Verantwoording
Module: Gespreksvoering rondom proactieve zorgplanning

Inhoudsopgave

Een methodebeschrijving van dit literatuuronderzoek is te vinden in bijlage 'Methodebeschrijving literatuuronderzoek – Proactieve zorgplanning'.

Hoe kan gecommuniceerd worden met mensen met cognitieve, communicatieve en/of verstandelijke beperkingen over proactieve zorgplanning?

Resultaten

Onderstaand is een beschrijving gegeven van de geïncludeerde studies die betrekking hebben op de vraag: ‘Hoe kan gecommuniceerd worden met mensen met cognitieve, communicatieve en/of verstandelijke beperkingen over proactieve zorgplanning?’.

Beschrijving van de studies

De zoekactie identificeerde 3 systematische literatuurreviews die van toepassing zijn op de onderzoeksvraag. Naar aanleiding van de tweede zoekactie naar individuele studies over proactieve zorgplanning bij mensen met een verstandelijke beperking werden 2 kwalitatieve studies geïncludeerd. De werkgroep heeft in aanvulling op bovenstaande zoekacties een artikel aangedragen met een secundaire analyse van drie Nederlandse kwalitatieve studies over de ervaringen met proactieve zorgplanning bij dementie. Een volledig overzicht van de karakteristieken van de geïncludeerde studies is gegeven in bijlage 1.

Sue et al., 2019 includeerden 34 studies in hun systematische review om inzicht te krijgen in de ervaringen van patiënten, familieleden en zorgverleners met het verlenen van palliatieve zorg aan mensen met een verstandelijke beperking.[Sue 2019] De details van de methodologie waren zeer beknopt beschreven. Om inzicht te krijgen in het gebruik en de effecten van proactieve zorgplanning in de palliatieve zorg voor mensen met een verstandelijke beperking voerden Voss et al., 2017 een systematische review uit.[Voss 2017] In totaal includeerden ze 7 kwantitatieve studies, 3 kwalitatieve studies en 4 mixed methods studies waarin de perspectieven over proactieve zorgplanning van mensen met een verstandelijke beperking, familieleden, zorgverleners en managers werden onderzocht. Visser et al., 2022 onderzochten communicatieproblemen met mensen met dementie en gesprekken over proactieve zorgplanning of toekomstige palliatieve zorg.[Visser 2022] Er werden 22 studies geïncludeerd in hun systematische review, waarin mensen met dementie, familieleden en/of zorgverleners werden onderzocht: 14 kwalitatieve studies, 3 kwantitatieve studies, 2 studies met mixed methods en 2 Delphi studies. In de drie systematische reviews werd proactieve zorgplanning niet vergeleken met een controlegroep.

McKenzie et al., 2017 namen in Nieuw-Zeeland op baseline en na een follow-up van 4-6 maanden interviews af bij 4 volwassen mensen met een verstandelijke beperking en een levensbeperkende aandoening, bij 4 familieleden en bij 15 leden van het ondersteuningsteam.[McKenzie 2017] Aanvullend werd er een documentonderzoek gedaan. De onderzoekers rapporteerden de ervaringen en bevorderende en belemmerende factoren van proactieve zorgplanning vanuit het perspectief van mensen met een verstandelijke beperking.

Om inzicht te krijgen in de ervaringen met en meningen over proactieve zorgplanning namen Voss et al., 2020 in Nederland interviews af met 5 volwassen mensen met een verstandelijke beperking, met 7 familieleden en met 8 zorgverleners.[Voss 2020] In beide kwalitatieve studies werd geen controlegroep onderzocht.

Lemos Dekker et al., 2022 voerden een secundaire analyse uit op basis van de data van drie kwalitatieve studies uitgevoerd in Nederland. [Lemos Dekker 2022] In de eerste studie werden 18 thuiswonende mensen met dementie onderzocht, in de tweede studie 32 familieleden en in de derde studie mensen met dementie, familieleden en zorgverleners (aantal niet gespecificeerd). De ervaringen met proactieve zorgplanning bij dementie waren in deze drie studies verzameld met behulp van interviews en etnografisch veldonderzoek.

Risk of bias

De volledige beoordeling is beschikbaar in bijlage 2. Hieronder wordt een korte samenvatting van de kwaliteitsbeoordeling per studie gegeven.

De geïncludeerde systematische reviews en kwalitatieve studies zijn onderzocht op het risico op bias. De systematische reviews zijn beoordeeld met de AMSTAR-2 checklist (*Assessing the Methodological Quality of Systematic Reviews*, Canada) om aan te tonen of de methodologische kwaliteit van de reviews hoog, matig, laag of zeer laag is.[Shea 2017] De kwalitatieve studies zijn beoordeeld met behulp van de NICE checklist voor kwalitatieve studies (*National Institute for Health and Care Excellence*, Verenigd Koninkrijk).[NICE] Een eindscore van '++', '+' of '-' geeft aan hoe goed de studie is uitgevoerd. De resultaten van de bias beoordelingen worden kort gerapporteerd in deze paragraaf, in bijlage X zijn per studie de details van het risico op bias gepresenteerd.

De methodologische kwaliteit van de drie geïncludeerde systematische reviews voor uitgangsvraag 4 was zeer laag op basis van de AMSTAR-2 checklist. De review van Sue et al., 2019 had meerdere methodologische beperkingen.[Sue 2019] De meta-analyse vragen waren niet van toepassing, de overige methodologische vragen werden vrijwel allemaal met 'nee' beantwoord. Ook de systematische reviews van Voss et al., 2017 [Voss 2017] en Visser et al., 2022 [Visser 2022] hadden meerdere methodologische beperkingen. De meta-analyse vragen waren niet van toepassing en een groot deel van de overige vragen werden met 'nee' of 'gedeeltelijk ja' beantwoord.

De kwalitatieve studies van McKenzie et al., 2017 en Voss et al., 2020 scoorden '++' met behulp van de NICE checklist. Een score van '++' houdt in dat er is voldaan aan alle of de meeste checklistcriteria, waar niet is voldaan aan de criteria, is het zeer onwaarschijnlijk dat de conclusies zullen veranderen.[NICE] De studie van McKenzie et al., 2017 scoorde goed op de onderdelen theoretische aanpak, studie design, data verzameling, analyse en ethiek.[McKenzie 2017] Voor het onderdeel betrouwbaarheid was de rol van de onderzoeker niet beschreven en

de context was niet geheel duidelijk. De kwalitatieve studie van Voss et al., 2020 scoorde goed op alle onderdelen van de checklist.[Voss 2020] De studie van Lemos Dekker et al., 2022 scoorde '+' met de NICE checklist. Over het algemeen was deze studie van goede kwaliteit, echter was voor het onderdeel betrouwbaarheid de rol van de onderzoeker niet beschreven en was de context onduidelijk. Door de onduidelijke context is het niet duidelijk of de geanalyseerde data voldoende gedetailleerd ('rich') is.[Lemos Dekker 2022]
De resultaten van de geïncludeerde systematische reviews en kwalitatieve studies voor deze uitgangsvraag waren narratief beschreven, zonder (kwantitatieve) onderbouwing met onderzoeksresultaten.

Beschrijving van de resultaten
Uit de geïncludeerde studies blijkt dat mensen met een verstandelijke beperking of dementie geïnformeerd willen worden over hun gezondheid en betrokken worden bij het proces van proactieve zorgplanning.[Visser 2022; Voss 2017; Sue 2019; McKenzie 2017; Voss 2020] Zo is er geen bewijs gevonden dat mensen met een verstandelijke beperking minder behoefte hebben aan informatie over ziekte, het sterfproces of de dood; wel blijkt dat zij minder geneigd zijn om een gesprek te initiëren of om vragen te stellen.[Sue 2019] Tegelijkertijd zijn zorgverleners vanwege uitdagingen met de communicatie minder snel geneigd om het gesprek te initiëren bij zowel mensen met een verstandelijke beperking of dementie.[Sue 2019; Visser 2022; Voss 2020] Daarnaast kunnen deze mensen moeite hebben met het begrijpen van moeilijke of abstracte concepten zoals de dood en palliatieve zorg, het uiten van gevoelens en praten over ziekte met anderen en vinden ze het lastig om anders te worden behandeld vanwege hun beperking.[Visser 2022; Sue 2019; McKenzie, 2017; Voss 2020]

In de geïncludeerde studies werden voor mensen met een verstandelijke beperking of dementie diverse suggesties gerapporteerd over hoe er gecommuniceerd kan worden met mensen met een cognitieve, communicatieve en/of verstandelijke beperking. Er was veel overlap tussen de resultaten. Onderstaand worden de belangrijkste bevindingen uit de geïncludeerde systematische reviews en kwalitatieve studies samengevat.

Persoonsgerichte aanpak
Het is van belang om te benadrukken dat proactieve zorgplanning een proces van maatwerk is, waarbij de mens centraal staat. Elk individu is anders en mensen met een verstandelijke beperking hebben een verschillende mate en complexiteit van de beperking, kwetsbaarheid en zorgbehoeften waarmee rekening moet worden gehouden. Er is niet één juiste manier om proactieve zorg te bieden; het dient een flexibel proces te zijn.[Voss 2017; Voss 2020] Het grootste deel van wat als belangrijk wordt ervaren door mensen met een verstandelijke beperking bij het proces van proactieve zorgplanning, kan eenvoudig opgepakt worden door de zorgverlener die hun proactieve planningsproces faciliteert.[McKenzie 2017] De aanpak van proactieve zorgplanning bij mensen met een verstandelijke beperking kwam overeen met wat de

zorgverleners normaal gesproken zouden doen bij het faciliteren van een algemeen persoonsgericht planningsproces.[McKenzie 2017] Verder zijn de aanvullende zorgbehoeften rond het levenseinde van mensen met een verstandelijke beperking in veel opzichten niet anders dan voor de algemene bevolking. Bij gebrek aan specifieke evidence-based begeleiding voor mensen met een verstandelijke beperking, bleek dat in het kwalitatieve onderzoek van McKenzie et al., 2017 de ondersteuningsteams met goede resultaten de richtlijnen voor de algemene bevolking hadden gevolgd en aangepast naar de populatie van mensen met een verstandelijke beperking.[McKenzie 2017]

Voor mensen met cognitieve achteruitgang, zoals dementie, is maatwerk voor proactieve zorgplanning ook sterk van belang. Eerder vastgestelde wensen rondom proactieve zorgplanning worden gemaakt zonder inzicht te hebben onder welke omstandigheden deze in de toekomst zouden kunnen plaatsvinden en daarom zouden die huidige wensen mogelijk niet passen bij de behoeften van mensen met dementie wanneer de feitelijke situatie zich voordoet.[Lemos Dekker 2022] Dit leidt tot een lastige paradox bij dementie. Aan de ene kant kan het vroegtijdig bespreken van proactieve zorgplanning een geruststelling zijn en iemand met dementie in staat stellen om de eigen wensen aan te geven en controle te houden over dit proces. Aan de andere kant kan het tijdig vastleggen van deze wensen juist het gevoel geven van een gebrek aan controle, omdat proactieve zorgplanning kan resulteren in gevoelens van angst om niet van deze plannen af te kunnen wijken als hun wensen veranderen in de toekomst.[Lemos Dekker 2022] Mensen met dementie dragen de verantwoordelijkheid om de juiste beslissing te nemen vaak over aan vertegenwoordigers of zorgverleners. Redenen hiervoor zijn bijvoorbeeld verschillende interpretaties en miscommunicatie rondom algemene wilsverklaringen, een gebrek aan kennis waardoor mensen met dementie zich niet zelfverzekerd genoeg voelen om zelf een keuze te maken, of ze gaan er vanuit dat een zorgverlener beter kan beoordelen wat de beste beslissing is. Dit legt de verantwoordelijkheid voor het maken van de juiste keuze conform de wensen van de persoon met dementie bij een ander.[Lemos Dekker 2022]

Interprofessionele samenwerking

In de literatuur over proactieve zorgplanning bij mensen met een verstandelijke beperking werd het belang van interprofessionele samenwerking beschreven. Om een goede invulling te geven aan het proces van proactieve zorgplanning is interprofessionele samenwerking onmisbaar, waarbij de betrokkenen worden geïnformeerd en beslissingen samen worden genomen.[McKenzie 2017; Voss 2020] Hierbij vervullen zorgverleners de rol om gesprekken over proactieve zorgplanning te initiëren, op een duidelijke wijze te informeren, de zorg te coördineren en een harmonieuze samenwerking tussen de betrokkenen te stimuleren. De rol van familie is gericht op het signaleren en interpreteren van het gedrag van hun naaste, het vertegenwoordigen van de mens met een verstandelijke beperking en een bijdrage te leveren aan de gesprekken over proactieve zorgplanning.[Voss 2020]

Betrekken van mensen met cognitieve, communicatieve en/of verstandelijke beperking

Het is van belang om inzicht te krijgen hoe mensen met een verstandelijke beperking of dementie aankijken tegen proactieve zorgplanning, moeite te doen om hen te betrekken bij gesprekken over proactieve zorgplanning en hen de mogelijkheid te bieden om eigen beslissingen te nemen.[Visser 2022; Voss 2017; Sue 2019; Lemos Dekker 2022; McKenzie 2017; Voss 2020]
Mensen met een verstandelijke beperking gaven aan dat ze het belangrijk vonden om hun eigen keuzes te kunnen maken.[McKenzie 2017] Op basis van hun eigen ervaringen en wensen kunnen mensen met een verstandelijke beperking zelf hun wensen aangeven, vaak ondersteund door een naaste.[Voss 2020] Wanneer er tijdens gesprekken te veel nadruk wordt gelegd op de cognitieve beperkingen kan dit negatieve gevolgen hebben, bijvoorbeeld door een beperking van mogelijke zorgopties. Zorgverleners moeten voorkomen dat zij taalgebruik hanteren die de waarde van het leven van een mens met een verstandelijke beperking lijkt te onderschatten, bijvoorbeeld door termen als ‘zinloos’ te gebruiken.[Sue 2019]
In de geincludeerde systematische review en kwalitatieve studies over proactieve zorgplanning bij dementie werden geen aandachtspunten beschreven voor het betrekken van mensen met dementie.

