

UNO Symposium 2022

ADVANCE CARE PLANNING IN DE PRAKTIJK

Waarom zou je advance care planning willen doen?

18 mei 2022

Nienke Fleuren en Eefje Sizoo



Afdeling Ouderengeneeskunde



Disclosure belangen sprekers

	(potentiële) belangenverstrengeling
Nienke Fleuren	Geen
Eefje Sizoo	Geen



Wie zijn wij?



Nienke Fleuren, AIOTO ouderengeneeskunde
Project 'Anticipating Old Age'



Eefje Sizoo, SO-onderzoeker
Lijn zorg in de laatste levensjaren



Wie zijn jullie?

Verzorgende of
verpleegkundige?





Wie zijn jullie?

Arts of
verpleegkundig
specialist?





Wie zijn jullie?

Behandelaar?





Wie zijn jullie?

Cliënt?





Wie zijn jullie?

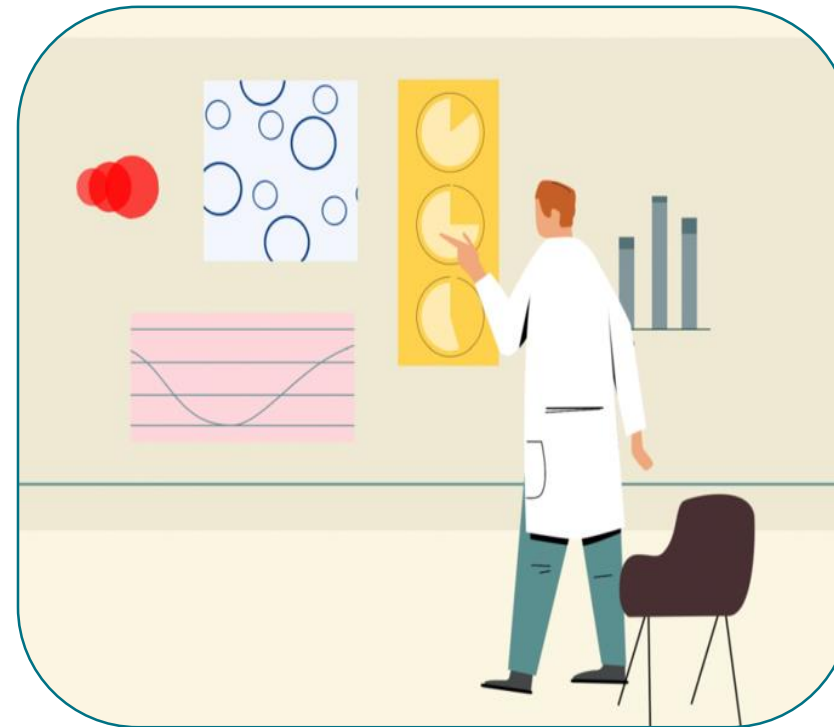
Kwaliteit of
management?





Wie zijn jullie?

Onderzoeker?





Wie zijn jullie?

Organisatie?





Wie zijn jullie?

Anders?





Advance care planning of proactieve zorgplanning

‘Proactieve zorgplanning is het proces van vooruit denken, plannen en organiseren. Met gezamenlijke besluitvorming als leidraad is proactieve zorgplanning een continu en dynamisch proces van gesprekken over huidige en toekomstige levensdoelen en keuzes en welke zorg daar nu en in de toekomst bij past’





Advance care planning of proactieve zorgplanning

- Verkennen
 - Hoe staat iemand in het leven?
 - Wat is belangrijk?
- Beslissen
 - Passende (anticiperende) afspraken maken





Waarom?

Waarom zou je advance care planning willen doen?

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Waarom?

Welke soorten 'goed' beogen we met advance care planning?





Systematisch literatuuronderzoek

➤ ACP

- advance care planning
- patient care planning
- advance health care planning
- advance medical planning

