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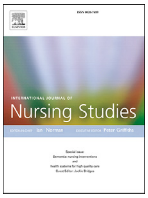

Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences

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ABSTRACT

Background: End of life care is often inadequate for people with dementia. Advanced care planning (ACP) has the potential to improve outcomes for people with dementia. The aim of this review is to establish the strength of the evidence and provide decision makers with a clear understanding of what is known about ACP for people living with dementia.

Design: Evidence synthesis including systematic reviews and primary studies. PROSPERO registration: CRD42018107718.

Data sources: PubMed, CINAHL Plus, SCOPUS, Social Care Online and Cochrane Library were searched (July 2018). No year limit applied. To be included, reviews had to evaluate effectiveness of ACP for people with dementia or report on views and experiences of ACP from the perspective of people with dementia, carers, or health and care professionals. Additional searches (September 2018) were conducted to identify recent primary studies not included in the reviews.

Review methods: Data extraction was undertaken by one reviewer and checked by a second. Methodological quality was assessed using AMSTAR-2 and Joanna Briggs Institute instruments by two authors independently. Outcomes were categorized and tabulated to assess effectiveness. Qualitative data was analysed using thematic synthesis.

Results: Nineteen reviews (163 unique studies) and 11 primary articles with a range of advance care planning definitions and of variable quality were included. Advance care planning was associated with decreased hospitalizations, increased concordance between care received and prior wishes and increased completion of advance care planning documents but quality of primary research was variable. Views of ACP for people with dementia can be clustered around six themes; 1) timing and tailoring, 2) willingness to engage, 3) roles and responsibilities of healthcare professionals, 4) relationships, 5) training and 6) resources needed. Diminishing decision-making capacity over time is a key overarching feature.

Conclusions: Advance care planning is acceptable for people with dementia and their carers and is associated with improved outcomes. Guidelines on which outcomes and which definition to use are necessary, as is research to test different approaches to ACP. Education on topics related to diminishing decision-making capacity is key to optimize advance care planning for people with dementia and their carers.

What is already known about the topic?

- Due to the neurodegenerative, terminal nature of dementia, advance care planning (ACP) is important for people with dementia and their carers.
- Less than half of people with dementia are involved in ACP conversations worldwide.

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What this paper adds

- A range of ACP definitions and outcomes are used in the current literature. The research field would benefit from consensus on which ACP outcomes to use, as well as validating these constructs for people with dementia.
- Evidence of effectiveness of ACP for people with dementia is of variable quality. However, the associations with ACP and decreased hospitalizations, increased concordance between care received and prior wishes and increased completion of ACP documents were found in the majority of reviews and studies which evaluated effectiveness.
- Future research should go beyond descriptive accounts of what is thought to work and test different approaches in different settings that can ensure all parties benefit from involvement in these discussions.

1. Introduction

Worldwide there are about 50 million people living with dementia. This number is expected to increase to 131.5 million in 2050 (Prince et al., 2015). Characteristic symptoms of dementia are difficulties with memory and language, impaired problem-solving and other cognitive skills that affect a person's ability to perform everyday activities, and disorientation in time, person and place. Dementia is currently irreversible and is, eventually, fatal (Karlawish et al., 2017). People can either die from the dementia itself or from other illnesses, such as pneumonia, a chronic illness or another terminal condition. The likelihood of cognitive and functional decline as the dementia progresses means that individuals' priorities for health, and end-of-life care often need to be discussed before there is obvious deterioration in health (Dixon et al., 2018). This can be done in the form of advance care planning (ACP). A consensus paper from the European Association for Palliative Care (EAPC) describes ACP as care planning that: '*enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate.*'(Sudore et al., 2017a).

