Advance care planning in dementia Delphi study

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Ethische beoordeling	Positief advies
Status	Werving nog niet gestart
Type aandoening	-
Onderzoekstype	-

Samenvatting

ID

NL-OMON23735

Bron
NTR

Verkorte titel
ACP in dementia

Aandoening

Dementia

Ondersteuning

Primaire sponsor: European Association for Palliative Care (EAPC) commissioned the task; Leiden University Medical Center, Leiden, the Netherlands is responsible for the research.
Overige ondersteuning: Leiden University Medical Center, Leiden, The Netherlands

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Consensus on a conceptualisation and recommendations for practice and policy and recommendations for further research on identified divergences.

We will ask the panellists to rate importance of specific issues concerning advance care planning in dementia on a 10-point scale where 0 = not important and 10 = very important. We will use the 5-point scale used previously in the EAPC dementia Delphi study, however with the numbers shown as well, thus representing a numerical scale with verbal descriptors. The response options are: ‘strongly disagree’ (1), ‘moderately disagree’ (2), ‘neither agree, nor disagree’ (3), ‘moderately agree’ (4) and ‘strongly agree’ (5) and a do not know option. The criteria for consensus from the EAPC dementia Delphi study apply, published as a white paper at

Toelichting onderzoek

Achtergrond van het onderzoek

Persons with dementia encounter diminished capacity for shared decision making about care and treatment in later stages of the disease. Therefore, in the early stages, conversations with professional and family caregivers about preferences for current, but also about future care may be encouraged. Involving family caregivers will help prepare and equip them for a central role in end-of-life decision making. Important goals and benefits of such proactive process called advance care planning or ACP, is that it can reduce uncertainty in decision making and facilitate providing of the preferred care. However, research has shown that in practice, advance care planning in dementia is often highly complex. Despite increasing research efforts, there is still little evidence how to best engage individuals with dementia and their family caregivers in advance care planning. There is clearly a need to synthesize what is known and to provide guidance based on evidence and on consensus among important stakeholders.

Based on evidence and consensus, we aim to conceptualise advance care planning in dementia in terms of its definition, elements, and any differences with advance care planning in persons with other diseases who are expected to retain capacity. Further, we aim to provide recommendations for optimal advance care planning in practice, for policy initiatives to promote advance care planning in dementia, and for areas that need research.

A multidisciplinary task force prepared initial guidance based on adaptation of guidance for those with capacity, extending it to dementia based on guidance on palliative care in dementia, literature and expertise within and around the task force. This is regarded a first, qualitative round of the Delphi study aimed at achieving consensus and highlighting any remaining divergence. This registration refers to the next rounds, a mixed quantitative and qualitative online survey among a wider Delphi panel of about 100 experts, in which we will also examine if personal and professional experience affects a consensus on guidance in advance care planning in dementia.

Doel van het onderzoek

We hypothesize that a consensus will be achieved on most items but on some items, ambiguity will remain. Although Delphi panellists are experts in the field, in view of the complexities around advance care planning in dementia, we hypothesize that personal and professional experience affects agreement with guidance and importance attached to domains. We expect that (a) medics (physicians, physician assistants and nurse practitioners) will prefer a figure with medically oriented care goals and find the domain of capacity more important than other professionals; further (b), those with dementia care experience personally would find advance care planning in dementia more important overall; finally (c) those with mainly expertise in advance care planning with no significant specific dementia expertise, will find advance care planning more important overall but will provide lower agreement and importance ratings regarding the adapted definition and conceptualisation of domains of divergence.

Onderzoeksopzet

Multiple online rounds, anticipating four or five are needed because of the complexity of the subject matter and because the extensive contents will be presented in batches.

Onderzoeksproduct en/of interventie

We will present statements and figures for evaluation, and the feedback from the panel as the main Delphi study instruments.

Contactpersonen

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Wetenschappelijk

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

Delphi panellists should:
- have expertise on advance care planning, dementia care, or advance care planning in dementia through practice, policy, research or clinical experience;
- be sufficiently capable to understand, read and write English;
- provide informed consent to participate in the Delphi study as indicated ahead of completing any online survey.

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

Experts will be advised not to participate if they self-identify as being overly emotionally involved in the topic. They will be excluded from participation if they do not agree that the data they provide will be collected, used and stored securely for this research.

Onderzoeksopzet

Opzet

Onderzoeksmodel:	Anders
Toewijzing:	N.v.t. / één studie arm
Blindering:	Open / niet geblindeerd
Controle:	N.v.t. / onbekend

Deelname

Nederland

Status:	Werving nog niet gestart
(Verwachte) startdatum:	20-09-2021
Aantal proefpersonen:	100
Type:	Verwachte startdatum

Voornemen beschikbaar stellen Individuele Patiënten Data (IPD)

Wordt de data na het onderzoek gedeeld: Ja

Toelichting

Data management considers restricted access. Any data sharing requests to the PI and the Leiden University Medical Center regarding deidentified (quantitative) data will be considered after the study has concluded and after publication of the main study results, and within the constraints of the informed consent which means we only offer access to data provided by panellists who agreed to reuse for further research.

Ethische beoordeling

Positief advies

Datum:	07-09-2021
Soort:	Eerste indiening

Registraties

Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

In overige registers

Register	**ID**
NTR-new	NL9720
Ander register	Medical Ethical Committee Leiden Den Haag Delft (METC LDD) : METC LDD number N21.105

Resultaten

Samenvatting resultaten
The approved study protocol, version 1.0 dated 16 June 2021, has been uploaded at the Open Science Framework (OSF) of the Center for Open Science, 7 September 2021 as part of an embargoed preregistration.

van der Steen JT. Developing guidance in addressing the challenges of advance care planning in dementia: an EAPC Delphi study. EAPC 17th World Congress online 6-8 October 2021. Abstract will be published in special issue of Palliative Medicine.