

Background

- In the United States, 47.8% of nursing home residents are diagnosed with Alzheimer's disease and related dementias (ADRD)
- Most ADRD nursing home residents lack advance care planning (ACP)
- Lack of ACP can lead to unwanted or unnecessary, aggressive, and costly interventions
- ACP can reduce unnecessary hospitalizations and improve quality of end-of-life (EOL)

Purpose

Examine the evidence on what is known about when, who and how ACP is being conducted with residents with ADRD and their family caregivers in nursing home settings.

Methods

Literature review

Data bases searched:

- PubMed
- Scopus
- CINAHL
- Hand search

MESH terms:

- Advance Care Planning
- Advanced directives
- End of life decision making
- Dementia
- Alzheimer's Disease

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Methods, contd.

Literature review, contd.

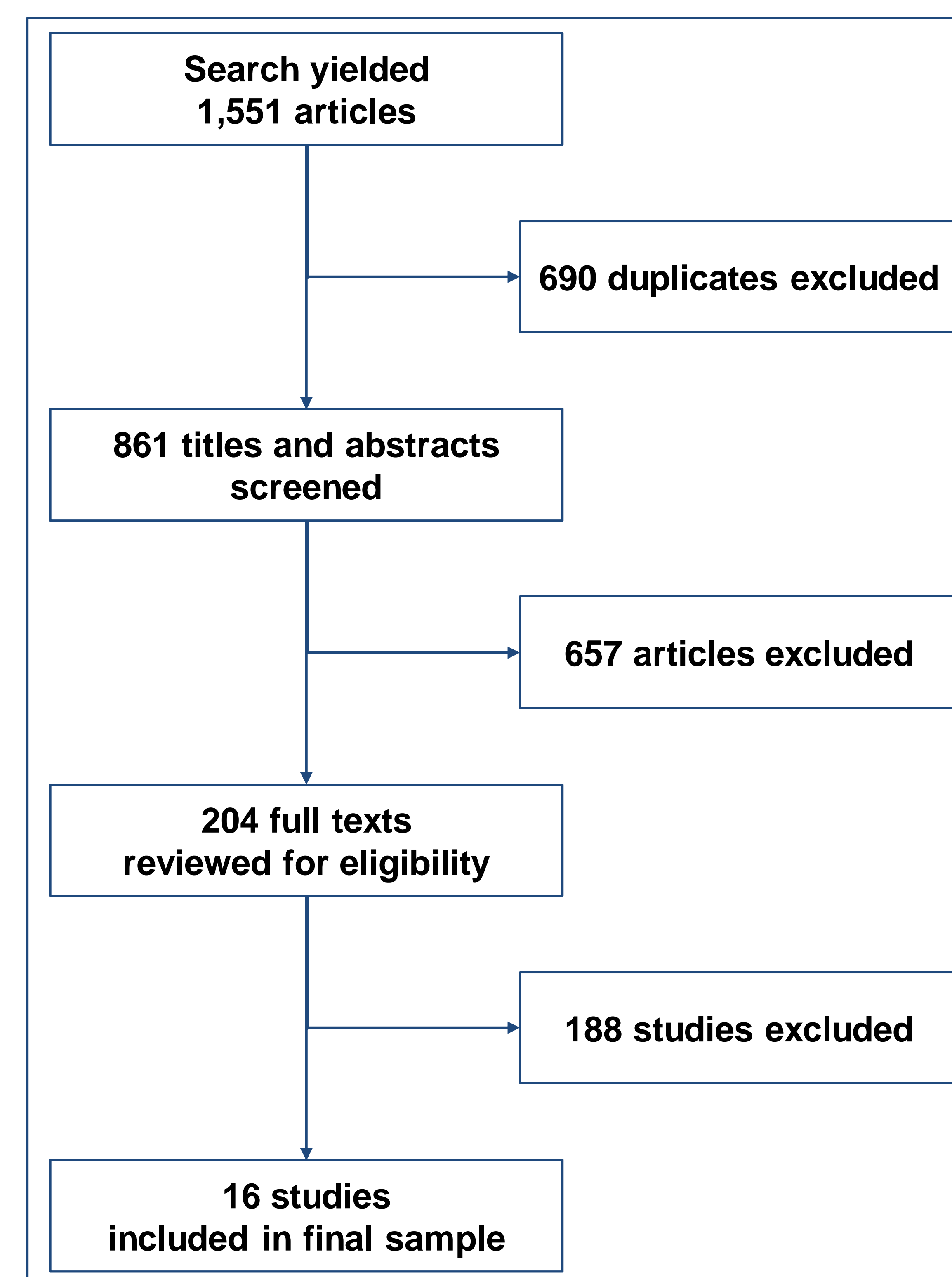
Inclusion criteria:

- Studies focusing on ACP process
- Published between 2011- 2021
- Full text, in English
- Including samples of residents with ADRD and/or their families
- In nursing home settings.

Exclusion criteria:

- Study limited to specific advance directive
- Other terminal diagnoses besides dementia
- Interventions did not address the process of ACP implementation (e.g., surveys or chart reviews)

PRISMA Chart



Results

Final sample included 16 studies

Origin:

- Europe (n=11)
- US (n=4)
- Australia (n=1)

Level of evidence (Johns Hopkins Evidence-based Practice Hierarchy of Evidence Guide):

- Level I (RCT, n=5)
- Level II (quasi-experimental, n=4)
- Level III (descriptive quantitative/qualitative, n=7)

Intervention Studies Only (n=9)

Study (year)	ACP in-person discussion	ACP Video+form	ACP Video + in-person discussion	Family caregivers only	Staff only	Both family caregivers and nursing home staff	Length of intervention
Brazil et al. (2017)	✓			✓			2 family meetings
Reinhardt et al. (2014)	✓			✓			1 family meeting
Ampe et al. (2017)	✓				✓		2, 4-hour workshops + homework
Goossens et al. (2020)	✓				✓		2, 4-hour workshops + homework
Wils et al. (2017)	✓				✓		2 education sessions, 4, 2-hour debriefing sessions
Livingston et al. (2013)	✓				✓		10 sessions
Saini et al. (2016)	✓					✓	Several sessions over 6 months
Mitchell et al. (2018)		✓		✓			1 session 12-minute ACP video
Hanson et al. (2017)			✓			✓	1 session 18-minute ACP video

- Majority (9/16) were intervention studies. Non-experimental studies (7/16) are not included in the table
- Majority (7/9) of the studies used in-person ACP discussions
- Only 2/9 studies included both nursing home staff and family caregivers
- Majority (6/9) had more than 1 session

ACP process

When – variable: at admission to facility (DNR status), with changes in residents' medical condition, during everyday conversations

Who – ACP education for staff alone, ADRD family caregivers alone, and staff and family together

How – ACP videos, structured family meetings, structured staff meetings (ranging from 1 to 10 sessions)

Conclusions

Major gaps found:

- Lack of ethnic and racial minorities in study samples
- Lack of consistent or systematic approach to conducting ACP in nursing homes
- Lack of clear roles in initiating ACP conversations
- Lack of staff knowledge and skills to conduct ACP conversations
- Family lack of understanding that dementia is a terminal illness