Ondersteunen van emotioneel welzijn
In het kwalitatieve onderzoek over mensen met een verstandelijke beperking werd benadrukt dat er bij proactieve zorgplanning moet worden uit gegaan van een menselijke aanpak in plaats van een meer technische of procedurele aanpak, waarbij rekening wordt gehouden met de impact die proactieve zorgplanning kan hebben.[Voss 2020] Door gesprekken over proactieve zorgplanning ervaarden mensen met een verstandelijke beperking verschillende perioden van verdriet, overstuur zijn en sterke emoties.[McKenzie 2017] Het is daarom van belang om naast de reguliere gesprekken over proactieve zorgplanning follow-up afspraken te plannen om de emotionele behoeften van mensen met een verstandelijke beperking te ondersteunen en zorgen weg te nemen.[McKenzie 2017; Voss 2020] Het verstrijken van de tijd bleek mensen met een verstandelijke beperking te helpen om de gesprekken te laten bezinken en bezinning te vinden over hun beslissingen.[McKenzie 2017]

Empathische, open en eerlijke houding van zorgverleners
Een empathische, open en eerlijke houding van zorgverleners en aandachtig luisteren kan een positieve bijdrage leveren aan het voeren van gesprekken over proactieve zorgplanning met mensen met een verstandelijke beperking of dementie.[Visser 2022; McKenzie 2017; Voss 2020] De verschillende aandachtspunten die in de geïncludeerde studies werden beschreven zijn voor beide populaties van belang en hangen met elkaar samen. Bij mensen met een verstandelijke beperking namen de gesprekken over proactieve zorgplanning angst weg, droeg het bij om veranderingen in hun gezondheid te bevatten en de juiste beslissingen te nemen.[McKenzie 2017] Het bleek makkelijker om open en eerlijk te praten over onderwerpen waar zorgverleners eerdere ervaring in of kennis over hadden. Training in communicatievaardigheden kan hierbij helpen.[Visser 2022; McKenzie 2017] Het is belangrijk

dat de zorgverlener de eigen voorkeuren opzij zet, inzicht krijgt in de normen en waarden zijn van de cliënt en de zorg vervolgens aanpastaan deze doelen en behoeften.[Voss 2020] Een goede cliënt-zorgverlener relatie met een vertrouwde zorgverlener kan een positief effect hebben op het verloop van een gesprek over proactieve zorgplanning, maar een vertrouwde zorgverlener is niet zo belangrijk voor succesvolle communicatie als goed opgeleide en empathische gesprekspartners.[Visser 2022]

Normaliseer conversaties over proactieve zorgplanning
Voor zowel mensen met een verstandelijke beperking als mensen met dementie werd aanbevolen om het praten over proactieve zorgplanning te normaliseren en het onderwerp van niet-acute zorg en sterven niet te vermijden.[Visser 2022; McKenzie 2017] Proactieve zorgplanning dient op een voorzichtige manier geïntroduceerd te worden, bijvoorbeeld door deze gesprekken in een informele omgeving te initiëren, zodat patiënten zich op hun gemak voelen en op een zinvolle manier kunnen deelnemen.[Visser 2022; McKenzie 2017] Daarbij is het van belang dat zorgverleners zich comfortabel voelen bij het praten over sterven en de dood; dit kan worden ondersteund door eerdere ervaring of trainingen.[McKenzie 2017] Voor mensen met een verstandelijke beperking of dementie is het verder belangrijk dat proactieve zorgplanning niet alleen gericht is op sterven, maar ook op het plannen van het leven en het heden.[Visser 2022; McKenzie 2017; Lemos Dekker 2022]

Eenvoudige taal
Om beslissingen te kunnen nemen is duidelijke en accurate informatie nodig, de vragen die gesteld worden tijdens gesprekken over proactieve zorgplanning dienen daarom aangepast te worden aan de ernst van de verstandelijke beperking of dementie en iemands persoonlijke behoeftes.[Visser 2022; Sue 2019; McKenzie, 2017; Voss 2020] De verschillende aandachtspunten die in de geïncludeerde studies werden beschreven zijn voor beide populaties van belang en hangen met elkaar samen. Wanneer het duidelijk gevraagd wordt, zullen de meeste mensen met een verstandelijke beperking eerlijk antwoorden wat er in hun omgaat.[Sue 2019] Net als bij de algemene bevolking zal een deel van de mensen met een verstandelijke beperking of dementie niet volledig op de hoogte willen zijn van zijn of haar medische situatie. De zorgverlener zal moeten uitzoeken wat een individu wil weten en of de informatie goed begrepen kan worden.[Sue 2019; Lemos Dekker 2022] Hierbij heeft eenvoudig taalgebruik de voorkeur waarbij één onderwerp tegelijk wordt geïntroduceerd met behulp van korte zinnen.[Sue 2019] Wees voorzichtig bij het geven van keuzes in een vraag, omdat sommige mensen met een verstandelijke beperking geen keuze maken maar alleen de laatst aangeboden optie herhalen. Het opnieuw stellen van de vraag in een andere bewoording, kan een bijdrage leveren om dit te verminderen.[Sue 2019]

Non-verbale communicatie

Tijdens gesprekken over proactieve zorgplanning is het belangrijk om niet alleen op de verbale communicatie te richten, maar ook te focussen op het non-verbale gedrag van mensen met een verstandelijke beperking of dementie.[Visser 2022; Voss 2017; Sue 2019; McKenzie 2017] Hierbij blijkt het niet gemakkelijk te zijn om de behoefte aan proactieve zorgplanning te detecteren; zorgverleners herkenden non-verbale signalen niet altijd of interpreteerden dit als symptomen van de verstandelijke beperking. Om te kunnen identificeren of mensen met een verstandelijke beperking palliatieve zorg nodig hebben, is het nodig om gebruik te maken van signalen uit verschillende informatiebronnen en interacties tussen de cliënt, zorgverleners en familie.[Voss 2017] Daarnaast kunnen non-verbale hulpmiddelen gebruikt worden als ondersteunende of alternatieve communicatiemethode. Hiermee kan informatie op een simpelere wijze gevisualiseerd worden of kunnen clienten afbeeldingen gebruiken om te helpen bij het uiten van hun gevoelens.[Sue 2019; McKenzie 2017]
In de geincludeerde systematische review en kwalitatieve studies over proactieve zorgplanning bij dementie werden geen aandachtspunten beschreven voor non-verbale communicatie met mensen met dementie.

Ondersteunende hulpmiddelen
Bij mensen met een verstandelijke beperking werd het belang aangegeven om zorgverleners die betrokken zijn bij proactieve zorgplanning ondersteunende hulpmiddelen te bieden.[McKenzie 2017; Sue 2019] Engelstalige voorbeelden die werden genoemd waren “Living well” van Helen Sanderson and Associates, 2010 [McKenzie 2017] en een template voor een “End-of-life book” voor mensen met een verstandelijke beperking van de National Health Service in het Verenigd Koninkrijk.[Sue 2019] Een voorbeeld van een non-verbaal communicatiehulpmiddel zijn de “Books Beyond Words series”, dit zijn 26 prentenboeken welke zijn ontworpen om volwassenen met een verstandelijke beperking te helpen met het begrijpen van en praten over moeilijke onderwerpen zoals over kanker en de dood.[Sue 2019]

Voor de communicatie over palliatieve zorg met mensen met cognitieve en/of communicatieve beperkingen stelden Sue et al., 2019 in hun systematische review het ARCH model voor.[Sue 2019] Dit model kan toegepast worden bij het voeren van een slechtnieuwsgesprek, waarbij het gaat om een voortdurend proces van informatieverschaffing in combinatie met de betrokkenheid van bekende verzorgers om geleidelijk begrip op te bouwen:

- ‘Ask’: Houd vragen eenvoudig. Zoek uit wat er al bekend is en wat de cliënt wil weten.
- ‘Repeat and clarify’: Wees voorbereid om informatie herhaaldelijk door te nemen, op verschillende manieren (met behulp van boeken, foto’s, enz.). Vereenvoudig indien nodig.
- ‘Check the level of understanding’: Ga na hoeveel de cliënt weet en wat het voor hem of haar betekent. Ga indien nodig een aantal stappen terug.
- ‘Help the person express feelings’: Moedig het uiten van gevoelens aan, luister goed en geef steun. Help gevoelens te beschrijven en onderzoek wat de cliënt denkt dat hij of zij vervolgens nodig heeft, toekomstige ondersteuningsopties en keuzes. Breng andere betrokkenen indien nodig op de hoogte.

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Voss H, Vogel A, Wagemans AMA, Francke AL, Metsemakers JFM, Courtens AM, et al. What is important for advance care planning in the palliative phase of people with intellectual disabilities? A multi-perspective interview study. Journal of applied research in intellectual disabilities : JARID. 2020;33(2):160-71.

Bijlage 1. Studie karakteristieken geselecteerde studies

Reference	Sue K, Mazzotta P, Grier E. Palliative care for patients with communication and cognitive difficulties. Can Fam Physician. 2019 Apr;65(Suppl 1):S19-S24.
Study characteristics	
Study design	Systematic review n=34 studies included in the review; study design not reported
Objective	To help increase the confidence of both caregivers and clinicians in providing palliative care to adults with intellectual and developmental disabilities (IDD) using an easy-to-follow framework to improve and overcome barriers to effective palliative care in this population
Methods	*Data source* PubMed, MEDLINE, EMBASE, Cochrane, CINAHL, Web of Science, Scopus, Google Scholar *Search period* Not reported *Language* Not reported *Inclusion/exclusion criteria* Not reported
Population	Adults with intellectual and developmental disabilities, caregivers and clinicians *Setting* Not reported *Sample size* Not reported
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Experiences of patients, caregivers and clinicians with providing palliative care to individuals with IDD
Results	*Review question 2: When to start ACP* - End-of-life situations can be difficult to predict in patients with IDD.29 - An early referral to palliative care allows for a longitudinal experience that over time can build trust and familiarity with staff, supports, and services.19,20 This is important in particular for patients with IDD and their caregivers, as lack of trust, continuity, and authentic relationships have been shown to negatively affect quality of care.20 This also allows palliative healthcare professionals to take the time to gain knowledge of a patient's lifestyle and usual behaviour.19 The goal is to integrate the palliative approach (symptom control, comfort, family support, discussions about goals of care, and ACP) into the existing pattern of care.11 *Review question 4: Communication with persons with intellectual and/or communication disabilities* - There is no evidence that people with IDD have less need for information about illness, dying, or death.3,17 There is evidence, that people with IDD are less likely to ask

questions and initiate conversations.3 Patients with IDD might have difficulties with abstract concepts such as death, knowing death is imminent, understanding difficult concepts (treatments, palliative care, informed consent), sharing feelings and talking about illness with others, and being treated differently because of their disability.9,17,18 However, people with mild IDD often indicate some awareness of their condition, either directly in conversation or indirectly by mood and behaviour changes.3 For people with severe or profound IDD, on the other hand, marked uncertainty exists as to whether they are aware of the development of life-limiting conditions such as cancer.3

- Good-quality end-of-life care depends on the clinician's ability to understand and communicate with the patient. Clinicians have expressed uncertainty about what and how information is understood or processed and dealt with by both patients and their caregivers.3 They might incorrectly assume that a person with IDD is not capable of participating in ACP.2,12 Therefore, they are commonly overreliant on carers to meet communication needs, rather than engaging in any direct communication with the person with IDD.3,12 A more collaborative relationship between palliative care and clinicians familiar with the needs of adults with IDD is needed.15
- To help facilitate ACP, National Health Service in the UK has produced a template for an "end-of-life book" designed for the IDD population.23,24
- An unreflective overemphasis on the role of cognitive limitation in QOL can lead to strongly negative consequences, such as limiting the spectrum of care options.11 Practitioners engaging in conversations about palliative and end-of-life care needs should avoid words such as futile or language that seems to undervalue a patient's life.28 As with the general population, risks and burdens of treatment need to be discussed.28
- Helpful communication strategies can be used to break the communication barrier. Instead of verbal communication, visual tools can be used to relay information from both sides, such as using a body map or pictures to indicate pain13 or using communication aides to help patients express themselves. Examples of such tools include the Books Beyond Words series, which includes 26 picture books designed to help adults with IDD understand and talk about difficult issues, including cancer and death.7 Participants reading books with a supporter soon interspersed the story in the book with personal experiences.8 Another strategy can be to show an image of someone in a similar situation and ask what the fictional person might need or want.30 Authors of a study of patients with mild to moderate IDD suggest many will base answers on personal experiences.30 Additional strategies might include allotting extra time for establishing the best way to communicate, rephrasing questions and explanations as needed, ensuring as much understanding as possible, and building on the therapeutic relationship by gaining trust.7 Avoid rushing on with questions if the patient does not immediately respond, as it might take longer for someone with IDD to think, process, and formulate responses.7 Because abstract thinking can be more difficult, explanations of what is happening might have to be based on the here and now.32 Even a concept like time or duration might need to be rephrased using index events (eg, "Did you have the pain at Christmas?" rather than "How long have you had pain?").7 Simple, noneuphemistic language introducing one concept at a time using short sentences is preferred.7 Be cautious when offering choices in a question, as some patients might simply repeat the final option offered. Re-asking by switching the words around can help mitigate this.7 When asked, many people with IDD relay that they want to be told truthfully and straightforwardly about what is going on.7 However, as in the general population, some prefer not to be told painful truths. Professionals still need to find out what the person wants to know.7 Whether the person has capacity to understand such information should be carefully thought through, but assumptions should not be made.8 Different people could have quite different opinions on the level of insight.3 When caregivers feel it is better to protect the person with IDD from bad news or discussions around death and dying, the person's right to information and involvement needs to be considered.8,18 Sensitivity is required to enable everyone involved to discuss the issue.8 When breaking bad news to people with IDD, a proposed model (the ARCH model for breaking bad news; see below) suggests an ongoing process of disclosure to help build understanding over time, with the involvement of familiar carers.17,19,33
- The ARCH model for breaking bad news:33
  - Ask: Keep questions straightforward. Find out what is already known and what the patient wants to know.