End-of-life care for people with dementia is often inadequate, either unnecessarily prolonging life with (inappropriate) interventions, such as tube feeding (Sampson et al., 2009), or failing to address the fundamentals of care such as nutrition, pain control and social support (World Health Organization, 2011). ACP could create opportunities for people with dementia to participate in decision-making about their end-of-life care (Dixon et al., 2018). However, less than 40% of people with dementia worldwide currently have the opportunity to participate in an ACP conversation and record their preferences (Sellars et al., 2019). The well documented challenges of talking about death and dying are compounded for someone with dementia who is faced with the difficult task of planning for a future unknown self (Dixon et al., 2018). When decisions about end-of-life care for someone with dementia are left to healthcare professionals and family carers this can cause uncertainty (Brazil et al., 2018) and stress and guilt for carers (Carter et al., 2018). Furthermore, there is evidence that carers may not have a good understanding of the preferences of the person with dementia for end-of-life treatment (Harrison Dening et al., 2016).

There is an increasing literature on ACP for people with dementia, and the last decade has seen the publication of many systematic reviews on the topic. These reviews have covered a variety of aspects of ACP, included different types of studies, and reported a range of different outcomes. Finding and interpreting this evidence may be challenging for practitioners and decision makers. The aim of this review, therefore, is to provide an overall examination of all the available quantitative and qualitative evidence on ACP for people with dementia. We undertook an overview of existing systematic reviews (Smith et al., 2011), also known as an umbrella review (Aromataris et al., 2015). In order to provide a comprehensive and up-to-date overview we also included primary studies not identified by the systematic reviews. The advantage of this approach was that it allowed us to include diverse types of evidence and compare findings from relevant reviews. The objectives of the review were to identify and summarize the evidence on; 1) how ACP is conceptualized by and for people with dementia, 2) the effectiveness of ACP for people with dementia and 3) the experiences and views of ACP of people with dementia, their carers and professionals.

2. Methods

The review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA) (Moher et al., 2009). The PRISMA checklist can be found in the Supplementary file.

2.1. Protocol and registration

The protocol is registered on the PROSPERO website under the registration number: CRD42018107718.

2.2. Eligibility criteria

The inclusion criteria were as follows:

- Study design: systematic reviews of quantitative or qualitative evidence or primary research not included in one of the reviews.
- Study population: people living with dementia, family or informal carers or healthcare professionals.
- Interventions: ACP with people living with dementia and/or carers.
- Outcomes: effectiveness of ACP (e.g. care consistent with wishes, number of ACP conversations, number of ACP related written outputs, resource use) and experiences, understanding, or perceptions of ACP.

2.3. Search strategy

The electronic databases PubMed, CINAHL Plus, SCOPUS, Social Care Online and The Cochrane Library (CDSR & DARE) were systematically searched for review articles, using a predefined search string composed with the help of a research librarian. In addition we checked reference lists and performed lateral searching using the 'related articles' option in PubMed and the 'cited by' option on Scopus. All searches were carried out on July 5th 2018. Experts within the ACP and dementia field were contacted ($N = 3$, one from the UK, one from Australia, one from the Netherlands) and asked for possible additional studies which we might have overlooked.

Box 2. PubMed search string – Reviews

Search ((advance care planning[MeSH T*erms*]) OR (advance care plan* OR healthcare directive OR advance medical directive OR health care proxy OR durable power of attorney OR advance directive OR end-of-life decision OR future care plan*)) AND ((dementia[MeSH T*erms*]) OR dement* OR cognitive impair*) OR Alzheimer*) OR Lewy body disease) OR frontotemporal dementia)) AND ((review) OR realist review OR meta-analysis OR narrative review OR systematic review)

Primary research studies included in the reviews were tabulated to check for overlap between the reviews. Following this, PubMed, CINAHL Plus and SCOPUS were searched (Jan 2016–18) for recent primary studies on ACP for people with dementia that were not included in any of the reviews. The search string was based upon the search string for the reviews but without the study type search terms.