Publicatiedatum \geq 1990

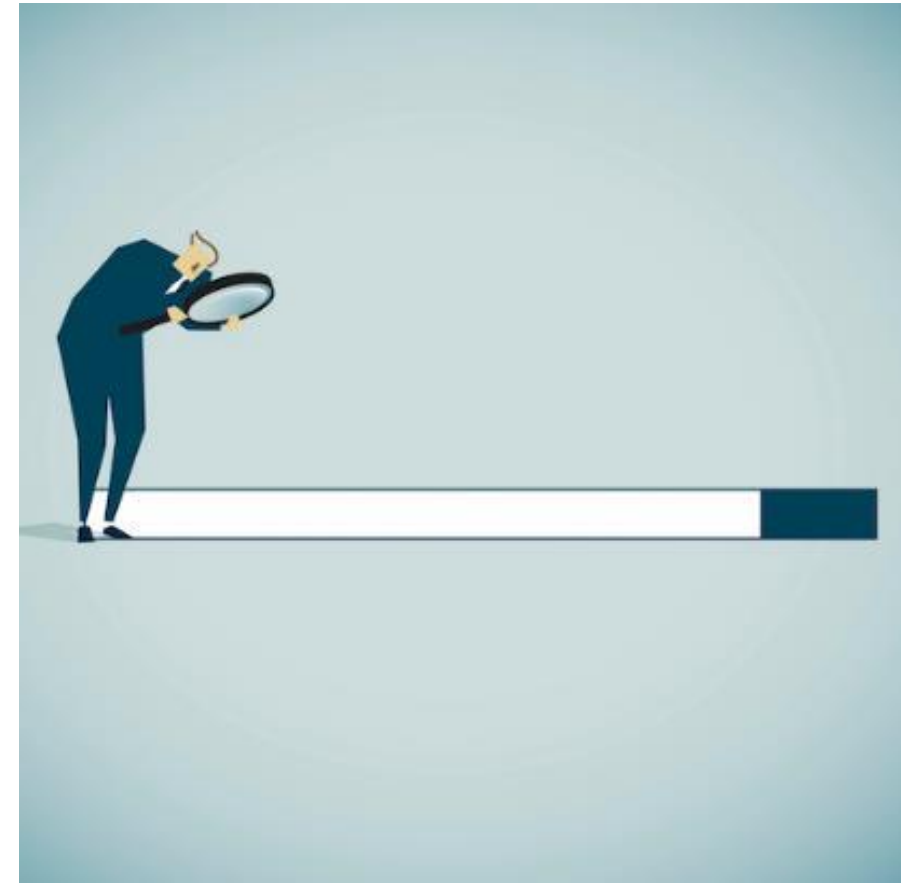
➤ Achterliggende gedachten

- goals [MeSH]
- ethics / ethical
- moral policy
- culture, cross-cultural comparison, cultural characteristics, cultural diversity, cultural competency
- spirituality
- religion / religiosity



Systematisch literatuuronderzoek

- PubMed: 4524
 - Embase: 1257
 - PsychInfo: 406
 - Cinahl: 526
 - Cochrane: 610
-
- 7323
- Na ontdebellen: 6497
 - In Engels/NL/Duits: 6273
 - Met samenvatting: 4402





Systematisch literatuuronderzoek

Inclusiecriteria:

- artikel over ACP (dus advance en over proces)
- achterliggende gedachten van ACP staan centraal
- minstens een doel genoemd in abstract, of reflectie op doel

Exclusiecriteria:

- ACP als onderdeel van meer complexe interventie
- uitsluitend over kinderen/adolescenten
- uitsluitend over psychiatrische aandoeningen





Inclusies (n = 183)

Kwalitatieve methode

- doelgericht selecteren
- analyse tot geen nieuwe informatie

Criteria

- soort artikel
- doelgroep

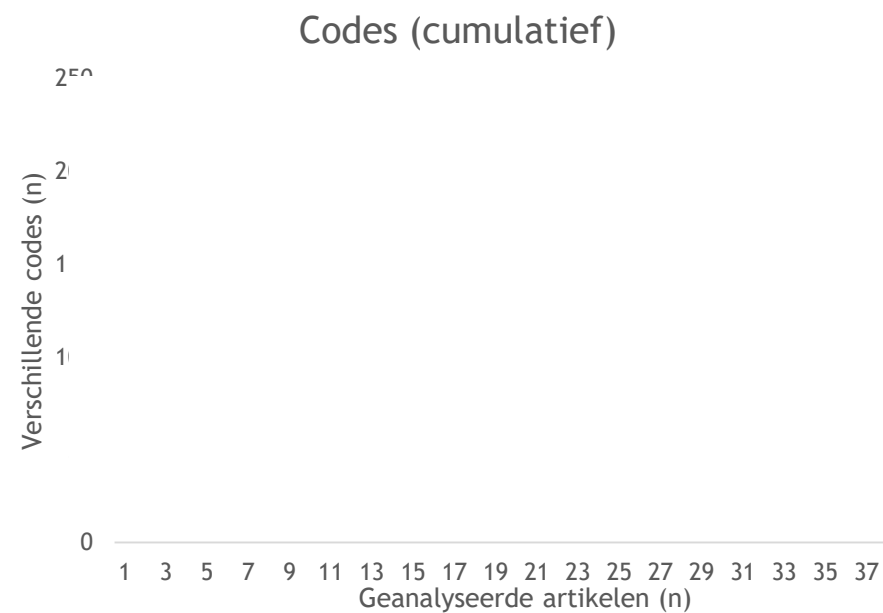




Analyse

start met 37 artikelen (= 20%)