	• Repeat and clarify: Be prepared to go over information repeatedly, in different ways (using books, photos, etc). Simplify if necessary. • Check the level of understanding: Explore how much the patient knows and what it means to him or her. Go back to previous stages as needed. • Help the person express feelings: Encourage expression of feelings, listen carefully, and give support. Help describe feelings and explore what the patient feels he or she might need next, future support options and choices, and letting other people know, if necessary.

Reference	Voss H, Vogel A, Wagemans AMA, Francke AL, Metsemakers JFM, Courtens AM, de Veer AJE. Advance Care Planning in Palliative Care for People With Intellectual Disabilities: A Systematic Review. J Pain Symptom Manage. 2017 Dec;54(6):938-960.e1.
Study characteristics	
Study design	Systematic review n=14 studies included in the review: - 7 quantitative studies - 3 qualitative study - 4 mixed methods studies
Objective	To gain insight into what is known about the use and effects of ACP in palliative care for people with intellectual disabilities (IDs)
Methods	*Data source* PubMed, PsycINFO, Embase, CINAHL *Search period* <June 2016 *Language* All languages *Inclusion criteria* Describes empirical qualitative, quantitative, or mixed methods research; concerns people with ID who receive palliative care and/or their relatives and/or professionals or concerns people with ID who died non-acutely (after an identifiable period of illness) and/or their relatives and/or professionals; describes the use of ACP or elements of ACP such as physical, psychological, social, or spiritual matters in palliative care, and/or effects of ACP or elements of ACP on the quality of palliative care and/or quality of life *Exclusion criteria* Letters, editorials, comments, or congress abstracts; case stories that are not analyzed systematically; literature studies (although their reference lists were studied to identify relevant empirical studies)
Population	People all ages with ID, relatives, healthcare professionals, managers *Setting* - Residential care facilities: 8 studies - Community facilities: 1 study

	- Mix of settings: 4 studies - Setting not reported: 1 study *Sample size* Range 47-247 people with ID, 3-30 relatives, 10-255 healthcare professionals, 31-84 managers
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Perspectives on ACP
Results	*Review question 1: For which persons should ACP be initiated* Effectiveness data on the specific study population with ID is not extracted; these data are incorporated in other included effectiveness reviews on ACP in multiple populations. *Review question 2: When to start ACP* - Professionals were not prepared to discuss end-of-life issues with the patient because they believed the patient would not understand and they did not know who had the authority to tell the patient directly.24 Therefore, if ACP occurred, it was often acute as a consequence of problems that had arisen, instead of anticipating possible problems that could appear in the future.26 - Physicians preferred to discuss ELDs in a stable and calm situation, when emotions were under control and enough time could be spent on a sensible discussion.34 However, this was often not possible because of late diagnosis of the illness.24 *Review question 4: Communication with persons with intellectual and/or communication disabilities* - Professionals did not always recognize non-verbal symptoms or saw symptoms as part of the disability.24,32 The need for ACP is not so easy to detect in people with ID with milder disabilities.26 Multiple signals from different information sources and interactions between the patient, professionals, and family are needed to be able to identify people with ID who are in need of palliative care.40 This shows that ACP for people with ID is not a uniform process but will take different forms depending on the degree and complexity of the disability and vulnerability of the person with ID. Professionals should therefore use ACP as a flexible process depending on the needs and preferences of the individual and their relatives. - Involve people with ID in ACP discussions in practice. ACP focuses on person-centered care. Without asking the patients themselves about their views and preferences, it remains uncertain whether their wishes will be respected and whether the care provided will satisfy their needs.20,42,43 However, allowances need to be made for the fact that people with ID find it more difficult to understand the concept of death, and self-determination in end-of-life planning is less developed.44 *Review question 5: Caregiver involvement in ACP* - Professionals noted the importance of nurturing good relationships with the patient's family.25 Physicians believed that a good working relationship with relatives and other professionals was the most important factor contributing to an effective decision-making process.34 • There are no clear organizational policies on ACP, which can cause confusion and uncertainty among professionals and relatives, about tasks and responsibilities.24,33 Therefore, professionals should be informed about their role and tasks in discussing end-of-life issues and trained in talking about this with people with ID and/or relatives. In that way, professionals will be better prepared for discussing end-of-life issues with people with ID and/or their relatives and be more comfortable with this.15

Reference	**McKenzie N, Mirfin-Veitch B, Conder J, Brandford S. "I'm still here": Exploring what matters to people with intellectual disability during advance care planning. J Appl Res Intellect Disabil. 2017 Nov;30(6):1089-1098.**
Study characteristics	
Study design	Qualitative study
Objective	To explore the experiences of persons with intellectual disabilities (IDs) and life-limiting conditions who have been engaged in ACP and to identify, from their perspectives, the factors that strengthen or inhibit ACP
Methods	- Initial and follow-up (after 4-6 months) semi-structured interviews with persons with IDs (and elected support persons if wanted), the person's family/whanau, and support team members (i.e. staff such as managers, health advisors and support workers employed by a disability service) - Documentation review
Population	Persons with a diagnosis of ID and a life-limiting condition, awareness that their condition was life-limiting, involvement in (or completion of) a process of ACP, and capable to participate in an interview situation *Setting* - Residential service n=2 - Supported independent living n=1 - Semi-independent situation attached to a residential service n=1 *Country* New Zealand *Sample size; gender; age* - n=4 persons with IDs; NR; range 28-68 years - n=4 family/whanau members; NR; NR - n=15 support team members; NR; NR
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	- Experiences with ACP - Factors that strengthen or inhibit ACP
Results	*Review question 4: Communication with persons with intellectual and/or communication disabilities* - A small set of factors were of key importance to the persons with IDs: wanting their ACP to be about living, not just dying; making my own decisions; going at my pace; being open and honest; making sure I understand. - Most of what the persons with IDs reported as being important to them was relatively easily addressed by the person who facilitated their planning process. The approach taken by these individuals aligned with what they would normally do when facilitating any other person-centred planning process. - The additional end-of-life care needs of persons with IDs are in many ways no different than for the general population, but ACP appears to require the adaptation of processes, systems, tools and approach to ensure equal access to ACP. In the absence of specific evidence-based guidance for persons with IDs, the support teams involved in this research followed and adapted the guidance for the general population, with good results. Facilitating skills needed to ensure that persons with IDs had a positive ACP experience:

	- Comfort in talking about death and dying of support team members by training and/or experience. - Being open and honest with the persons with IDs; this allayed the persons with IDs' fears, enabled them to come to terms with changes in their health or situation and make decisions based on what was right for them. Support teams and families/whanau reported that it was easier to be open and honest on topics they were familiar with or had prior experience and sound knowledge of. - Introducing ACP gently so that the persons with IDs were comfortable and could take part in a meaningful way. - Supporting emotional well-being. All persons with IDs experienced different periods of upset, sadness and strong emotions, as did their family/whanau and support team members. Besides ACP discussions, need to plan for follow-up that met each person's emotional needs. Support teams found ways to make sure that the person with IDs was well supported, and they also identified that the passage of time helped the persons with IDs to come to terms with the conversations and find peace with their decisions. Pro-actively planning emotional support strategies appeared to have a positive effect in allaying the persons with IDs' concerns and in minimizing difficulties. - Having ongoing conversations: a conversation had to be over a period of time, with time to ponder and consider options, and to be revisited as required. Those leading/facilitating the process followed the persons with IDs' lead regarding how quickly they progressed—they checked in with them, and made sure they were comfortable and willing to continue. They looked for signs (such as being unsettled, acting out with behaviour or asking to stop) that the person may need to have a break for a number of days or weeks, but were conscious of the need to prompt the restart of the conversation after taking a break. - Working as a team (collaboration between disability service providers and medical/palliative care providers to ensure strong leadership), directly involving the person with IDs. - Sharing the plan with the wider disability support team, family/whanau, medical professionals and hospice. Supporting the persons with IDs' decision making: - Having clear and accurate information to make decisions. - Adapting the process/information to suit me, e.g. easy-read versions or visualization of information. - Making my own decisions. A key concern for persons with IDs was that they were able to make their own choices and be in control of the decisions being made. Despite genuinely wanting to fully involve the persons with IDs in their planning, there were times when some family/whanau and/or support team members took a substitute decision-making approach. They perceived this to be in the person with IDs' best interests. What is needed in terms of content and structure of ACP: - Covering typical content areas. Fully involve persons with IDs in all decisions, including treatment preferences, advance directives, and other legal matters. - Significant focus on planning the life they were still living (not only their death). - Having a resource to guide the support team. Guidance material such as "Living Well" (Helen Sanderson and Associates, 2010) helped the support team structure their conversations and find out what the person with IDs thought and felt without being leading. It helped the team to approach topics that they had not considered the person with IDs having an opinion about (such as cremation versus burial).

Reference	Voss H, Vogel A, Wagemans AMA, Francke AL, Metsemakers JFM, Courtens AM, de Veer AJE. What is important for advance care planning in the palliative phase of people with intellectual disabilities? A multi-perspective interview study. J Appl Res Intellect Disabil. 2020 Mar;33(2):160-171.
Study characteristics	
Study design	Qualitative study

Objective	What is important for ACP in the palliative phase of people with intellectual disabilities (IDs)
Methods	Individual in-depth interviews with people with moderate IDs, relatives and professionals
Population	People ≥18 years old with moderate IDs, having an understanding of the concept of death and dying, previous experience with being seriously ill and/or being hospitalized themselves, and without a life-limiting illness or receiving palliative care themselves *Setting* - Intellectual disability residential care: n=5 *Country* The Netherlands *Sample size; gender; age* - People with moderate IDs n=5; 40% male; mean age 72 years - Relatives n=7; 29% male; NR (related to n=5 people with IDs; 60% male; mean age 41 years) - Professional caregivers n=8; NR; NR
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Experiences with/opinions on ACP
Results	*Review question 4: Communication with persons with intellectual and/or communication disabilities* Tailoring care: ACP is a tailor-made process; each individual is different and has various care needs that needed to be taken into account; there is no single right way to provide ACP. What is needed to provide tailored care: - Have close and harmonious relationships between individuals with IDs, their relatives and professionals. Good knowledge of the person with IDs is necessary in order to shape the ACP process to suit the individual with IDs and their relatives. - Connecting with the person with IDs to be able to reflect his/her wishes. It is import to set aside own preferences and to model what that person stands for in their life, and adjust care according to their goals and needs. Adapt the ACP process to suit the level of understanding and experiences of the person with IDs. ACP process requires teamwork: - Work together, inform one another and decide together. - Trusting each other. Trust was essential in discussing insecurities and fears, and in making decisions for future care. Honesty and openness within a team of people caring for a person with IDs contributed to a more positive and calmer ACP process. Professional and personal experience of professionals with palliative care and losses plays a role in their ability to feel comfortable and openly discuss ACP. - Make room for emotions. ACP should be considered as a 'human approach' rather than a more technical or procedural approach. Take the impact that ACP in the palliative phase can have into consideration. Roles of people with IDs in ACP: - Participants with IDs wanted to be informed about their health situation. - Expressive role. Based on their own previous experiences and wishes, people with IDs can communicate their preference, sometimes verbally but more often in non-conventional ways, often represented by their relatives. - People with IDs often find direct participation in decisions about future care difficult.

	Roles of relatives in ACP: - Signalling role. In cases where relatives have a lifelong, close relationship with the person with IDs, relatives can have an important role in interpreting the person with intellectual disability expressions/behaviour. - Contributing role. Relatives often want and should have a contributing role in ACP discussions, depending on their own involvement and desire to be involved in the care for the person with IDs. - Representing role. Relatives can participate in ACP as a representative of the person with IDs and articulate wishes on their behalf if the individual is not able to do so themselves. Roles of professionals in ACP: - Informing role. Clearly and realistically explain possible scenarios for care options to relatives and/or person with IDs, taking the level of cognitive functioning into account. - Collaborating role. ACP is teamwork, professionals should maintain harmonious relationships and provide a safe environment where all involved are able to openly discuss wishes and options for future care. Take the initiative to discuss this with relatives and/or the person with IDs. - Coordinating role. Professionals monitor the changing behaviour of the person with IDs; they are responsible for providing care in line with what the person with IDs wants/needs. Explore and collate the views/wishes of everybody involved in the care for a person with IDs. Experience is required to become comfortable and confident in leading ACP discussions.

