

A systematic review of the moral barriers and facilitators physicians encounter in advance care planning conversations about the end of life with people living with dementia and their relatives

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Review question

What barriers and facilitators do physicians encounter in advance care planning conversations about what matters at the end of life with people living with dementia and their relatives, in relation to moral considerations?

Searches

A systematic search of the PubMed, Web of Science and PsycINFO databases will be carried out for relevant material published from 2005 to 2018.

The search may be updated before publication.

Types of study to be included

Inclusion criteria:

1. Primary studies reporting on empirical data or systematic reviews;
2. Studies involving populations with a diagnosis of dementia (all), or involving an identifiable subgroup;
3. Advance care planning in the context of communication as part of a relationship between the physician/nurse practitioner, and the patient with dementia and relatives;
4. Long-term care settings;
5. Studies focussing on the barriers and facilitators to physicians/nurse practitioners in advance care planning conversations with people with dementia and their relatives, about what is important at the end of life (the barriers/facilitators may be considered from various perspectives).
6. Additionally, we will select the studies in which the moral considerations are considered to be a barrier or facilitator for this conversation.

Exclusion criteria:

1. Articles regarding consent for participation in research;
2. Advance care planning limited to the drawing up of an advance directive without involvement of a physician;
3. Articles regarding theoretical legal and ethical issues.

Condition or domain being studied

In this systematic review, we will focus on the moral considerations which are a barrier or facilitator to conversations about what really matters at the end of life.

Conversations about what is important at the end of life, in order to elicit personal preferences, are especially relevant in cases of declining capacity due to progressive cognitive impairment related to dementia. This systematic review will focus on the moral considerations that facilitate or impede physicians' conversations with people living with dementia and their relatives about the last phase of life.

These moral considerations may encompass reference to values or dilemmas, from the perspective of the physician or nurse practitioner, or from the perspective of the person with dementia, or their relatives.

Participants/population

Professional caregivers, limited to physicians and nurse practitioners, providing long-term care to people living with dementia, at home or in institutional settings.

Intervention(s), exposure(s)

Advance care planning: conversations between physicians and nurse practitioners, and people with dementia and their relatives, about what is important at the end of life, and the moral considerations that facilitate or impede these conversations.

Comparator(s)/control

No comparator.

Main outcome(s)

The moral considerations on the part of the physicians (or nurse practitioners), concerning the initiation and following up of advance care planning conversations about the end of life with people living with dementia and their relatives.

Moral considerations that may constitute a barrier or facilitator to advance care planning conversations will be considered, although subsequent qualitative analyses will result in a categorization of the moral considerations as the main outcome of the article.

* Measures of effect

Moral considerations will be categorized later as the main outcome of the review.

Additional outcome(s)

None.

* Measures of effect

Not applicable.

Data extraction (selection and coding)

Two researchers will independently screen the titles and abstracts of the records identified through the searches for those that potentially meet the inclusion criteria. The researchers will not be blinded to the studies. The full texts of these potentially eligible studies will then be retrieved and independently assessed for eligibility by two researchers. Any disagreements over the eligibility of particular studies will be resolved through discussion with a third researcher.

Once the studies for inclusion have been agreed, all full text papers will be analyzed for the moral considerations which may constitute a barrier or facilitator for advance care conversations on part of the physician. The codes will be derived inductively, and clusters of codes will be labeled to form main themes of moral considerations.

Further, to describe the included studies, from each study we will extract data on study goals, languages,

types of studies (primary study or systematic review), study designs and whether they are quantitative, qualitative or mixed-method studies.

In addition, for systematic reviews, also the scope of the review, the setting, the number of participants, and the type of data that is relevant to the moral considerations, including whose perspective is represented, will be recorded, together with an appraisal of the quality of the study.

Risk of bias (quality) assessment

To assess the quality of the primary studies, the Mixed Methods Appraisal Tool (MMAT, Quan Nha Hong, 2018) will be used by two researchers independently.

Strategy for data synthesis

Thematic analysis:

We will provide a narrative (descriptive) synthesis of an aggregate of the data we extracted from the included studies on moral considerations that may constitute a barrier or facilitator to advance care planning conversations on the part of the physician/nurse practitioner. We will not collect individual patient data.

After the articles to be included have been decided, these considerations will be coded inductively using the qualitative analysis software Atlas-ti version 7. The coding of all included articles will be carried out by the researcher who will be the first author. A second researcher will also code ten articles independently. The coding will be compared and discussed until agreement is reached. In the event of disagreement, a third researcher will adjudicate. The coded data will then be clustered to form themes and, if appropriate, also subthemes, concerning moral barriers and facilitators. The project team, with three to five members present, will then discuss the codes and emerging themes multiple times for relevance to the research question, on the basis of whether they are distinct and clearly described, and whether they fit with the data. The themes will be described in the results section of the review, and an overview of themes will be tabulated. The study characteristics extracted from the articles will also be described in a table.

Analysis of subgroups or subsets

None planned.

Contact details for further information

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Type and method of review

Intervention, Narrative synthesis, Service delivery, Systematic review

Anticipated or actual start date

01 June 2018

Anticipated completion date

01 December 2019

Funding sources/sponsors

Argos Zorggroep

Conflicts of interest

Language

English

Country

Netherlands

Published protocol

Stage of review

Review Ongoing

Details of final report/publication(s) or preprints if available

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Advance Care Planning; Communication Barriers; Dementia; Ethics; Family; Humans; Moral Obligations; Morals; Nurse-Patient Relations; Nurse Practitioners; Physician-Patient Relations; Physicians; Physician's Role; Professional Role; Terminal Care; Terminally Ill

Date of registration in PROSPERO

16 July 2019

Date of first submission

08 February 2019

Stage of review at time of this submission

| Stage | Started | Completed |
|---|---------|-----------|
| Preliminary searches | Yes | Yes |
| Piloting of the study selection process | Yes | No |
| Formal screening of search results against eligibility criteria | No | No |
| Data extraction | Yes | No |
| Risk of bias (quality) assessment | No | No |
| Data analysis | Yes | No |

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

16 July 2019

PROSPERO

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