Palliative care Outcome scale"/ (36)  
92 \*\*unmet medical need"/ (300)  
93 88 or 91 or 92 (223623)  
94 75 and 82 and 84 and 93 (125)  
95 "filter observationele studies emb sign".ti. (0)  
96 Clinical study/ (158420)  
97 Case control study/ (189216)  
98 family study/ (25449)  
99 Longitudinal study/ (174026)  
100 Retrospective study/ (1262193)  
101 Prospective study/ (773547)

102 Randomized controlled trials/ (228983)  
103 101 not 102 (764507)  
104 Cohort analysis/ (855713)  
105 (Cohort adj (study or studies)).tw,kw. (397772)  
106 (Case control adj (study or studies)).tw,kw. (155181)  
107 (follow up adj (study or studies)).tw,kw. (69569)  
108 (observational adj (study or studies)).tw,kw. (219297)  
109 (epidemiologic\$ adj (study or studies)).tw,kw. (116337)  
110 (cross sectional adj (study or studies)).tw,kw. (292572)  
111 96 or 97 or 98 or 99 or 100 or 103 or 104 or 105 or 106 or 107 or 108 or 109 or 110 (3451978)  
112 "rct filter embase".ti. (0)  
113 randomization/ (94004)  
114 exp randomized controlled trial/ (715341)  
115 exp controlled clinical trial/ (905229)  
116 Major Clinical Study/ (4500974)  
117 random\$.tw,kw. (1807769)  
118 double blind procedure/ (196068)  
119 or/113-118 (6049259)  
120 "emb SR filter".ti. (0)  
121 meta analysis/ (248947)  
122 "systematic review"/ (350388)  
123 (meta-analy\$ or metaanaly\$).tw,kw. (308089)  
124 (systematic\$ adj4 (review\$ or overview\$)).tw,kw. (331186)  
125 (quantitativ\$ adj5 (review? or overview?)).tw,kw. (6789)  
126 (methodologic adj5 (overview? or review?)).tw,kw. (415)  
127 (review\$ adj3 (database? or medline or embase or cinahl)).tw,kw. (35326)  
128 (pooled adj3 analy\$).tw,kw. (38862)  
129 (extensive adj3 review\$ adj3 literature).tw,kw. (4434)  
130 (meta or synthesis or (literature adj8 database?) or extraction).tw,kw. (1663210)  
131 review.pt. (2918277)  
132 130 and 131 (206789)  
133 or/121-129,132 (734819)  
134 94 and 133 (8)  
135 "conference abstract"/ (1561502)  
136 134 not 135 (5)  
137 (94 and 119) not 133 (54)  
138 (94 and 111) not (133 or 119) (8)  
139 66 and 82 and 84 (37)  
140 exp symptomatology/ (1094672)  
141 from 134 keep 1-6 (6)  
142 from 137 keep 1-51 (51)  
143 from 138 keep 1-7 (7)  
144 from 139 keep 1-37 (37)  
145 75 and 82 and 84 and (93 or 140) (664)  
146 75 and 82 and 84 and (93 or 140) and 133 (37)  
147 (75 and 82 and 84 and (93 or 140) and 119) not 133 (180)  
148 147 and 76 (9)  
149 "sensitivity and specificity"/ (435047)  
150 from 146 keep 1-33 (33)  
151 receiver operating characteristic/ (170908)  
152 diagnostic accuracy/ or exp general pathological parameters/ (664852)  
153 exp diagnostic error/ (114067)  
154 149 or 151 or 152 or 153 (1143468)  
155 147 and 154 (16)  
156 satisfaction/ or patient satisfaction/ (224422)  
157 154 or 156 (1364450)  
158 147 and 157 (18)  
159 (94 and 111) not (158 or 146) (32)  
160 exp qualitative research/ (101806)  
161 from 158 keep 1-16 (16)  
162 from 159 keep 1-29 (29)  
163 major clinical study/ (4500974)  
164 94 and 160 (4)  
165 145 and 160 (5)  
166 (145 and 119) not 146 (180)  
167 166 and 163 (159)



- 168 166 and 163 and 75 (159)  
 169 (145 and 111) not (168 or 133) (50)  
 170 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 (1099560)  
 171 31 and 170 (9805)  
 172 exp Parkinson disease/dm, dt, rt, rh, su, th [Disease Management, Drug Therapy, Radiotherapy, Rehabilitation, Surgery, Therapy] (43299)  
**173 (dt or rt or rh or su or th).fs. (6942033)= behandel opties**  
 174 81 and 173 (6680)  
 175 172 or 174 (45325)  
 176 170 and 175 (1691)  
 177 133 and 176 (69)  
**178 33 or 34 or 39 or 40 or 41 or 42 (98534)= terminale fase**  
 179 177 and 178 (5)  
**180 31 and 111 and 178 (76)=P + observat + terminale fase**  
**181 31 and 178 (749)= P + terminale fase**  
 182 181 not 111 (673)  
**183 173 and 182 (140)= P + terminale fase + behandelopties + alle overiges studietypen**

### Overzicht van geëxcludeerde studies

Reference	Reason for exclusion
Hindmarsh J, Hindmarsh S, Lee M. Idiopathic Parkinson's Disease at the End of Life: A Retrospective Evaluation of Symptom Prevalence, Pharmacological Symptom Management and Transdermal Rotigotine Dosing. Clin Drug Investig. 2021 Aug;41(8):675-683. doi: 10.1007/s40261-021-01054-1. Epub 2021 Jul 2. PMID: 34213758.	Wrong outcomes
Calne SM, Kumar A. Nursing care of patients with late-stage Parkinson's disease. J Neurosci Nurs. 2003 Oct;35(5):242-51. doi: 10.1097/01376517-200310000-00002. PMID: 14593935.	Narrative review, does not include references on terminal phase
Chen JJ, Trombetta DP, Fernandez HH. Palliative Management of Parkinson Disease: Focus on Nonmotor, Distressing Symptoms. Journal of Pharmacy Practice. 2008;21(4):262-272. doi:10.1177/0897190008318370	Narrative review, does not include references on terminal phase
Gonsalkorale M. Palliative care in Parkinson's disease. CME Journal Geriatric Medicine 2005;7(0):22-28.	Full text unavailable
Gonzalez F. Diphenhydramine may be useful as a palliative treatment for patients dying with Parkinson's disease and tremors: a case report and discussion. Am J Hosp Palliat Care. 2009 Dec-2010 Jan;26(6):474-5. doi: 10.1177/1049909109338937. Epub 2009 Aug 21. PMID: 19700649.	Wrong study type
Richfield EW, Jones EJ, Alty JE. Palliative care for Parkinson's disease: a summary of the evidence and future directions. Palliat Med. 2013 Oct;27(9):805-10. doi: 10.1177/0269216313495287. Epub 2013 Jul 9. PMID: 23838377.	Does not look at interventions