Bijlage 2. Risk of bias

Sue et al., 2019		
Item	**Yes, partial yes or no**	**Explanation**
1. Did the research questions and inclusion criteria for the review include the components of PICO?	Partial 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?	No	
3. Did the review authors explain their selection of the study designs for inclusion in the review?	No	
4. Did the review authors use a comprehensive literature search strategy?	Partial yes	
5. Did the review authors perform study selection in duplicate?	No	
6. Did the review authors perform data extraction in duplicate?	No	
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?	No	
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?	No	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	

OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

Voss et al., 2017		
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?	No	
3. Did the review authors explain their selection of the study designs for inclusion in the review?	No	
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?	Partial yes	
7. Did the review authors provide a list of excluded studies and justify the exclusions?	Partial yes	
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?	Partial yes	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	

16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Partial yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

McKenzie et al., 2017	
Study quality (NICE Quality appraisal checklist – qualitative studies)	
Theoretical approach 1. Is a qualitative approach appropriate? 2. Is the study clear in what it seeks to do?	Appropriate / ~~Inappropriate~~ / ~~Not sure~~ Clear / ~~Unclear~~ / ~~Mixed~~
Study design 3. How defensible/rigorous is the research design/methodology?	Defensible / ~~Indefensible~~ / ~~Not sure~~
Data collection 4. How well was the data collection carried out?	Appropriately / ~~Inappropriately~~ / ~~Not sure; inadequately reported~~
Trustworthiness 5. Is the role of the researcher clearly described? 6. Is the context clearly described? 7. Were the methods reliable?	~~Clearly described~~ / ~~Unclear~~ / Not described ~~Clear~~ / ~~Unclear~~ / Not sure Reliable / ~~Unreliable~~ / ~~Not sure~~
Analysis 8. Is the data analysis sufficiently rigorous? 9. Is the data 'rich'? 10. Is the analysis reliable? 11. Are the findings convincing? 12. Are the findings relevant to the aims of the study? 13. Conclusions	Rigorous / ~~Not rigorous~~ / ~~Not sure; not reported~~ Rich / ~~Poor~~ / ~~Not sure; not reported~~ Reliable / ~~Unreliable~~ / ~~Not sure; not reported~~ Convincing / ~~Not convincing~~ / ~~Not sure~~ Relevant / ~~Irrelevant~~ / ~~Partially relevant~~ Adequate / ~~Inadequate~~ / ~~Not sure~~
Ethics 14. How clear and coherent is the reporting of ethics?	Appropriate / ~~Inappropriate~~ / ~~Not sure; not reported~~
Overall assessment (++ /+ /-)	++

ACP: advance care planning, ID: intellectual disabilities, NICE: National Institute for Health and Care Excellence, NR: not reported

McKenzie et al., 2017	
Study quality (NICE Quality appraisal checklist – qualitative studies)	
Theoretical approach 1. Is a qualitative approach appropriate? 2. Is the study clear in what it seeks to do?	Appropriate / ~~Inappropriate~~ / ~~Not sure~~ Clear / ~~Unclear~~ / ~~Mixed~~
Study design 3. How defensible/rigorous is the research design/methodology?	Defensible / ~~Indefensible~~ / ~~Not sure~~
Data collection 4. How well was the data collection carried out?	Appropriately / ~~Inappropriately~~ / ~~Not sure; inadequately reported~~
Trustworthiness 5. Is the role of the researcher clearly described? 6. Is the context clearly described? 7. Were the methods reliable?	Clearly described / ~~Unclear~~ / ~~Not described~~ Clear / ~~Unclear~~ / ~~Not sure~~ Reliable / ~~Unreliable~~ / ~~Not sure~~
Analysis 8. Is the data analysis sufficiently rigorous? 9. Is the data 'rich'?	Rigorous / ~~Not rigorous~~ / ~~Not sure; not reported~~ Rich / ~~Poor~~ / ~~Not sure; not reported~~

10. Is the analysis reliable? 11. Are the findings convincing? 12. Are the findings relevant to the aims of the study? 13. Conclusions	Reliable / ~~Unreliable~~ / ~~Not sure; not reported~~ Convincing / ~~Not convincing~~ / ~~Not sure~~ Relevant / ~~Irrelevant~~ / ~~Partially relevant~~ Adequate / ~~Inadequate~~ / ~~Not sure~~
Ethics 14. How clear and coherent is the reporting of ethics?	Appropriate / ~~Inappropriate~~ / ~~Not sure; not reported~~
Overall assessment (++ /+ /-)	++

ACP: advance care planning, ID: intellectual disabilities, NICE: National Institute for Health and Care Excellence

Hoe kunnen naasten van mensen in de langdurige zorg worden betrokken bij proactieve zorgplanning?

Resultaten

Onderstaand is een beschrijving gegeven van de geïncludeerde studies die betrekking hebben op de vraag: 'Hoe kunnen naasten van mensen in de langdurige zorg worden betrokken bij proactieve zorgplanning?'.

Beschrijving van de studies

De zoekactie identificeerde 11 systematische literatuurreviews die van toepassing zijn op de onderzoeksvraag. Een volledig overzicht van de karakteristieken van de geïncludeerde studies is gegeven in bijlage 3.

In 8 van de systematische reviews werden per review 14 tot 57 studies geïncludeerd met verschillende designs, veelal kwalitatieve studies, kwantitatieve studies of studies met een mixed methods design.[Combes 2019; Dening 2011; Keijzer-Van Laarhoven 2020; Nimmons 2020; Petriwskyj 2014; Silies 2021; Voss 2017; Wendrich-van Dael 2020] Twee van deze systematische reviews includeerden ook reviews.[Keijzer-Van Laarhoven 2020; Wendrich-van Dael 2020] In de systematische review van Hall et al., 2019 werden alleen reviews (n=55) geselecteerd.[Hall 2019] Voor de systematische reviews van Frandsen et al., 2021 (n=7 studies) [Frandsen 2021] en Mignani et al., 2017 (n=9 studies)[Mignani 2017] werden alleen kwalitatieve studies geïncludeerd. In de reviews werden diverse populaties en settingen onderzocht. Mignani et al., 2017 onderzochten de perspectieven over proactieve zorgplanning van ouderen die in langdurige zorglocaties woonden en hun familieleden.[Mignani 2017] Petriwskyj et al., 2014 brachten de wetenschappelijke kennis in kaart over familiebetrokkenheid bij besluitvorming voor mensen met dementie die in een verpleeghuis wonen.[Petriwskyj 2014] Drie systematische reviews rapporteerden geen details over de settingen en onderzochten proactieve zorgplanning voor mensen met chronisch nierfalen[Frandsen 2021], de ziekte van Parkinson[Nimmons 2020] en diverse populaties [Hall 2019]. De overige zes systematische reviews waren gericht op proactieve zorgplanning in een mix van verschillende settingen voor mensen met dementie[Dening 2011; Keijzer-Van Laarhoven 2020; Wendrich-van Dael 2020], kwetsbare ouderen [Combes 2019], mensen met een verstandelijke beperking[Voss 2017] en diverse populaties[Silies 2021]. De resultaten over proatieve zorgplanning voor deze uitgangsvraag werden in de elf geïncludeerde systematische reviews niet vergeleken met een controlegroep.

Risk of bias

De volledige beoordeling is beschikbaar in bijlage 4. Hieronder wordt een korte samenvatting van de kwaliteitsbeoordeling per studie gegeven.

De geïncludeerde systematische reviews zijn onderzocht op het risico op bias met behulp van de AMSTAR-2 checklist (*Assessing the Methodological Quality of Systematic Reviews*, Canada).[Shea 2017] AMSTAR-2 wordt gebruikt om aan te tonen of de methodologische kwaliteit van de reviews hoog, matig, laag of zeer laag is. De resultaten van de bias beoordelingen worden kort gerapporteerd in deze paragraaf, in bijlage X zijn per review de details van het risico op bias gepresenteerd.

De resultaten van de geïncludeerde systematische reviews voor deze uitgangsvraag waren narratief beschreven, zonder (kwantitatieve) onderbouwing met onderzoeksresultaten. De meta-analyse vragen van de AMSTAR-2 checklist waren niet van toepassing. Een aanzienlijk deel van de overige vragen werd met 'nee' of 'gedeeltelijk ja' beantwoord. Vijf reviews hadden een lage methodologische kwaliteit.[Frandsen 2021; Keijzer-Van Laarhoven 2020; Nimmons 2020; Silies 2021; Wendrich-van Dael 2020] In tegenstelling tot de andere reviews hadden deze vijf reviews wel een protocol opgesteld. Wanneer er geen gebruik wordt gemaakt van een voorafgaand opgesteld protocol, wordt dit als kritieke fout voor de reviewmethodologie beoordeeld door de AMSTAR-2 checklist. De overige zes systematische reviews hadden een zeer lage methodologische kwaliteit.[Combes 2019; Dening 2011; Hall 2019; Mignani 2017; Petriwskyj 2014; Voss 2017]

Beschrijving van de resultaten

Hoe het proces van proactieve zorgplanning in detail wordt vormgegeven, is afhankelijk van de voorkeuren en reacties van alle betrokkenen en van de vaardigheden van de zorgverlener die dit proces faciliteert. Er is geen 'one size fits all' aanpak.[Hall 2019; Silies 2021] In de systematische reviews werden diverse suggesties gerapporteerd over hoe naasten van mensen in de langdurige zorg betrokken kunnen worden bij proactieve zorgplanning. Er was overlap tussen de resultaten. Onderstaand worden de belangrijkste bevindingen uit de geïncludeerde systematische reviews samengevat.

Rol van naasten

Er is vaak geen duidelijk organisatiebeleid ten aanzien van proactieve zorgplanning, wat tot verwarring en onzekerheid over taken en verantwoordelijkheden kan leiden bij zorgverleners en naasten.[Voss 2017] De rol van naasten bij besluitvorming, hun mate van betrokkenheid en hoe naasten deze rol ervaren kan variëren, maar de meeste naasten wensen betrokken te worden bij gedeelde besluitvorming.[Frandsen, 2021; Mignani 2017; Petriwskyj 2014] Naasten worden formeel of informeel aangewezen als vertegenwoordigers en moeten door de betrokken zorgverleners worden geïdentificeerd (uitgangsvraag 6, module organisatie van zorg). Hierbij is het van belang om inzicht te krijgen in en af te stemmen over het gewenste niveau van betrokkenheid van de naaste bij proactieve zorgplanning en mogelijke relationele aspecten die het proces kunnen belemmeren of bevorderen.[Petriwskyj 2014; Silies 2021; Wendrich-van Dael, 2020] Gedurende het verloop van een ziekte als dementie zullen naasten meer betrokken worden als vertegenwoordiger.[Dening, 2011]

Vertrouwensrelatie en communicatie met zorgverleners
Een goede vertrouwensrelatie met de betrokken zorgverleners is essentieel voor het proces van proactieve zorgplanning, waarbij de perspectieven van zowel patiënten als naasten van belang zijn.[Frandsen 2021; Keijzer-van Laarhoven 2020; Mignani 2017; Petriwskyj 2014; Silies 2021; Voss 2017; Wendrich-van Dael, 2020] De communicatiestijl en houding van zorgverleners heeft invloed op hoe comfortabel patiënten en naasten zich voelen met proactieve zorgplanning.[Frandsen 2021; Silies 2021] Het gebruik van medisch jargon resulteerde in afstand, verwarring en onbegrip.[Frandsen 2021] Naasten prefereren een gepersonaliseerde aanpak van de zorgverleners gebaseerd op vertrouwen, respect, openheid en empathie.[Mignani 2017; Silies 2021] In de systematische review van Silies et al., werd aangegeven dat naasten een aanpak waardeerden waarbij gebruik werd gemaakt van scenario's of voorbeelden van andere personen, in plaats van een directe confrontatie met hun eigen dood.[Silies 2021]
De kwaliteit van de relatie en communicatie tussen zorgverleners en naasten varieert en is afhankelijk van verschillende interpersoonlijke factoren (o.a. de houding en het gedrag van de zorgverleners en de frequentie en kwaliteit van de zorgverlener-naaste conversaties), contextuele factoren (o.a. de verpleeghuis setting) en culturele factoren (zie paragraaf over normen en waarden).[Petriwskyj 2014; Wendrich-van Dael, 2020] Het is van belang om rekening te houden met deze factoren, omdat dit invloed kan hebben op de mate waarin naasten en zorgverleners kunnen samenwerken in het besluitvormingsproces en de reactie op de beslissingen die vervolgens worden genomen.

Normen en waarden
Zorgverleners en naasten kunnen verschillende opvattingen hebben over proactieve zorgplanning, bijvoorbeeld op religieus, spiritueel en cultureel gebied. Het is van belang om de normen en waarden van naasten te respecteren om te vermijden dat dit een belemmering kan vormen voor proactieve zorgplanning.[Keijzer-van Laarhoven 2020; Silies 2021; Petriwskyj 2014] Naasten merkten dat zorgverleners zich vaak niet comfortabel voelden bij het praten over lastige onderwerpen of deze conversaties vermijden. Dit creëert geen goede basis voor proactieve zorgplanning en dwingt zorgverleners om hun eigen normen, waarden en houdingen te blijven reflecteren.[Silies 2021]

Voorlichting
Naasten zijn vaak onvoldoende voorbereid op proactieve zorgplanning en het nemen van beslissingen, daarom is het van belang om naasten goed te informeren over de ziekte, de prognose, behandelmogelijkheden, de rol van een vertegenwoordiger en het proces van proactieve zorgplanning.[Combes 2019; Dening 2011; Frandsen 2021; Hall 2019; Keijzer-van Laarhoven 2020; Mignani 2017; Nimmons 2020; Voss 2017; Petriwskyj 2014; Silies 2021; Wendrich-van Dael 2020] Hierbij kunnen diverse formele en informele voorlichtingsbronnen ingezet worden, zoals folders, film en internet; deze informatie kan algemeen zijn of specifiek gericht op een bepaalde ziekte.[Combes 2019; Dening 2011; Silies 2021]

Ondersteunen van emotioneel welzijn

Door de besluiten die genomen moeten worden, kan proactieve zorgplanning stress veroorzaken bij zowel de patiënten als naasten, daarom hebben naasten ook behoefte aan steun en begeleiding tijdens dit proces.[Dening 2011; Hall 2019; Keijzer-van Laarhoven 2020; Nimmons 2020; Petriwskyj 2014; Silies 2021] Naasten hebben hierbij hun eigen individuele behoeften. Met behulp van emotionele ondersteuning door zorgverleners kunnen naasten worden ontlast, wat een positieve invloed zal hebben op het welzijn van de naaste en degene voor wie ze zorgen en voor het verloop van de proactieve zorgplanning.[Nimmons 2020]