- analyse genoemde doelen in ATLAS.ti





Resultaten

- 211 codes
 - 141 doelen
 - 70 bezwaren

Goals of ACP - literature review - version 4 - with abstracts of unselected articles - ATLAS.ti

Project Edit Documents Quotations Codes Memos Networks Analysis Tools Views Windows Help

P-Docs P 8: 008 - ref 2088 - cat 3 - Sudore 21 Quotes 8:21 Despite the limitations of adva. Codes C decrease conflict (11-0) Memos

Codes

Search

Name

- C more agreement between patient and health care provider
- C resolve ethical conflicts
- C shared experiences
- C social functions
- D avoid crisis decision making
- D decisions based on a set of considerations including context
- D decisions that are 'best' for all
- D decisions that are 'best' for the patient
- D decisions that are ethically sound
- D decisions that reflect patient preferences
- D document preferences / completion of advance directives
- D facilitate decision making
- D facilitate surrogate decision making
- D handling the risk of uncertainty / measured flexibility in responding to clini...
- D improve applicability of advance directives
- D improve decision making
- D making advance decisions
- F address needs of the family
- F appoint surrogate decision maker
- F describe role and duties of surrogate
- F determine who might help surrogate
- F emotional preparation of loved ones for death and loss
- F family empowerment
- F help family
- F increase awareness among young people of acting as a surrogate
- F increase family satisfaction with care
- F increase surrogate's confidence in decision-making
- F make family understand the patient's illness
- F more agreement among family members
- F prepare surrogate decision maker
- F protect and legitimize nontraditional kinship relationships
- F protect surrogates
- F reduce cost for patient/family
- F reduce depressive symptoms
- F reduce family stress / relief of family burden
- F reduce feelings of guilt and regret
- G acceptable / no serious adverse effects
- G has legal force
- G multifaceted
- G no alternative available
- G part of our way of life
- G serves patients and families well
- G thought of as a good idea
- H decrease emotionality of discussing end-of-life issues
- H facilitate decision making for health care professionals
- H physician empowerment
- H protect health care providers / decrease liability risk
- H reduce burden on health care providers
- H reduce conflict within healthcare team
- H remind health care professionals to value patient involvement
- H service provision
- H standardise practice / organizational maintenance
- M achieve a good death
- M avoid inappropriate use of resources

Preparing for End-of-Life Decision Making | ACADEMIA AND CLINIC

lead to better decisions and improved patient care (46). Perhaps because of an inherent understanding of the need for surrogates to base their decisions on multiple considerations, most patients want their loved ones to have leeway in decision making (4, 47–49).

A NEW OBJECTIVE FOCUSED ON PREPARATION FOR IN-THE-MOMENT DECISION MAKING

Given the problems with prespecified treatment preferences, we propose that the main objective of advance care planning be to prepare patients and surrogates to participate with clinicians in making the best possible in-the-moment decisions. Preparing patients for such decisions shifts the focus away from premature treatment decisions based on incomplete or hypothetical information and ensures that complex health care decisions are based on a more comprehensive set of considerations, including the current clinical context, shifting and evolving goals, and patients' and surrogates' needs. These factors must be synthesized by clinicians who, depending on the patients' and surrogates' desire to be involved in decision making, can provide specific recommendations and help patients and surrogates choose from among the available alternatives (13, 14, 39, 50). This approach does not preclude the completion of an advance directive but recognizes that it is just one piece of information to be used during in-the-moment decision making (51, 52).

The complexities of in-the-moment decision making for patients with advanced illness have been well recognized and have led to efforts that focus on preparing clinicians to help patients and surrogates navigate the process (14–16, 53, 54). Furthermore, system-level constraints on end-of-life care, including bed availability and access to palliative care-trained clinicians (55, 56), have led to efforts focused on increasing the palliative care workforce and providing care options better suited to patient needs (57–59). Both clinician- and system-level changes are needed to improve care for patients with advanced illness. However, whether patients and surrogates can or should receive preparation for in-the-moment decision making in addition to these efforts is less clear. Many substantial barriers impede patients' and surrogates' meaningful participation in preparation for in-the-moment decision making.

First, it can be difficult, if not impossible, for patients and surrogates to consider all of the implications of in-the-moment treatment decisions, including the substantial logistic, financial, and caregiver burdens that may occur (56). Second, many patients and surrogates do not want to think

complexities of medical decision making to them. Rather, clinicians cannot make high-quality in-the-moment treatment recommendations or guide patients and surrogates through the decision-making process without incorporating the patients' and surrogates' values and needs. Because these perspectives are highly individual, they can be provided only by the patient or surrogate. Given the extreme stress experienced by patients and surrogates (13) and the frequent absence of a previous relationship with the clinician at the time a decision must be made (63), patients and surrogates will likely be unable to communicate effectively without some form of preparation (2, 13).