2.4. Study selection

One author (AW-vD) removed duplicates, using Mendeley reference manager software, and screened the titles and abstracts for relevance. A second author (JL) independently screened twenty percent of records. No relevant records were missed by the first author (AW-vD). Full text of potentially relevant papers were screened against the eligibility criteria by one reviewer (AW-vD) and checked by a second author (JL and FB). Discrepancies were resolved by discussion.

2.5. Data extraction

The following data were collected using a piloted form: aim(s) and methods, search strategy, setting(s), participants, number of studies included, outcomes reported, ACP definition used, barriers and facilitators, quantitative and qualitative outcomes and main results of the study. Data were extracted by one author (AW-vD) and discussed with two other authors (JL and FB).

2.6. Quality appraisal

Included reviews were appraised using the AMSTAR-2 tool (Shea et al., 2017). Because the tool is focused on systematic reviews of randomized controlled trials we adapted it for the purpose of our review, which included reviews of studies of all designs. We omitted three questions concerning meta-analysis and adapted the questions about Risk of Bias (RoB). Critical Appraisal Tools from the Joanna Briggs Institute were used to appraise the quality of primary studies including randomized controlled trials (Tufanaru et al., 2017), qualitative research (Lockwood et al., 2015) and analytical cross-sectional studies (Moola et al., 2017). More details on the appraisal tools can be found in the supplementary file (Table 1e). All appraisal was done by two reviewers independently (AW-vD, FB, BE, NE). No reviews or studies were excluded on the basis of the quality assessment score.

2.7. Synthesis

Reviews and primary studies were classified as quantitative, qualitative or mixed methods. Primary studies in each review were tabulated to assess the overlap between reviews. Effectiveness was investigated by categorizing the different outcomes reported and tabulating data including an indication of whether the effects of the intervention were positive, negative or not statistically significant.

For qualitative data, a thematic synthesis (Thomas and Harden, 2008) was done using NVivo 12 software. Thematic synthesis had three stages; 1) coding ‘line-by-line’, 2) developing ‘descriptive themes’ and 3) generating ‘analytical themes’. To be as comprehensive as possible, the line-by-line coding included both the results and the discussion section of the included articles. Differences between groups of stakeholders (people with dementia, carers and healthcare professionals) and settings (home, care home, hospital) were explored. AW-vD performed the initial line-by-line coding of the text. This process was closely monitored by FB. Themes were synthesized by AW-vD and FB and refined after further discussion with JL.

3. Results

3.1. Study characteristics

Nineteen reviews and 11 primary studies met the inclusion criteria. A flow chart detailing the identification of the reviews and primary studies can be seen in Fig. 1. A total of 329 primary articles were included in the reviews. When overlap was accounted for 163 unique articles were identified.

3.1.1. Systematic reviews

The focus of the reviews was as follows:

- evaluations of the effectiveness of ACP $n = 4$ (Bryant et al., 2019; Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014),
- facilitators and barriers for ACP $n = 9$ (Arcand M., 2015; Brooke and Kirk, 2014; Dening et al., 2011; Jethwa and Onalaja, 2015; Petriwskyj et al., 2014a; Read et al., 2018; Tilburgs et al., 2018a; Van Der Steen et al., 2014b; Westenhaver et al., 2010),
- perspectives on and experiences of ACP for people with dementia $n = 5$ (Beck et al., 2017a; Jones et al., 2016; Mignani et al., 2017; Petriwskyj et al., 2014b; Ryan et al., 2017).
- clinical recommendations as a support tool for healthcare professionals working with people with dementia $n = 1$ (Piers et al., 2018).