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Bijlage 3. Studie karakteristieken geselecteerde studies

Reference	Combes S, Nicholson CJ, Gillett K, Norton C. Implementing advance care planning with community-dwelling frail elders requires a system-wide approach: An integrative review applying a behaviour change model. Palliat Med. 2019 Jul;33(7):743-756.
Study characteristics	
Study design	Systematic review n=42 studies included in the review: - 8 empirical papers with quantitative methods - 11 empirical papers with qualitative methods - 10 empirical papers with mixed methods - 6 expert commentaries - 4 service improvements - 2 guidelines - 1 theoretical
Objective	To understand how ACP can be better implemented for community-dwelling frail elders and to develop a conceptual model to underpin intervention development
Methods	*Data source* CINAHL, Embase, Ovid Medline, PsycINFO, Cochrane Library, and University of York Centre for Reviews and Dissemination *Search period* 1990-October 2018 *Language* English *Inclusion criteria* Adults ≥65 years, community dwelling, living with frailty, cognitively able to discuss ACP, papers that describe the implementation of ACP *Exclusion criteria* Acute care settings or papers that only discuss non-acute settings peripherally, papers that only minimally describe the implementation of ACP, systematic review papers were treated as sources of original papers only
Population	Community-dwelling frail elders ≥65 years whose main residence is home or a long-term care facility, caregivers and healthcare professionals *Setting* - Long-term care: 18 studies - Home: 7 studies - Mixed community: 16 studies - Mixed community and acute: 1 study Baseline characteristics are reported only for 11 of the 42 studies
Intervention	ACP
Comparison	Not applicable

Outcome measures (applicable to our review)	Attitudes to, and necessary behaviours for, implementing ACP with community-dwelling frail elders
Results	*Review question 2: When to start ACP* Personal ability: - For frail elders, personal ability focused on their physical and psychological ability to engage with ACP and how these would likely reduce with time.43,45,48–55,57–60,62–64,66,69–72,74–77,79–81,83 Abilities included difficulties reading and understanding documentation58,60 and remembering ACP decisions.59,60,66,70 The focus was on early engagement, prior to potential physical or cognitive deterioration43,45,48,51–55,57–60,62,64,66,71,72,74,75,77,79–81 where '… the person may already be too sick to interpret their treatment preferences'.43 Early engagement meant '… meaningful plans could be put in place […] so that the patient's quality of life could be enhanced …'80 and that decisions could be reassessed throughout the frail elders' end-of-life trajectory.45,48,52,57–59,62–64,69,76,81,83 - Early engagement means frail elders are most likely to be able to engage with ACP. This is supported by ACP becoming part of everyday practice and the provision of targeted materials. Recognosing triggers: - Recognising triggers related to professionals recognising, acting on and creating opportunities to engage frail elders.43,44,47,48,53,54,58–60,62,64,66,67,69–72,75,78,83 Triggers included recognising poor prognostic indicators,54,58,61,66,72,77,78,82,83 transitions, such as admission to homecare services,45,58,63,67 and environment, particularly living in long-term care,43,47,48,53,57–59,72–74,81 which '… allows for continuity of end-of-life care discussion …'43 Policy and guidelines that promoted ACP were also triggers,54,60,67,72–75,78,79,81,83 particularly when linked to funding or accreditation.72 However, there were also multiple barriers. Frailty prognostication is difficult.47,48,60,75,78,80,83 The lack of a terminal diagnosis means frail elders '… are not identified as being, or do not see themselves as being, at the "end-of-life"',48 especially when they present with '… apparent wellness […] during initial consultations …'47 Opportunities provided by frail elders were also not always recognised, for example, when a frail elder '… refused a percutaneous endoscopic gastrostomy tube and had indicated that he wanted to die …'.72 Furthermore, policies and guidelines regarding ACP responsibility were often unclear,47,51,52,65,71,73,78 not relevant to frail elders lives,48,54 could potentially undermine frail elders' strategies '… to maintain positivity and motivation',54 and often focused on institutional admission with no motivation for ongoing review or relevance to those living in domestic settings.67 - Frail elders are more likely to engage with ACP if it becomes part of everyday practice as part of an integrated, comprehensive, system-wide approach that occurs over time, rather than as a one-off event. - Professionals need to recognise, act on, and create opportunities for frail elders to engage with ACP throughout their end-of-life trajectory. *Review question 5: Caregiver involvement in ACP* Education and training: - Education and training recommended multiple, diverse formal and informal education and training packages to support stakeholders to better understand, engage with and implement ACP. For frail elders and their families, this included education to improve understanding of ACP,44,64,69,72 how to complete documentation,60 its relevance for frail elders53 and their likely end-of-life trajectory.44,56,73 - Time was recognised as important for education or training: time to understand necessary concepts and how they related to the frail elder, and time to make decisions.44,62,64,68,73 Strategies included making ACP part of routine practice,57,58,69,73,78 providing targeted materials,62,70 and preparing frail elders and families for potential future decision-making.48

Reference	Dening KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. Int Psychogeriatr. 2011 Dec;23(10):1535-51.
Study characteristics	
Study design	Systematic review n=17 studies included in the review: - 11 quantitative studies - 1 qualitative study - 5 mixed methods studies
Objective	- What are the facilitators and inhibitors to ACP for people with dementia? - What are the key themes that emerge from the literature?
Methods	*Data source* - PubMed, CINAHL, AMED, PsychINFO, EMBASE, BNI, Cochrane Database, Trial Registers, Conference Papers Index, unpublished library sources (e.g. SIGLE) *Search period* <March 2010 *Language* English *Inclusion criteria* Papers reporting empirical studies using any methodology, reported characteristics of the patient population studied, reported details about the type of ACP under investigation, provided information about the study setting, and involved people with dementia (diagnosed clinically or using research criteria) or family members and professional carers of people with dementia *Exclusion criteria* Papers that reported reviews, opinions and comments only
Population	People with dementia, caregivers and healthcare professionals *Setting* - Nursing home: 5 studies - Memory disorders clinic/Alzheimer's disease center: 4 studies - Psychogeriatric teams/program: 4 studies - Aging and dementia research center: 1 study - Alzheimer's disease support group: : 1 study - Primary care: 1 study - Community: 1 study *Sample size* Range 12-745
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Key themes that indicate how ACP may benefit people with dementia and their carers, and the barriers and facilitators for this
Results	*Review question 5: Caregiver involvement in ACP* - Family caregivers were unprepared for decision-making (Forbes et al., 2000; Hirschman et al., 2004; 2006; 2008); yet when older people with dementia are deemed no longer able to make

	decisions about their care and treatment, family carers are often called upon to do so. Forbes et al. (2000) found that feelings such as guilt and a sense of failure when the person with dementia was placed into long-term care, together with a lack of information on the disease and its prognosis, left family carers unprepared to make effective decisions about end-of-life care for their relative with dementia. - The threshold in capacity for people with dementia to engage meaningfully in ACP would appear to be early in the disease trajectory. As the disease progresses carers become more involved in proxy decision-making but importantly require support, information and education to be able to make effective decisions (Caplan et al., 2006; Forbes et al., 2000; Hirschman et al., 2008; Mezey et al., 2000). - Targeted end-of-life care education and a supportive ACP program for both relatives and professionals reduces unnecessary hospital admission and reduces mortality of care home residents (Caplan et al., 2006). Although their findings are based on a small sample, Hirschman et al. (2008) suggest that barriers to ACP discussions may be overcome by active intervention of professionals involved early on in the care of the person with dementia and in positive engagement of the family carers. - Decisions about life-sustaining treatment are often presented at times of health and social care crises and therefore at times of great stress for carers: this is a critical moment for professionals to support carers in providing information and support to make effective choices on end-of-life care issues (Mezey et al., 2000).

Reference	Frandsen CE, Dieperink H, Detering K, Agerskov H. Patients' with chronic kidney disease and their relatives' perspectives on advance care planning: A meta-ethnography. J Ren Care. 2021 Oct 7.
Study characteristics	
Study design	Systematic review n=7 studies included in the review: - 7 qualitative studies
Objective	To describe experiences of and perspectives on ACP among patients with chronic kidney disease (CKD) and their close relatives
Methods	*Data source* PubMed, Embase, Cinahl, PsycINFO, Scopus *Search period* <February 2021 *Language* English *Inclusion criteria* Qualitative studies using individual, dyad, or focus group interviews to explore the experiences and perspectives of adult patients with CKD (Stages 1-5) and their close relatives, in relation to ACP *Exclusion criteria* Studies about end-of-life care, articles not written in the English language, and non-peer reviewed literature
Population	Patients with chronic kidney disease and close relatives *Setting*

	Not reported *Sample size* Range 9-24 patients; 0-15 relatives
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Perspectives on ACP of patients with CKD and their relatives
Results	*Review question 2: When to start ACP* - To some patients and relatives, ACP was associated with being very sick and seriously ill, and therefore some felt that they were not sick enough for ACP conversations (Davison, 2006; Elliot & Gessert, 2016; Hutchison et al., 2017). - Patients and their families preferred ACP conversations to be ongoing, including discussions about treatment options and adjustments over time, and would have liked ACP to start earlier—before the start of renal replacement therapy (Davison, 2006; Goff et al., 2015; Sellars et al., 2018). An earlier start to ACP would inform them about the illness, treatment options, and prognosis, which would better prepare them to deal with their situation and make well-informed, shared treatment decisions (Davison, 2006; Goff et al., 2015; Sellars et al., 2018). - ACP is useful at all stages of CKD and that the goal of ACP differs at different stages. In the early stages, the goal of ACP is to inform and guide the patients and their families in life with CKD and the prognosis and treatment options. In the later stages, the goal is to clarify and support preferences for end-of-life. *Review question 5: Caregiver involvement in ACP* Trusting relationship and communication with healthcare professionals - ACP discussions were experienced as a key to building a trusting relationship with HCPs (Davison, 2006). The patients' and relatives' views and preferences were seen as important. Patients and relatives believed that the HCPs would like to know about their preferences and that the collaborative relationship with the HCPs would influence both how they were treated and the outcome of the treatment. These experiences were a powerful mechanism to stimulate and engage with ACP (Davison, 2006; Goff et al., 2015; Hutchison et al., 2017). - A close and supportive relationship with the HCPs and clear communication were vital to the ACP process and to sustain hope for both patients and relatives (Bristowe et al., 2015; Davison & Simpson, 2006; Goff et al., 2015). The way in which HCPs communicated had an impact on how comfortable patients and relatives were in the ACP process. The use of medical jargon led to distance, confusion, and misunderstanding (Davison, 2006; Goff et al., 2015). - Some patients and relatives had had bad experiences of ACP, compared to their expectations of ACP, because they felt that the HCPs did not take the time to listen to their preferences for medical treatment and find out about their everyday life with CKD (Davison, 2006; Hutchison et al., 2017). - Some patients and relatives were concerned that their treatment preferences could be overruled, despite having completed ACP documentation, and therefore they felt a loss of control (Davison, 2006). Furthermore, ACP was perceived as an emotionally challenging process, which could bring up taboos, entail opting out of treatment, or involve discussions about death (Davison, 2006; Hutchison et al., 2017; Sellars et al., 2018). Lack of or a bad relationship with HCPs were reasons for not wanting ACP (Goff et al., 2015; Hutchison et al., 2017). Information - Information about disease and prognosis provided clarity about higher mortality for people with CKD and made patients and families more realistic about the patient's mortality. This made them feel vulnerable but also allowed them to prepare for what awaited them in the future (Sellars et al., 2018). Relatives felt relieved because discussions about future treatment options

	were no longer their responsibility. They expressed that very different choices would have been made without an ACP process and that they would have acted in a way that was inconsistent with the patients' preferences (Hutchison et al., 2017). - Patients and relatives had a considerable need for information (Bristowe et al., 2015; Davison, 2006; Davison & Simpson, 2006). They experienced a need for additional information about illness, treatment, and prognosis. Being informed about illness and treatment impact on daily life and benefits and harms in life with dialysis or kidney a transplant could help them to make more informed choices (Davison, 2006; Davison et al., 2006). Information about the clinical condition and treatment options gave patients and relatives a sense of certainty about the present and the future and provided insight, which led to a higher degree of empowerment (Davison, 2006; Sellars et al., 2018). Some relatives experienced a lack of involvement and wished to be more involved, to support their sick relatives, and be a party to decision-making (Goff et al., 2015; Sellars et al., 2018). - Patients and their families were encouraged to be a part of ACP discussions (Bristowe et al., 2015; Sellars et al., 2018). They required that ACP be an individual and private conversation that would entail a clear and honest discussion about their prognosis and future (Goff et al., 2015). Patients and relatives needed help to cope with grief, fear, and denial when they received the diagnosis and treatment started (Davison, 2006; Sellars et al., 2018). The role of close relatives - The role of relatives varied (Davison, 2006; Hutchison et al., 2017). Some patients wished to be honest about their ACP preferences and wanted to share these with their families. They considered it of great value that the family knew about their preferences and life goals and could advocate for their preferences (Davison, 2006; Goff et al., 2015). Patients experienced isolation and hopelessness when they did not have the opportunity to involve and discuss ACP with their families (Bristowe et al., 2015). Patients without family were less likely to discuss ACP. Some patients did not want to be a burden to their family or did not want to upset them, and therefore they refused to be involved with ACP (Davison, 2006; Davison & Simpson, 2006). Some patients experienced pressure from their family to continue treatment or follow the family's preferences for treatment and, for that reason, some patients made decisions without involving their family (Sellars et al., 2018).