Considering the specific challenges of in-the-moment decision making and how they contribute to stress, conflict, and decision-making burden for patients and surrogates can help to identify essential preparatory steps. Up to 76% of patients will be unable to participate in some or all of their own end-of-life decisions (8, 63–65). Surrogates who have made medical decisions for others report being unprepared (34) and describe the process as highly stressful (42, 66–68). Despite the limitations of advance statements of preference, surrogates find decision making more difficult if they do not have a sense of what the patient may have wanted, and in fact, they frequently lack this sense (34, 37, 68).

A major challenge is to help patients identify and articulate their values in a way that can guide decisions. Although it is impossible to know with certainty what a patient would have wanted, and although advance statements of preference should not be the sole consideration on which in-the-moment decisions are based, it is nonetheless possible for surrogates to use a fundamental understanding of the patients' values as one of the many considerations informing in-the-moment decisions (2, 13, 50). In contrast to eliciting preferences for specific interventions, what matters most to patients when thinking about health care decisions is the potential outcomes of treatment (33, 69–72). Therefore, asking patients to consider what outcomes they most hope for or fear can effectively identify their values in a way that can inform decision making (72–75). Asking patients to do this over time can help patients, surrogates, and clinicians recognize whether and how patients are either adapting to their illness or reaching a point where the burdens involved in fighting their illness become too great.

However, understanding patients' preferences is not enough. Surrogates may still need to make decisions that conflict with this understanding. This conflict greatly contributes to surrogate stress, especially if surrogates were not

- D facilitate decision making
- Z disadvantage: patients want surrogates to have leeway
- C increase communication / breaking taboos
- P prepare for future decision making
- D decisions based on a set of considerations including context
- F prepare surrogate decision maker
- Z disadvantage: difficult/impossible to consider all implications
- Z disadvantage: people avoid thinking about end-of-life / people consider it

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Resultaten

- 5 onderliggende doelen
 - Respecteren van individuele autonomie
 - Verbeteren kwaliteit van zorg
 - Versterken van relaties
 - Voorbereiden op het levenseinde
 - Verminderen van overbehandeling





Respecteren van individuele autonomie

- Zorgverlener informeert de patiënt zo feitelijk mogelijk.
- Patiënt bepaalt of hij/zij een beslissing neemt en zo ja, welke beslissing.

Valkuilen:

- Belooft te veel controle
- Ontkent dat besluitvorming betrokken en emotioneel is





Verbeteren kwaliteit van zorg

- Zorgverlener bepaalt welke aspecten relevant zijn en informeert de patiënt.
- Patiënt maakt een keuze uit de reële opties.
- Zorgverlener levert patiëntgerichte zorg.

Valkuil:

- ACP kan een moreel imperatief worden: patiënt **MOET** meedoen anders kan de zorgverlener geen goede zorg leveren.





Versterken van relaties

- Iedereen spreekt betrokkenheid uit: we willen allemaal het beste voor de patiënt.
- Dit versterkt het wederzijdse vertrouwen.

Valkuil:

- Belangen van het systeem gaan boven belangen van de patiënt





Vorbereiden op het levenseinde

- Patiënt kan angsten en zorgen bespreken.
- Patiënt voelt zich NU beter omdat hij/zij voorbereid is op wat komen gaat.

Valkuilen:

- Risico dat ACP gezien wordt als oplossing, terwijl de goede zorg nog moet beginnen.
- Wat de patiënt niet wil bespreken wordt niet besproken.





Verminderen van overbehandeling

- Bij ingrijpende of dure behandelingen met weinig mogelijke gezondheidswinst wordt geïnformeerd of de patiënt dit wel wil.

Valkuilen:

- Patiënt kan druk ervaren om behandeling te weigeren
- Tegennatuurlijk





Doelen en valkuilen

Onderliggend doel	Valkuil
Respecteren van individuele autonomie	Belooft te veel controle; gaat voorbij aan huidige belangen van patiënt; ontkent dat besluitvorming betrokken en emotioneel is
Verbeteren kwaliteit van zorg	Risico dat ACP moreel imperatief wordt
Versterken van relaties	Focus niet meer op de patient; risico dat kinderen het te vroeg overnemen
Vorbereiden op het levenseinde	Risico dat ACP gezien wordt als panacee
Verminderen van overbehandeling	Druk om behandeling te weigeren; wantrouwen in gezondheidszorg; tegennatuurlijk



Opdracht

- Bespreek de laatste casus waarin je iets van ACP hebt gedaan
- Welke doelen had je daarbij?
- Heb je je doelen bereikt?
- Wat maakt dat je je doelen wel of niet bereikt hebt?





Terugkoppeling

- Welke doelen kwamen aan bod?
- Zijn doelen bereikt?
- Wat was bevorderend?
- Wat was belemmerend?

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Terugkoppeling

- Wat neem je mee uit deze workshop?