The number of articles included in the reviews ranged from 4 to 67. Six reviews included only quantitative articles (Arcand M., 2015; Bryant et al., 2019; Dixon et al., 2018; Petriwskyj et al., 2014a; Robinson et al., 2012; Wickson-Griffiths et al., 2014). The rest included either qualitative or a mixture of quantitative and qualitative articles (Beck et al., 2017a; Brooke and Kirk, 2014; Dening et al., 2011; Jethwa and Onalaja, 2015; Jones et al., 2016; Mignani et al., 2017; Petriwskyj et al., 2014b; Piers et al., 2018; Read et al., 2018; Ryan et al., 2017; Van Der Steen et al., 2014a; Westenhaver et al., 2010). Most reviews included either all settings ($N = 10$), or the long-term care setting only ($N = 6$). The views of people with dementia were incorporated in 13 reviews (Dening et al., 2011; Dixon et al., 2018; Jethwa and Onalaja, 2015; Jones et al., 2016; Mignani et al., 2017; Piers et al., 2018; Read et al., 2018; Robinson et al., 2012; Ryan et al., 2017; Tilburgs et al., 2018a; Van Der Steen et al., 2014b; Westenhaver et al., 2010; Wickson-Griffiths et al., 2014). Three reviews (Beck et al., 2017a; Brooke and Kirk, 2014; Piers et al., 2018) included reviews (Dening et al., 2011; Robinson et al., 2012; Van Der Steen et al., 2014b) that were also included as a source within this manuscript. Three reviews had no unique articles (Brooke and Kirk, 2014; Robinson et al., 2012; Ryan et al., 2017). In total 163 unique articles were incorporated, furthermore 33 studies were included in two reviews, 21 in three, 7 in four, 1 in five and 1 in six of the reviews. Tabulation of all reviews and their included articles can be found in the supplementary file (Table 2e) as well as characteristics of included reviews (Table 3e).

3.1.2. Primary research articles

The focus of the primary research was as follows

- effectiveness of an ACP programme $n = 1$ (Mitchell et al., 2018)
- effectiveness of ACP training for healthcare professionals $n = 1$ (Katwa et al., 2018)
- facilitators and barriers for ACP $n = 3$ (Lo et al., 2017; McGlade et al., 2017; Tilburgs et al., 2018b)
- views, perspectives and experiences of ACP for people with dementia $n = 6$ (Ashton et al., 2016; Beck et al., 2017b; de Vries and Drury-Ruddlesden, 2018; Givens et al., 2018; Jung et al., 2017; Sinclair et al., 2016).

Table 1
Effectiveness of advanced care planning
Oucome data provided by the reviews ($n = 3$) and *primary study* ($n = 1$).

