

## 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.

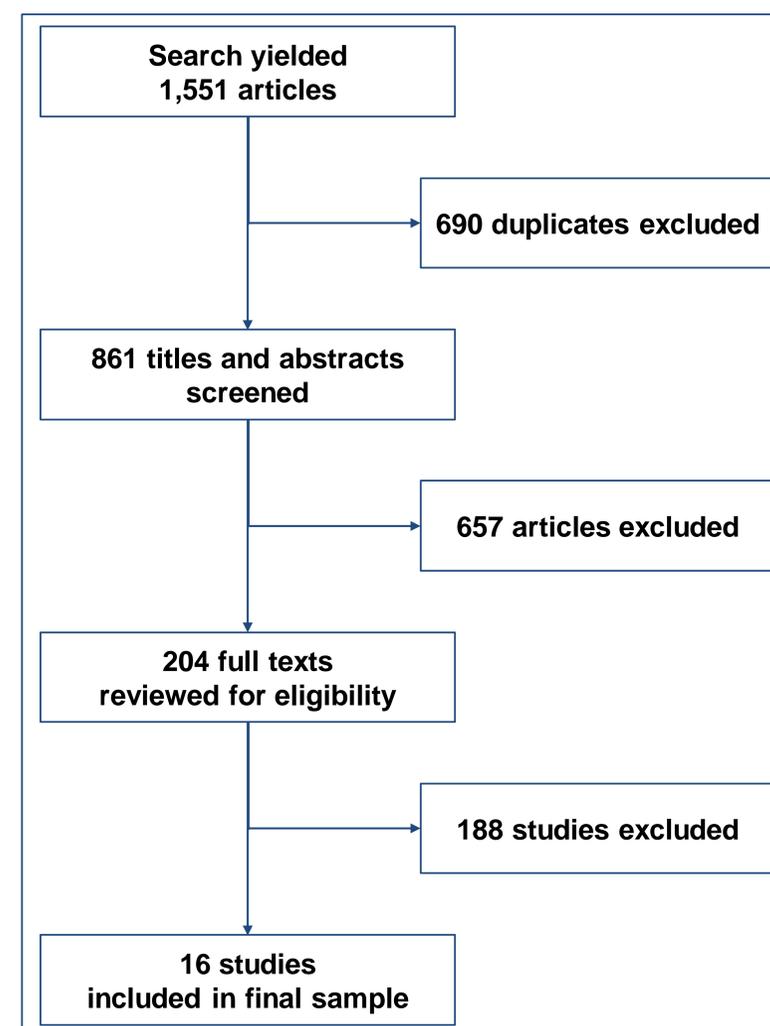
Inclusion criteria:

- 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