Reference	Hall A, Rowland C, Grande G. How Should End-of-Life Advance Care Planning Discussions Be Implemented According to Patients and Informal Carers? A Qualitative Review of Reviews. J Pain Symptom Manage. 2019 Aug;58(2):311-335.
Study characteristics	
Study design	Systematic review n=55 studies included in the review: - 55 reviews
Objective	How should end-of-life ACP discussions be implemented according to patients and informal carers?
Methods	*Data source* Cochrane Database of Systematic Reviews, Web of Science, PubMed, CINAHL, PsycINFO *Search period* 2007-July 2018 *Language* English *Inclusion criteria*

	Reviews of primary research, applied a systematic approach to searching literature, included information on ACP for adults at end of life *Exclusion criteria* Papers that focused on ACP with children, ACP for conditions that were not related to end of life (e.g. during temporary incapacitation from mental illness), and papers where it was not possible to identify patients' and carers' perspectives on ACP discussions
Population	Different patient populations and carers engaged in ACP: - 21 reviews focused on specific conditions: dementia (n=10), cancer (n=3), heart disease (n=2), chronic respiratory disease (n=2), renal disease (n=2), frailty (n=1), motor neuron disease (n=1) - Multiple conditions: 2 reviews (cancer/COPD/heart failure/CKD/end-stage renal disease; dementia/ frailty/brain injury) - People with intellectual disabilities: 2 reviews - Ethnic minority groups, without specific condition: 6 reviews - Homeless people, without specific condition: 2 reviews - Unspecified: n=22 *Setting* Not reported in detail *Sample size* Range 0-102 studies included in the reviews; sample size primary studies not reported
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Patients' and carers' perspectives on ACP discussions
Results	*Review question 2: When to start ACP* Optimum timing for ACP discussions - Patient and carers held a broad range of views on the optimum timing for ACP discussions. Some reviews indicated preferences for earlier initiation of discussions57 particularly among patients and carers facing dementia48,52,54,66 who recognized a time-sensitive need to discuss ACP while the patient retained capacity. Yet in a dementia context, optimum timing may depend on a complex array of factors including the readiness of patients and carers to begin ACP discussion, the acceptance of the diagnosis, the knowledge of patients and carers about dementia, and carers overcoming their own reluctance arising from fear, guilt, and lack of knowledge.26,54,66 People lacked knowledge about the terminal nature of dementia, and it was hard for patients with dementia to imagine future scenarios.53,67 - Reviews with other patient groups highlighted mixed perceptions, with some patients and carers preferring earlier discussion, and some preferring to wait until deterioration in health.39,45,46,55 Although some research indicated preferences for earlier discussion, other research found that patients may lack readiness to think about ACP and need time to cope with the initial shock of a diagnosis.68 For COPD and respiratory illnesses, a lack of knowledge among patients about the terminal nature of COPD could present a challenge to identifying when best to begin ACP discussions.61,65 Recurring ACP discussions - Some reviews showed that patients and carers recognized that ACP discussions may be recurring events rather than one-off exercises. This seemed to be particularly relevant in the

	context of heart disease44,59 where patients may wish to discuss their options at specific transitions in their care and revise their opinions on the use of implantable defibrillators. - Other reviews that did not focus on a particular health condition also found preferences for recurring ACP discussion.36,43,49,50,56,58 In long-term care, patients and carers wanted health care professionals to anticipate illness trajectories and use this to judge the level of information provided to them to help them make decisions.50 *Review question 5: Caregiver involvement in ACP* - Some reviews highlighted that ACP could be difficult if family carers were unwilling to engage.45,46 This was particularly apparent in the context of dementia and long-term care, where families often become proxy decision makers; they may face uncertainty around legalities and patient wishes and are often unprepared for involvement in ACP.47-51 Families and healthcare professionals may disregard the patient's ability to consent, or their preferences for end-of-life care50; family carers were also likely to be guided by healthcare professionals and may not have had conversations with the person with dementia.52,53 However, patients and carers would prefer all stakeholders to be involved in ACP discussion.54 - In the absence of ACP, people want close family members to make decisions on their behalf, believe that their family knows their wishes, and do not want to burden their families, but family members often do not know their relative's wishes and experience considerable burden.78 Therefore, the primary benefits to patients and carers from ACP discussion may in some cases come more from reducing future stress on family members than preserving individual patient autonomy. - After considering patients' and carers' perspectives on ACPs, practice recommendations made by review authors highlighted a tension between standardization and flexibility. Some reviews called for better standardization of ACP practice.36,49,57,61,67 Many reviews recommended the need to approach ACP in flexible ways that respected patient and carer preferences. This included the acknowledgments that ACP is not a set of concrete skills but rather may require creative communication approaches, collaboration between different professionals, and the need to match the kind of ACP intervention to the individual patient's needs and circumstances, which all may be unique. These reviews were heterogeneous, including a range of health conditions, cultural groups, and populations.22,26,28,29,33,34,39,44,51,53,54,56,60,62,64,66,68,73,75 This means that there is a need to think very carefully about which aspects of ACP might benefit from standardization, and which should be more flexible and amenable to individualization. Any standardization of implementation processes in the delivery of ACP would need to reflect patients' and carers' preferences for discussions to be initiated by a professional with whom they have a good and knowledgeable relationship, rather than any particular role of professional defined in advance. In the context of dementia, ascertaining the views of people with dementia rather than reliance on proxies should be of primary concern.48 This meant that healthcare professionals would need more training in ACP processes and prognostic implications of dementia to be able to confidently discuss with people with dementia and their carers. Similarly, in long-term care settings, there was a need for clinicians to be able to recognize illness trajectories to be able to facilitate individualized ACP,50 and a need for ACP to include nonmedical issues.46

Reference	Keijzer-van Laarhoven AJ, Touwen DP, Tilburgs B, van Tilborg-den Boeft M, Pees C, Achterberg WP, van der Steen JT. Which moral barriers and facilitators do physicians encounter in advance care planning conversations about the end of life of persons with dementia? A meta-review of systematic reviews and primary studies. BMJ Open. 2020 Nov 12;10(11):e038528.
Study characteristics	
Study design	Systematic review n=24 studies included in the review: - 11 systematic reviews - 13 primary studies (9 qualitative research, 2 quantitative research, 2 mixed-methods)

Objective	To better understand the moral considerations that present physicians and nurse practitioners in long-term care and primary care settings with ethical dilemmas regarding ACP with patients with dementia and their family caregivers
Methods	*Data source* PubMed, Web of Science, PsycINFO *Search period* January 2005-August 2019 *Language* English, Dutch, French, German *Inclusion criteria* Reporting on empirical data; a population or an identifiable subgroup diagnosed with dementia; ACP in the context of a long-standing relationship between the physician, the patient with dementia and his/her relatives; care provided in long-term care and primary care settings; barriers to and facilitators of ACP on the part of the physician and described from various perspectives; studies emphasising moral considerations as a barrier or facilitator for the physician *Exclusion criteria* Studies about consent for research participation; ACP limited to drawing up an advance directive that is not brought to the attention of a physician; theoretical, legal and ethical issues that are not barriers to or facilitators of ACP for the physician; studies that exclusively consider advance decision making on euthanasia
Population	Physicians and nurse practitioners providing long-term care to people with dementia *Setting* - Long-term care: 2 studies - Nursing homes: 6 studies - Primary care: 7 studies - Community: 2 studies - Mix of settings: 7 studies *Sample size* - Range 4-49 studies included in the 11 systematic reviews; sample size primary studies not reported - Range 15-176 persons included in the 13 primary studies
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Physicians' moral considerations involving ethical dilemmas for ACP
Results	*Review question 2: When to start ACP* - Physicians regard timely initiation and a structural follow-up of ACP as beneficial for people with dementia, which indicates that barriers to implementation should be overcome. *Review question 5: Caregiver involvement in ACP* - Physicians aim to avoid adding emotional burden to the patient,1 3 8 9 21 31 33 35 and provide emotional support to family caregivers.2 8-10 12 34 These intentions will on the one hand

	motivate starting and conducting ACP conversations.2 6 9 10 12 34 On the other hand, fear of inducing anxiety or emotional harm may induce reluctance to start conversations about the EOL. - Family caregivers regard communication with and coordination of care by physicians in agreement with relatives as important conditions to achieve an EOL free from distress and suffering.1 3 8 15-17 21 33 34 36 The planning of care and EOL choices,1 6 8 10 11 22 for instance, concerning the place to die,1 9 are seen as important aspects of a good death. A facilitator of ACP is increasing patient's and family members' control over the dying process.13 A barrier for ACP is disregarding decisions agreed on due to families' poor understanding of how death happens, causing gaps between expectations and reality.10 - Long-term relationships with physicians facilitate ACP through better understanding of patients' needs, preferences and fears, and of family dynamics.1-3 8 9 35 38 Both long-standing relationships and a professional relationship that is characterised by continuity, intensity and trust among all involved,2 11-13 16 17 23 35 can lead to acceptance, understanding and sincerity.1 When the physician-family relationship lacks trust,13 15 38 physicians note passive avoidance or even reluctance on the side of the family to be involved in ACP.10 11 16 This may also appear when there are different views between family caregiver and nursing staff. Additionally, a strong family attachment,1 21 23 35 and an involved family caregiver who encourages the patient, facilitate physicians, whereas a family-patient relationship lacking empathy and warmth serves as a barrier for physicians to take the initiative.1 8 9 23 35 - Respect cultural, spiritual and religious beliefs. Family and professional caregivers holding different religious, spiritual and cultural beliefs regarding practicing ACP is a barrier to ACP.8 9 16 23 32 34 35 - When a family caregiver's view appears to conflict with the patient's own wishes, whether previously expressed or currently experienced, physicians perceive this as a serious barrier to ACP and hesitate to make decisions at the EOL.1 8 11 16 21 35

Reference	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.
Study characteristics	
Study design	Systematic review n=9 studies included in the review: - 9 qualitative studies
Objective	To systematically search and synthesize qualitative studies exploring the perspectives of older people living in long-term care facilities and of their family members about ACP discussions
Methods	*Data source* PubMed, CINAHL, PsycINFO *Search period* January 2000-November 2015 *Language* English *Inclusion criteria* Studies with a study population including older people (age >65 years) living in long-term care facilities (including nursing homes and care homes) and/or their family members; qualitative studies or mixed method studies including a qualitative component; studies whose main aim included exploring participants' opinions and attitudes about ACP discussions *Exclusion criteria*

	Studies with a study population including only people younger than 65 years old; studies with a study population including only people living at home or hospitalized; studies addressing only the completion of advance directives (including living wills and lasting power of attorney) but not ACP discussions; studies published in book chapters, dissertations, and abstracts
Population	Older people living in long-term care facilities and family members *Setting* - Long-term care facilities: 5 studies - Long-term care facilities and other settings (i.e. community center, acute geriatric ward, medical oncology ward, palliative care unit, home services for older people): 4 studies *Sample size* Range 3-38 elders; 0-33 family members
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Opinions or attitudes of older people living in long-term care facilities and of their family members about ACP
Results	*Review question 1: For which persons should ACP be initiated* Effectiveness data on the specific study population older people living in long-term care facilities is not extracted; these data are incorporated in other included effectiveness review on ACP in nursing homes. *Review question 2: When to start ACP* - Some elders and family members believed that ACP would be initiated gradually15,18 and sensitively18 in the context of routine care.16 They also believed that ACP would require more time and attentiveness from health care professionals than was typical during a visit.16 Many elders and family members stressed that ACP discussions should take place at “the right time”, but opinions about “the right time” varied. Some stated that discussions should start early (i.e. before the onset of serious health problems or cognitive impairment)16,18 or “as soon as possible”,23 while others wanted to postpone these types of conversations until the patient’s health deteriorated.23 Regarding ACP conversations in long-term care facilities, some family members believed that it should take place early,18 while others believed that it would be somewhat overwhelming to have those conversations so soon after admission20 since it would be emotionally difficult.23 *Review question 5: Caregiver involvement in ACP* - Both residents and family members had scarce or incomplete knowledge about ACP and advance directives, even in countries in which ACP is well recognized by law. - Several studies reported that family members’ attitudes toward EOL care decision-making varied and that they were influenced by both their trust in healthcare providers and family dynamics.21 Most family members preferred shared decision-making with the staff,22,23 while others found it acceptable for the staff to make the decisions as long as the family members were informed.23 Some relatives appeared to be used to taking over decision-making and organizing most of the residents’ matters,22 while others felt burdened by decision-making,21,22 especially when they did not know the residents’ wishes.22 Some elders and family members reported that they did not proceed with ACP due to trust that physicians would respect the patient’s wishes or would do the “right thing” related to the patient’s EOL care.19,21 - Studies included in this review showed consistently that even if family members’ positions about decision-making varied widely, most of them preferred to take part in shared decision-making. Shared decision-making gave them an opportunity to be guided and advised by health

	care professionals and thereby feel relieved from the burden of decision-making. On the other hand, this review disclosed that this need for advice and guidance on EOL issues is often unmet. - According to family members, the main barriers to ACP were dementia/lack of cognitive capacity,15,18 reluctance of some residents to discuss EOL issues,18 resident's personality,15 and avoidance of the discussion altogether.15,21 In fact, while ACP could be experienced as a form of release for some family members,17,22 for others initiating conversations could be uncomfortable or burdensome for several reasons.17,21–23 Some family members reported experiencing ambivalence since they considered the decision-making process to be representative of either "letting go" or "letting (their loved one) suffer".17 Other family members wanted to spare their loved one from dealing with this emotional issue or feared that their loved one would react with blame, believing that the family members were waiting for him/her to die.21 Interestingly, the fear of future feelings of regret may have been both a barrier and a facilitator to family involvement in ACP.21 Family members of residents with dementia reported that barriers to ACP included the following: not recognizing the importance of ACP until their relative's cognitive impairment prevented them from having the discussion; never having considered the need to have ACP conversations; and the residents' denial of their dementia diagnosis.15 - Healthcare professionals who knew the elder well were considered the ideal group of people to initiate ACP,16,22 and family members would appreciate if the staff took the initiative23 and organize regular meetings.22 Elders and their families desired a personalized approach by healthcare professionals, within a relationship based on trust, respect, and sensitivity.

