Bijlage Evidence tabellen

Onderzoeksvraag 1b:

Wat is de diagnostische accuratesse dan wel wat zijn de klinimetrische eigenschappen van screeningsinstrumenten om pijn vast te stellen bij mensen met dementie in de palliatieve fase?

Patients	Patiënten met dementie in de palliatieve fase
Intervention	Instrumenten om pijn in de palliatieve fase vast te stellen
Control	Geen instrument of een ander instrument
Outcomes	Diagnostische accuratesse (sensitiviteit, specificiteit, AUC), klinimetrische eigenschappen

Evidence tables

Author, publication year: Buzgova, 2016						
Study characteristics	**Patient characteristics**	**Intervention (I)**	**Comparison / control (C)**	**Follow-up**	**Outcome measures and effect size**	**Comments**
Type of study: cross-sectional study Setting: hospital Country: Czech republic Source of funding: Czech ministry of health	Inclusion criteria: - Hospitalized for severe illness - End-stage non-cancer conditions or cancer and discontinued curative therapy - Degree of severe cognitive impairment: Mini-Mental State Examination (MMSE) score 10 - Generally unfavorable health status with disability and high nursing dependency - Age > 60 years. Exclusion criteria: None N total at baseline: 306	1. Cognitively Impaired Life Quality (CILQ) scale 2. Quality of Life in Late-Stage Dementia (QUALID) scale	N.A.	Five days	*QUALID:* Floor effect: 0.0% Ceiling effect: 0.0% Internal consistency (Cronbach's alfa): 0.812 (0.762-0.898) Test-retest reliability (ICC): 0.847 (0.795-0.896) Inter-rater reliability (Cohen's kappa): 0.760 (0.701-0.789) Spearman correlation – SM-EOLD: r=-0.424 (p<0.01) *CILQ:* Floor effect: 0.0% Ceiling effect: 0.0% Internal consistency (Cronbach's alfa): 0.703 (0.699-0.743) Test-retest reliability (ICC): 0.925 (0.896-0.946) Inter-rater reliability (Cohen's kappa): 0.801 (0.764-0.853) Spearman correlation – SM-EOLD: r=0.313 (p<0.01)	

	Important baseline characteristics: Gender: 56% female Mean age: 76.1 years (SD 10.3) Diagnosis: 39% cancer 51% dementia-type neurological disease 37% aging-associated multimorbidity and frailty 6% heart failure					

Onderzoeksvraag 2:

Wat zijn de (on)gunstige effecten van niet-medicamenteuze en medicamenteuze interventies in de palliatieve fase voor patiënten met dementie en gedragsproblemen/ stemmingsstoornissen of pijn of tonusstoornissen of problemen hebben met vocht, voeding en kunstmatige toediening?

Patients	Patiënten met dementie in de palliatieve fase en/of *gedragsproblemen/ stemmingsstoornissen of pijn of tonusstoornissen of problemen hebben met vocht, voeding en kunstmatige toediening*
Intervention	Medicamenteuze en niet-medicamenteuze behandelopties
Control	Een andere interventie of placebo
Outcomes	Kwaliteit van leven, kwaliteit van sterven, gedrag/ stemming, bijwerkingen, patiënttevredenheid bij naasten, mortaliteit, bijwerkingen/ negatieve effecten

Evidence tables

Author, publication year: Davies, 2021							
Included studies in the review	**Study characteristics**	**Patient characteristics**	**Intervention (I)**	**Comparison / control (C)**	**Follow-up**	**Outcome measures and effect size**	**Comments**
A. Alvarez-Fernandez, 2005 B. Arinzon, 2008 C. Bentur, 2015 D. Chou, 2020 E. Cintra, 2014 F. Hwang, 2014 G. Meier, 2001	Type of study: Systematic review Search date: 14 April 2021	N total at baseline: A. 67 B. 167 C. 117 D. 169 E. 67 F. 6261 G. 99	A. Permanent NGT feeding B. Enteral feeding via NGT or PEG C. Tube feeding D. NG tube feeding E. Alternative feeding as NGT or not specified F. PEG tube	A. Non-permanent NGT feeding B. Oral nutritional support C. No tube feeding D. Advanced hand feeding E. Oral route F. No enteral tube feeding G. No new PEG tube insertion	Length of follow-up: A. 24 months B. Not reported C. Not reported D. Not reported E. 180 days F. 6 months G. Not reported	PEG vs. no tube: *Survival time* No difference *Mortality* One study reported higher mortality in PEG group (70% vs.	

