

Bijlage 6. Evidence tabellen en Risk of bias beoordelingen

6.1.1: Wat zijn de (on)gunstige effecten van advance care planning bij patiënten met de ziekte van Parkinson?

Geen literatuur geïncludeerd.

6.1.2: Wat zijn de waarden en voorkeuren van patiënten, naasten en zorgverleners ten aanzien van ACP?

Author, Year	Aim/Objective	Population or condition	Number of databases searched (search date)	Number of studies included	Designs of studies	Countries of studies	Risk of bias
Nimmons, 2020	To explore the experiences of ACP for people with Parkinson disease or atypical parkinsonian disorders, their family carers and healthcare professionals.	Parkinson disease or atypical parkinsonian disorders (progressive supranuclear palsy, multiple system atrophy and corticobasal degeneration)	5 (April 2019)	27	15 qualitative, 12 quantitative	USA (10), UK (7), Ireland (2), Canada (3), the Netherlands (2), Australia (1), Italy (1), Singapore (1)	Critical Appraisal Skills Programme Low – medium risk

Nimmons, 2020	<p>Findings were grouped into five themes:</p> <ul style="list-style-type: none"> • What is involved in ACP discussions? Advance care planning discussions included a range of topics, but coverage was inconsistent and there was a lack of standardization on what should be included. Advance care planning resulted in greater patient choice in determining end-of-life preferences, yet these decisions were not always adhered to or shared with physicians. • When and how are ACP discussion initiated? People with parkinsonian disorders often felt it was left to them to initiate ACP but would prefer the HCP to initiate the discussion. There was variability in views when the ACP should be initiated as it depends on several patient and disease-related factors, patient readiness, as well as HCP willingness to discuss the topic. This often resulted in discussions first taking place in response to a crisis, e.g. hospital admission. Whilst the majority of patients do not want to have discussions at the time of diagnosis, a proportion of patients would like to have discussions early. Advance care planning should be team-based and person-centered with family input. • Barriers to ACP discussions in patients and carers included lack of knowledge about progression of parkinsonian disorders and about palliative care. Barriers to ACP discussions in HCPs included deficit in skills, knowledge, lack of resources and time to undertake ACP discussions. Features of advanced disease can limit the ability to have ACP discussions. • Role of the professional: Multidisciplinary team access to and collaboration with palliative care services were facilitators to delivering effective ACP, leading to clear plans and appropriate access to specialist palliative care services. Both general and specialist palliative care approaches should be available, depending on need at the time. • Role of family carers: Carers were a key facilitator to ACP but could also be a barrier if emotionally burdened.
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Nimmons, 2020	
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Item	Yes, partial yes or no	Explanation
1. Did the research questions and inclusion criteria for the review include the components of PICO?	Yes	
2. Did the report of the review contain an explicit statement that the review methods were established prior to the conduct of the review and did the report justify any significant deviations from the protocol?	Yes	
3. Did the review authors explain their selection of the study designs for inclusion in the review?	Yes	
4. Did the review authors use a comprehensive literature search strategy?	Yes	
5. Did the review authors perform study selection in duplicate?	Yes	
6. Did the review authors perform data extraction in duplicate?	Yes	
7. Did the review authors provide a list of excluded studies and justify the exclusions?	No	
8. Did the review authors describe the included studies in adequate detail?	Yes	
9. Did the review authors use a satisfactory technique for assessing the risk of bias (RoB) in individual studies that were included in the review?	Yes	

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

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

Ibrahim, 2021						
Study characteristics	Patient characteristics	Intervention (I)	Comparison / control (C)	Follow-up	Outcome measures and effect size	Comments
Type of study: Retrospective cohort Setting: Inpatient hospital Country: UK	<u>Inclusion criteria:</u> - Formal diagnosis of PD - Were prescribed Rotigotine during their admission <u>Exclusion criteria:</u>	Rotigotine correct dose according to the OPTIMAL drug conversion calculator.	Rotigotine dose too low or too high.	<u>Length of follow-up:</u> Not reported <u>Loss-to-follow-up:</u> Not reported. <u>Incomplete outcome data:</u> Not reported.	<u>Delirium:</u> - Recommended dose: 4/25 - High dose: 12/31 - Low dose: 4/28	No testing was done.

<p>Source of funding: None</p>	<p>- Patients taking Rotigotine prior to admission - Patients admitted electively under the neurology service</p> <p><u>N total at baseline:</u> Group 1: 25 Group 2: 31 Group 3: 28</p> <p><u>Important prognostic factors:</u> Baseline characteristics are not reported by group</p>					
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