Reference	Nimmons D, Hatter L, Davies N, Sampson EL, Walters K, Schrag A. Experiences of advance care planning in Parkinson's disease and atypical parkinsonian disorders: a mixed methods systematic review. Eur J Neurol. 2020 Oct;27(10):1971-1987.
Study characteristics	
Study design	Systematic review n=27 studies included in the review: - 12 quantitative studies - 15 qualitative studies
Objective	To explore the experiences of ACP for people with Parkinson's disease or atypical parkinsonian disorders, their family carers and healthcare professionals
Methods	*Data source* Medline, Embase, PsycInfo, AMED, EBSCO CINAHL *Search period* <April 2019 *Language* English *Inclusion criteria* Papers exploring the use, experiences and attitudes towards ACP in Parkinson's disease and/or atypical parkinsonian disorders; studies involving participants who developed dementia after being diagnosed with Parkinson's disease or atypical parkinsonian disorders *Exclusion criteria* Review articles, commentaries, conference proceedings, studies where dementia with Lewy bodies was the primary diagnosis

Population	People with Parkinson's disease and/or atypical parkinsonian disorders (progressive supranuclear palsy, multiple system atrophy and corticobasal degeneration), family carers and healthcare professionals *Setting* Not reported *Sample size* Range 0-246,625 people with Parkinson's disease; 0-52 family carers; 0-125 healthcare professionals
Intervention	ACP
Comparison	People without Parkinson's disease or not applicable
Outcome measures (applicable to our review)	The use, experiences and attitudes towards ACP in Parkinson's disease and/or atypical parkinsonian disorders
Results	*Review question 1: For which persons should ACP be initiated* Effectiveness data on the specific study population with Parkinson's disease is not extracted; these data are incorporated in other included effectiveness reviews on ACP in multiple populations. *Review question 2: When to start ACP* - Timing of ACP discussions was covered in 16 studies (qualitative and quantitative). Studies varied in their approach to delivering information and the amount given. In early disease stages, patients often did not want this information due to fear, denial, hope of a cure, wanting to live a normal life or to focus on symptom control [5,6,23,25,26,35,40,43]. On the other hand, some patients and family carers wanted to know about prognosis and the disease trajectory early. In a large survey of patients with PD in Oregon, approximately half wanted to discuss advance care documents early, although some patients wanted to discuss life expectancy, end-of-life care planning and end-of-life care options (e.g. hospice) when their disease worsened. A small number felt these issues should never be discussed [35]. Carers were often prepared for ACP discussion earlier than patients [32]. Important factors influencing attitudes towards ACP discussions included patient understanding and personal definition of ACP, information on the prognosis and choices available, level of education and desire to direct their own care, as well as care partners taking an active role [23,35]. - Healthcare professionals from a range of disciplines involved in caring for patients with PD believed that ACP should be discussed early [5,28,31], as the risk of developing dementia and cognitive issues increases with time [31,39]. However, it was suggested that neurologists do not discuss ACP at diagnosis as the focus at that point is to optimize medical treatment [5]. In a qualitative study of 30 HCPs (doctors, nurses and therapists), HCPs highlighted that it is better for patients and families to be clear from the outset that the disease is incurable but they were divided when to initiate further discussions. Opinions ranged from at diagnosis to advanced disease, highlighted by a number of triggers indicating decreasing effectiveness of treatment. Others suggested an individualized approach, responding sensitively to cues from the patients to initiate the conversation [31]. - It can be difficult, however, to gauge when patients are ready for these discussions due to the above individual patient factors, and as some patients and carers may be ambivalent themselves [32,33]. In addition, due to the high variability in disease progression some patients will never develop certain symptoms, e.g. dysphagia, and ACP discussions at diagnosis or early in the disease course would therefore be inappropriate [6]. This uncertainty often meant that discussions occurred in response to a crisis, e.g. hospital admission [31,34,36], at the start of cognitive decline or the terminal phase [15,28]. The need for discussion therefore depends on the individual and disease characteristics including diagnosis, symptom progression, age, values, personality, attitude, disease state and care needs [6,27,32].

	- A diagnosis of atypical parkinsonian disorder was more often reported as a trigger to discuss ACP [6,38]. These patients experience rapidly progressive symptoms compared to people with PD, and have been reported to be more informed about prognosis and ACP [6]. - There was variability in how these ACP discussions were initiated and conducted between studies, but overall it was concluded that family carers should be present [35] and physicians should initiate assessments of readiness for ACP discussions at least annually, advocating for a palliative care approach with team-based and whole-person care tailored to the individual [23,32]. The most common situation when ACP was discussed was during a crisis, e.g. a hospital admission, and challenges and situations presented by patients were often used as opportunities to initiate ACP. - As there is no clear time when ACP discussions should occur, they need to be individualized and tailored in timing, content and approach. *Review question 5: Caregiver involvement in ACP* - A lack of information on parkinsonian disorders, palliative care and ACP was consistently identified as a barrier by patients, family carers and HCPs. In addition, patients and carers often did not know how to initiate ACP discussions [29]. Many patients and family carers felt they were not given enough information on disease progression and prognosis, and wanted this earlier [6,25,29,30,32,33]. However, some appeared not to want any information at all. The latter group presents the greatest challenge to ACP. It is important to respect individuals' wishes, but a basic understanding about symptom progression and palliative care should be encouraged, with opportunities to revisit the topic over time. They should also be aware of why it is important to plan in advance and be provided with adequate information about future options, e.g. CPR. - Some people felt they were not fully informed regarding prognosis and progression. To improve this, HCPs should invite patients to discuss planning ahead early and regularly, as willingness to discuss future plans fluctuates, e.g. when symptoms change. They should provide information to patients and carers early so they can make informed decisions about their future. Regular meetings would avoid overloading them and allow more difficult topics to be introduced. This would result in more meaningful ACP discussions. - Some carers expressed a desire for more support and guidance on ACP from HCPs for themselves [24,25,30,32,34]. Carers should also be offered support; carers and patients have separate and individual needs, which should be addressed. This would help to alleviate their burden, positively impacting on them and those they care for. - The burden felt by carers was reported by several studies, and it was felt that this often went unrecognized [5,24,25,27,28,30,32,34]. Whilst carers were seen as facilitators in ACP, particularly when they played an active role, some HCPs commented that emotionally burdened carers could instead be a barrier [5,23], particularly when the wishes of people with PD differed from those of the carer or there was a lack of discussion of wishes between the carer and person with PD previously.

Reference	Petriwskyj A, Gibson A, Parker D, Banks S, Andrews S, Robinson A. A qualitative metasynthesis: family involvement in decision making for people with dementia in residential aged care. Int J Evid Based Healthc. 2014 Jun;12(2):87-104.
Study characteristics	
Study design	Systematic review n=16 studies included in the review: - 15 qualitative studies - 1 mixed methods study
Objective	To appraise existing knowledge about family involvement in decision making for people with dementia living in residential aged care
Methods	*Data source* CINAHL, Medline, PsycInfo, ISI Web of Science, PubMed, Embase, APAIS-Health, Ebsco Health Source, Sociological Abstracts, Proquest Digital Dissertations, PsycArticles, Proquest academic research library, Google Scholar, Mednar, Caresearch

	Search period 1990-2013 *Language* English *Inclusion criteria* Dementia was not restricted to any specific diagnosis, stage or severity; studies including at least 70% participants with dementia in residential care (nursing home); no participant age limit; care staff included any staff providing care to people with dementia in residential aged care (i.e. nurses, personal carers, assistants in nursing, therapies staff, allied health staff, physicians) *Exclusion criteria* Other sites of care than residential care, including assisted living
Population	People with dementia living in residential aged care, families and care staff *Setting* Residential aged care (nursing home) *Sample size* Range 0-35 people with dementia; 0-39 family carers; 0-12 healthcare professionals
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Family involvement in decision making for people with dementia living in residential aged care
Results	*Review question 2: When to start ACP* - One strategy to improve engagement between staff and family members would be the early consultation between these groups (and the resident themselves where possible) through in-depth meetings upon resident's arrival to the residential care. Such meetings could ascertain the family member's knowledge of dementia and their communication preferences, resulting in more targeted responses. - In addition, the initial meeting could elicit family members' preferences for future meetings or participation in case conferences (e.g., timing, scheduling, frequency, length, etc.), and how information sharing between family and staff would best take place (e.g., discussion of family preferences, staff availability, who else should be involved in case conferences, etc.). Subsequent follow up meetings with family members may then review preferences or needs for communication and information-sharing, given that these can change over time. *Review question 5: Caregiver involvement in ACP* - The role families take in decision making and how they acquire it, their degree of involvement, and how they perceive this role can vary. This appears to be associated with their opportunities for involvement and can lead to quite different courses of action in their decision making. - The relationship between staff and family and the extent to which staff discuss with and involve family varies. Good information, communication and relationships between staff and family help to facilitate shared decision making; poor communication and relationships, conversely, can negatively impact shared decision making. - Trust is important in family involvement in decision making. - The quality of staff-family relationships and communication varies and depends on a range of interpersonal and contextual factors, including staff attitudes and behaviours, extent and quality of staff-family interaction, contextual factors such as the nursing home environment, and

	cultural factors. It is vital that these factors are considered, as communication and relationships between staff and families impact on the capacity of family members to partner with staff in both the decision making process, and in responding to the decisions that are subsequently made. - Family decision makers have variable knowledge about the wishes of the person with dementia. The values, attitudes, and beliefs of the family are vital to decision making. Families can differ considerably in their approach to decision making, as multiple factors shape what, and how, decisions are made. Decision making is affected by the family's understanding and knowledge of their relative's condition and its progression, concerns regarding quality of life, and other values and beliefs. - Participation in decision making has important implications for caregivers. Family caregivers face challenging and difficult decisions in their surrogate role. Caregivers may also need to make decisions with inadequate information, or incomplete or conflicting understandings of illness and death. The decision making role can be positive but also stressful, challenging, and emotionally strained. Family face difficult decisions, sometimes without adequate or clear information or ideas. Conclusion: - It is clear that family involvement in decision making for people with dementia in residential care is challenging. A number of practice implications can be identified. Surrogates value their role in decision making and mostly want to maintain this role in the residential setting, although their preferred involvement varies. Family decision makers, whether formally or informally designated, should be identified and their preferred level of involvement ascertained by staff. Involvement should then be discussed and negotiated by staff and family. - Time spent with staff, particularly physicians, and discussions with staff are important for families to participate successfully in decision making. Effective communication is crucial, and needs to be developed and supported. Regular opportunities (both formal and informal) for information sharing should be provided as a matter of course in care provision, with the frequency and regularity of contact negotiated between staff and families. Supplementary information to support decision making, such as information about illnesses and their trajectories, treatment options and prognosis, and ACP and advance directives should be provided as the need arises, as this information is important in decision making. - Attention to effective communication processes is warranted, as it is clear that ambiguous communication and relationships are detrimental to family members' ability to participate effectively. - Decision making can be stressful and emotionally challenging for family, who face difficult decisions and can experience uncertainty and guilt. Support for caregivers in this role is important. Staff play an important role for families and relationships with them are a vital part of the family experience of care. Regular contact between staff and families would contribute to greater support for these family decision makers, and support and information for staff regarding how to best support family members would assist them. - Surrogates use a range of information from various sources in decision making. Knowledge of their own and their relative's life story, values, and wishes, and the information they receive about the illness, treatment options, and their relative's quality of life affect decisions. Adequate opportunities for sharing this information by all concerned parties need to be provided and supported. This may be supported by more regular scheduled contact between family decision makers and staff, as well as thorough admission processes which allow for discussion of care plans and wishes.

Reference	Silies KT, Köpke S, Schnakenberg R. Informal caregivers and advance care planning: systematic review with qualitative meta-synthesis. BMJ Support Palliat Care. 2021 May 5:bmjspcare-2021-003095.
Study characteristics	
Study design	Systematic review n=57 studies included in the review: - 5 quantitative studies