H. Mitchell, 1997 I. Murphy, 2003 J. Takayama, 2017 K. Takenoshita, 2017 L. Teno, 2012a M. Teno, 2012b N. Ticinesi, 2016	<u>Number of included studies:</u> N= 14 <u>Country</u> A. Spain B. Israel C. Israel D. Taiwan E. Brazil F. USA G. USA H. USA I. USA J. Japan K. Japan L. USA M. USA N. Italy <u>Source of funding:</u> Marie Curie, Alzheimer's Society, NIHR <u>Inclusion criteria</u>: - RCTs or CCT - Adults with a diagnosis of primary degenerative dementia of any cause, with severe cognitive and functional impairment and poor nutritional intake - Study evaluates the effectiveness and complications of enteral tube feeding via a nasogastric or gastrostomy tube, or via	H. 1386 I. 41 J. 185 (129 dementia) K. 58 L. 36,492 M. 4421 N. 184 <u>Disease staging:</u> A. DSM-IV diagnosis of dementia and staged as FAST 7A or greater B. Advanced vascular and degenerative type of dementia C. Advanced dementia, stage 6 or above on GDS D. Advanced dementia staged as FAST 7A or greater E. Possible or probable Alzheimer's dementia staged 7A to 7F on FAST F. Advanced dementia G. Advanced dementia, staged FAST 6D or greater H. Advanced dementia with CPS score progressed to 6 I. Advanced dementia with life expectancy of at least 30 days J. Dementia and short life expectancy K. Advanced dementia staged	G. PEG tube H. Feeding tube I. PEG tube J. NG or PEG tube K. NG or PEG tube L. PEG tube M. PEG tube N. PEG tube	H. No feeding tube I. No feeding tube J. PVN with oral intake K. PVN with oral intake L. No feeding tube M. No feeding tube N. Oral nutrition	H. Not reported I. Not reported J. Not reported K. Not reported L. 4 months M. 6 months N. 18 months	40%), other study reported no difference (52% vs 50%) *Pressure ulcers* PEG was associated with increase in risk (OR 2.27, 95%CI 1.95-2.65) <u>Nasogastric tubes vs. no tube:</u> *Mortality* One study reported increased risk in tube group (RR 3.53, 95%CI 1.5-8.3), other study reported no difference (OR 2.38, 95%CI 0.58-9.70) *Improvement of nutritional parameters* One study showed a reduction in albumin levels in the tube group (3.29 g/dL vs. 3.66 g/dL) <u>Any tube vs. no tube:</u> *Survival time* Three studies observed longer survival times in tube groups, one study found no difference *Mortality* One study reported no difference (42% vs. 27%), another study found increased mortality in tube group (RR 2.33, 95%CI 1.16-4.67) *Pressure ulcers*	

	jejunal post-pyloric feeding, in comparison with (enhanced) standard care <u>Exclusion criteria</u>: n.a.	6e or above on FAST L. Advanced dementia staged 6 or over on CPS M. Advanced cognitive impairment staged 6 or over on CPS N. Dementia staged FAST of 5 or over and CDR of 1 or over				Two studies found increased risk in tube group (2.74 vs. 1.31, and 26% vs. 12%), one study found no difference (34% vs. 38%) *Pain and comfort* No difference *Improvement of nutritional parameters* One study reported improvement in blood count, renal function tests and electrolytes, hydration status, serum osmolarity and serum proteins	