	- 45 qualitative studies - 7 mixed methods studies
Objective	To explore the experiences and attitudes of informal family caregivers, and their knowledge, regarding ACP
Methods	*Data source* MEDLINE, PsycINFO, CINAHL, Cochrane Library *Search period* <October 2020 *Language* English, German *Inclusion criteria* Population: caregivers defined as family members, spouses or other loved ones/persons of trust, mostly named as primary caregiver by care recipients, and involved in daily care or taking over major responsibility for adult care dependent persons; Setting: long-term care at home or residential facilities (e.g. nursing homes), hospitals or outpatient clinics; abstract available *Exclusion criteria* Population: caregivers of children/adolescents, of persons with psychiatric conditions or congenital intellectual disability, of persons wishing to commit assisted suicide; Setting: emergency situations, intensive care unit; Intervention: prevalence of ACP documents only without referring to a communication process; Outcomes: no specific caregiver outcomes reported, or caregivers' perspectives not explicitly reported in the results section; Design: books, book chapters, reviews of books/book chapters, study protocols, editorials, comments, legal issues, case reports
Population	Caregivers of different populations of adult care-dependent persons (care recipients) *Setting* - Long-term care (several settings of permanent residency in professional care): 11 studies - Medical setting (hospitals or outpatient medical centres as recruiting facilities): 23 studies - Community setting: 15 studies - Mixed settings or not reported: 8 studies *Sample size* Range 4-1006
Intervention	ACP or description of a communication process on a person's life goals and wishes for future care
Comparison	Not applicable
Outcome measures (applicable to our review)	Experiences, knowledge, attitudes or behaviour related to ACP interventions expressed by caregivers, as well as anticipated needs, wishes or expectations of caregivers, if related to ACP
Results	*Review question 2: When to start ACP* - The right time point of ACP initiation is subjective and difficult to find out.20 22 29 31 34 58 On the one side, ACP should be initiated when the care recipient is still able to participate fully in reflecting, pronouncing and deciding on preferences.13 17 22 23 26 31 34 36 39 43 46–48 55–58 On the other side, ACP is strongly connected to death and dying. The motive of focusing on the present, not giving up, maintaining hope and denial as an effective coping strategy are reasons for omitting ACP, often connected to the wish to protect the care recipient. Especially

	dementia poses a challenge for the right timing, as the decision-making capacity of the care recipient decreases stepwise and irrevocably, whereas health crises and death may still be deemed to be far away. - If ACP is broached in a non-confrontative manner and repeatedly, caregivers and care recipients can decide to engage in their own time.29 39 48 56 64 The frequency of ACP processes is not fixed and should be individually tailored. Routinely established or preplanned meetings, as well as more informal opportunities, are described positively.15 20 23 27 31 34 35 39 48 *Review question 5: Caregiver involvement in ACP* - HCPs need to assess whether the caregivers' individual conceptualisation of ACP or relational aspects pose barriers which must be addressed, or facilitators that can support engaging in ACP. A special focus when shaping the ACP intervention should be laid on families' culture in dealing with death and dying, and, in care recipients with chronic diseases, on lived experiences in the disease trajectory. A reasonable approach to strengthen ACP acceptance and thus care recipients' autonomy at the end of life could be to view family caregivers as experts and closely cooperate with them. On a meta-level, the principle of autonomy should be discussed as a multifaceted concept, taking individual as well as relational aspects into account. - How the ACP process is shaped in detail depends on the full range of all participants' reactions and preferences and is subject to the skills of the ACP facilitator. There is no 'one size fits all' model. Recommendable are the initiation of ACP by HCPs22 27 34 38 51 54, clarifying ACP conceptualisations and raising awareness through providing repeated opportunities. In addition to conversations, information using a variety of channels (written material, films, the internet), and specific to the health condition of the care recipient, supports the process.27 HCPs need to be equipped with sufficient time resources to be able to tailor ACP to the unique situation of their clients.23 34 39 47 55 This can be remedied if, for example, nurses are present, and physicians can be contacted if needed.39 The manner of 'broaching the topic' is intricately linked to communication style and attitude of HCPs. The communication about ACP should be performed in an honest and open, empathetic, compassionate, respectful and informative manner.14 16 23 25 26 33 34 39 44 53 55 Caregivers value an approach using scenarios or vignettes28 52 or other people's stories,58 instead of confronting care recipients directly with their own death. Relevant aspects should be explained clearly and understandably25 63 and adjusted to care recipient's level of cognitive impairment.34 55 Caregivers are also sensitive to the attitude of HCPs. They expect a caring attitude16 25 33 with an HCP who shows commitment to help,19 25 59 listens to the care recipient and to the family,15 34 55 honours the care recipient's person and wishes,26 34 53 56 and creates a trusting relationship.14 23 26 34 55 Caregivers occasionally feel that HCPs themselves are frightened of or avoid talking about difficult topics.41 47 Indeed, this does not create a comfortable basis for ACP conversations and challenges HCPs to constantly reflect on their own values and attitudes to be comfortable talking about it, develop a caring attitude and practise their communication skills. As most caregivers feel a strong desire to 'do the right thing' and end-of-life decisions are perceived as difficult, they feel the need to be supported and confirmed in their decisions. HCP should acknowledge this role, be sensitive to power differentials caregivers might perceive and treat them as partners whose knowledge of the care recipient is respected instead of disregarded. - Regarding life after ACP, HCP should focus on caregivers' adjustment to bereavement, supporting them to accept their decisions in retrospect and to develop new roles to prevent illness in caregivers themselves.

Reference	Voss H, Vogel A, Wagemans AMA, Francke AL, Metsemakers JFM, Courtens AM, de Veer AJE. Advance Care Planning in Palliative Care for People With Intellectual

	Disabilities: A Systematic Review. J Pain Symptom Manage. 2017 Dec;54(6):938-960.e1.
Study characteristics	
Study design	Systematic review n=14 studies included in the review: - 7 quantitative studies - 3 qualitative study - 4 mixed methods studies
Objective	To gain insight into what is known about the use and effects of ACP in palliative care for people with intellectual disabilities (IDs)
Methods	*Data source* PubMed, PsycINFO, Embase, CINAHL *Search period* <June 2016 *Language* All languages *Inclusion criteria* Describes empirical qualitative, quantitative, or mixed methods research; concerns people with ID who receive palliative care and/or their relatives and/or professionals or concerns people with ID who died non-acutely (after an identifiable period of illness) and/or their relatives and/or professionals; describes the use of ACP or elements of ACP such as physical, psychological, social, or spiritual matters in palliative care, and/or effects of ACP or elements of ACP on the quality of palliative care and/or quality of life *Exclusion criteria* Letters, editorials, comments, or congress abstracts; case stories that are not analyzed systematically; literature studies (although their reference lists were studied to identify relevant empirical studies)
Population	People all ages with ID, relatives, healthcare professionals, managers *Setting* - Residential care facilities: 8 studies - Community facilities: 1 study - Mix of settings: 4 studies - Setting not reported: 1 study *Sample size* Range 47-247 people with ID, 3-30 relatives, 10-255 healthcare professionals, 31-84 managers
Intervention	ACP
Comparison	Not applicable
Outcome measures (applicable to our review)	Perspectives on ACP

Results	*Review question 1: For which persons should ACP be initiated* Effectiveness data on the specific study population with ID is not extracted; these data are incorporated in other included effectiveness reviews on ACP in multiple populations. *Review question 2: When to start ACP* - Professionals were not prepared to discuss end-of-life issues with the patient because they believed the patient would not understand and they did not know who had the authority to tell the patient directly.24 Therefore, if ACP occurred, it was often acute as a consequence of problems that had arisen, instead of anticipating possible problems that could appear in the future.26 - Physicians preferred to discuss ELDs in a stable and calm situation, when emotions were under control and enough time could be spent on a sensible discussion.34 However, this was often not possible because of late diagnosis of the illness.24 *Review question 4: Communication with persons with intellectual and/or communication disabilities* - Professionals did not always recognize non-verbal symptoms or saw symptoms as part of the disability.24,32 The need for ACP is not so easy to detect in people with ID with milder disabilities.26 Multiple signals from different information sources and interactions between the patient, professionals, and family are needed to be able to identify people with ID who are in need of palliative care.40 This shows that ACP for people with ID is not a uniform process but will take different forms depending on the degree and complexity of the disability and vulnerability of the person with ID. Professionals should therefore use ACP as a flexible process depending on the needs and preferences of the individual and their relatives. - Involve people with ID in ACP discussions in practice. ACP focuses on person-centered care. Without asking the patients themselves about their views and preferences, it remains uncertain whether their wishes will be respected and whether the care provided will satisfy their needs.20,42,43 However, allowances need to be made for the fact that people with ID find it more difficult to understand the concept of death, and self-determination in end-of-life planning is less developed.44 *Review question 5: Caregiver involvement in ACP* - Professionals noted the importance of nurturing good relationships with the patient's family.25 Physicians believed that a good working relationship with relatives and other professionals was the most important factor contributing to an effective decision-making process.34 • There are no clear organizational policies on ACP, which can cause confusion and uncertainty among professionals and relatives, about tasks and responsibilities.24,33 Therefore, professionals should be informed about their role and tasks in discussing end-of-life issues and trained in talking about this with people with ID and/or relatives. In that way, professionals will be better prepared for discussing end-of-life issues with people with ID and/or their relatives and be more comfortable with this.15

Reference	Wendrich-van Dael A, Bunn F, Lynch J, Pivodic L, Van den Block L, Goodman C. Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. Int J Nurs Stud. 2020 Jul;107:103576.
Study characteristics	
Study design	Systematic review n=30 studies included in the review: - 19 reviews (163 unique articles) - 11 primary studies
Objective	To provide an overall examination of all the available quantitative and qualitative evidence on ACP for people with dementia
Methods	*Data source* PubMed, CINAHL Plus, SCOPUS, Social Care Online, Cochrane Library

	Search period <September 2018 *Language* English *Inclusion criteria* Systematic reviews of quantitative or qualitative evidence or primary research not included in one of the reviews; ACP with people living with dementia, family or informal carers or healthcare professionals; ACP with people living with dementia and/or carers *Exclusion criteria* Protocols and conference abstracts
Population	People with dementia, carers, healthcare professionals *Setting* Reviews: long-term care 6 studies, all settings 10 studies, mix of 2 or 3 settings 3 studies Primary studies: long-term care 5 studies, community 3 studies, hospital 2 studies, primary care 1 study *Sample size* - Range 4-67 studies included in the 19 systematic reviews; sample size primary studies not reported - Range 12-402 persons included in the 11 primary studies
Intervention	ACP
Comparison	Care as usual or not applicable
Outcome measures (applicable to our review)	- Effectiveness of ACP (e.g. care consistent with wishes, number of ACP conversations, number of ACP related written outputs, resource use) - Experiences, understanding, or perceptions of ACP
Results	*Review question 1: For which persons should ACP be initiated* Effectiveness data on the specific study population dementia is not extracted; these data are incorporated in other included effectiveness reviews on ACP in multiple populations. *Review question 2: When to start ACP* - Some carers and healthcare professionals stated that immediately post diagnosis would be a suitable time to discuss ACP, others argued that a person should be given some time to become familiar with the dementia diagnosis and some felt that a decrease in the general health status of a person with dementia (e.g. pneumonia, broken hip) would be the right point to initiate ACP. Ryan et al. (2017) described finding the right moment as a balancing act between an individual's understanding of the implications of a dementia diagnosis and their diminishing decision-making capacity. As well as routine discussions as part of doctors' appointments ACP can involve informal, spontaneous conversations. Recommendations for tailoring ACP to be suitable for people with dementia and their carers included, reflecting a commitment to personalized care, a recognition that ACP was likely to be an ongoing, repeated process over time, and communication approaches that fit with the style and level of the person with dementia. *Review question 5: Caregiver involvement in ACP* - Complex family dynamics can hinder ACP conversations, while a trusting relationship between carers and healthcare professionals can facilitate ACP conversations. The latter is especially important when the person with dementia is in the advanced stages of dementia. The quality of

	the healthcare professional-carer relationship depends on a range of interpersonal and contextual factors. How this can be assessed however, was not discussed in the evidence reviewed. Recent research argued that these supporting relationships help overcome difficult emotions such as anxiety and stress for carers of people with dementia (Parkinson et al., 2017). - Education and training were identified as important in preparing and enabling people to engage in ACP. Carers of people with dementia could also benefit from training on these themes, as well as education on life-sustaining treatment, the role of a surrogate decision maker, ACP and palliative and end-of-life care.

Bijlage 4. Risk of bias

Combes et al., 2019		
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?	No	
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?	Partial yes	
6. Did the review authors perform data extraction in duplicate?	No	
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?	Partial 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?	No	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	

16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

Dening et al., 2011		
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?	No	
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?	Partial yes	
5. Did the review authors perform study selection in duplicate?	Yes	
6. Did the review authors perform data extraction in duplicate?	No	
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?	No	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	

15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

Frandsen et al., 2021

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?	Partial yes	
6. Did the review authors perform data extraction in duplicate?	Partial yes	
7. Did the review authors provide a list of excluded studies and justify the exclusions?	Partial yes	
8. Did the review authors describe the included studies in adequate detail?	Partial 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	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	

14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Low**	

Hall et al., 2019		
Item	**Yes, partial yes or no**	**Explanation**
1. Did the research questions and inclusion criteria for the review include the components of PICO?	Partial 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?	No	
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?	No	
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?	Partial 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?	Partial yes	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	

13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

Keijzer-van Laarhoven et al., 2020		
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?	Partial yes	
7. Did the review authors provide a list of excluded studies and justify the exclusions?	Partial yes	
8. Did the review authors describe the included studies in adequate detail?	Partial 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	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	

12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Low**	

Mignani et al., 2017		
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?	No	
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	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	

11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	Yes	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

Nimmons et al., 2020		
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?	No	
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?	Partial yes	
8. Did the review authors describe the included studies in adequate detail?	Partial 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?	Partial yes	

10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Low**	

Petriwskyj et al., 2014		
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?	No	
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?	No	
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?	Partial 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?	No	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

Silies et al., 2021		
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?	Partial yes	
7. Did the review authors provide a list of excluded studies and justify the exclusions?	Partial yes	

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	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Low**	

Voss et al., 2017		
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?	No	
3. Did the review authors explain their selection of the study designs for inclusion in the review?	No	
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?	Partial yes	

7. Did the review authors provide a list of excluded studies and justify the exclusions?	Partial yes	
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?	Partial yes	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Partial yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Critically low**	

Wendrich-van Dael et al., 2020		
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?	No	

6. Did the review authors perform data extraction in duplicate?	No	
7. Did the review authors provide a list of excluded studies and justify the exclusions?	Partial yes	
8. Did the review authors describe the included studies in adequate detail?	Partial 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	
10. Did the review authors report on the sources of funding for the studies included in the review?	No	
11. If meta-analysis was performed did the review authors use appropriate methods for statistical combination of results?	NA	
12. If meta-analysis was performed, did the review authors assess the potential impact of RoB in individual studies on the results of the meta-analysis or other evidence synthesis?	NA	
13. Did the review authors account for RoB in individual studies when interpreting/discussing the results of the review?	No	
14. Did the review authors provide a satisfactory explanation for, and discussion of, any heterogeneity observed in the results of the review?	No	
15. If they performed quantitative synthesis did the review authors carry out an adequate investigation of publication bias (small study bias) and discuss its likely impact on the results of the review?	NA	
16. Did the review authors report any potential sources of conflict of interest, including any funding they received for conducting the review?	Yes	
OVERALL CONFIDENCE IN THE RESULTS OF THE REVIEW (high/moderate/low/critically low)	**Low**	