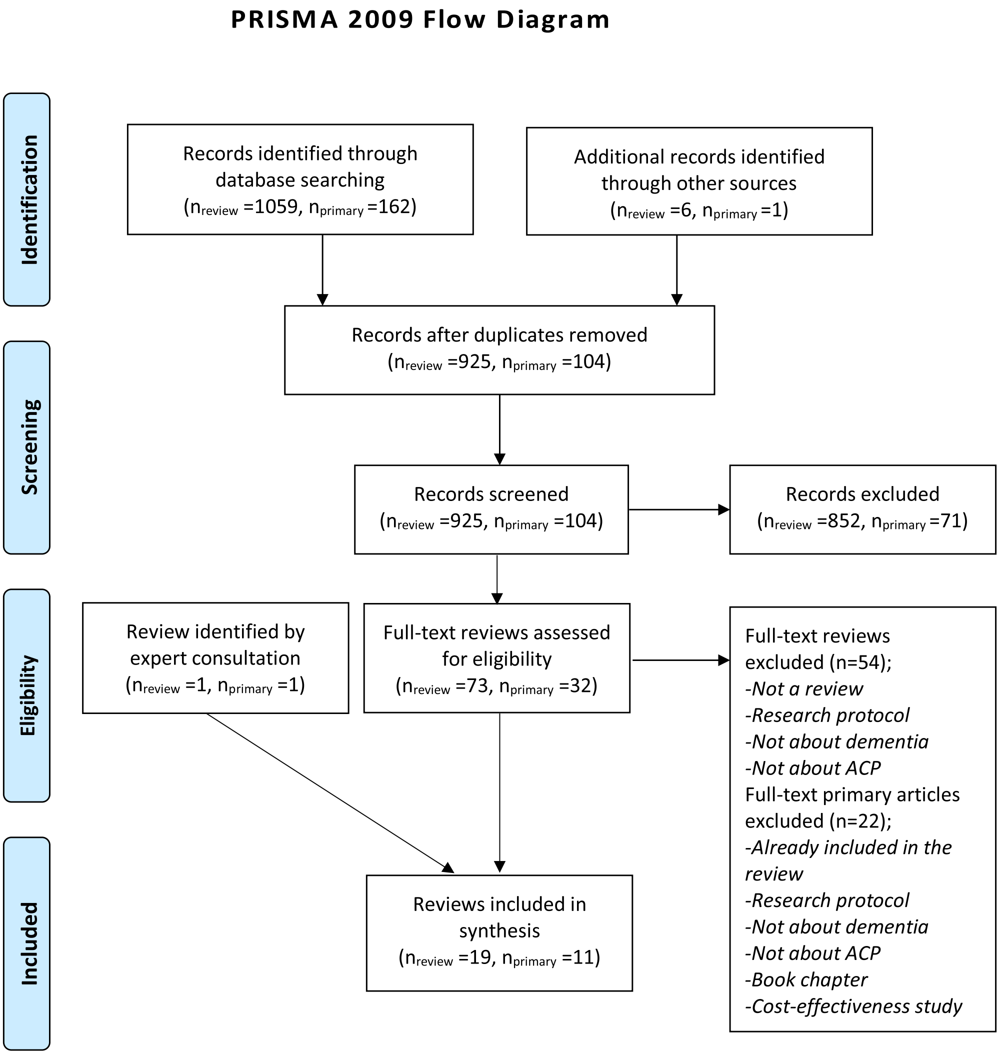
Outcome measure	Reviews and studie(s) reporting outcome (N)	Positive outcome (significant result reported)	No change	Study quality score (out of 13)
ACP and end-of-life outcomes				
Concordance between care and wishes	Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014 ($N = 3$)	Increase (all primary studies in all reviews)		8.5 10 7.5
Burdensome transitions	Dixon et al., 2018 ($N = 1$)	Decrease (all primary studies)		8.5
Place of death	Dixon et al., 2018 ($N = 1$)	Increase in dying in preferred place (2/3 primary studies)	No effect found (1/3 primary studies)	8.5
Completion of ACP documents (incl. DNR)	Bryant, 2019; Robinson et al., 2012; Wickson-Griffiths et al., 2014; *Mitchell, 2018* ($N = 4$)	Increase (1/2 primary studies in Wickson-Griffiths et al., 2014), increase (all primary studies in Robinson et al., 2012; Mitchell, 2018)	No effect found (1/4 primary studies in Bryant et al., 2019)	8.5 10 7.5 12
Number of ACP referrals	Robinson et al., 2012 ($N = 1$)		No effect found (all primary studies)	10
Number of ACP discussions	Robinson et al., 2012; Wickson-Griffiths et al., 2014 ($N = 2$)	Increase (1/6 primary studies in Wickson-Griffiths et al., 2014)	No effect found (all primary studies in Robinson et al., 2012)	10 7.5
Number of residents receiving palliative care and pain treatment	Robinson et al., 2012 ($N = 1$)	Increase in pain assessment (all primary studies)	No difference found in use of pain medication (all primary studies)	10
Knowledge of residents wishes	Wickson-Griffiths et al., 2014 ($N = 1$)	Increase (all primary studies)		7.5
Adherence to family's preferences	Wickson-Griffiths et al., 2014 ($N = 1$)	Increase (all primary studies)		7.5
Burdensome treatments	*Mitchell, 2018 (N = 1)*		No effect found	12
Level of care preferences	*Mitchell, 2018 (N = 1)*		No effect found	12
Health utilization				
Hospitalization	Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014; Bryant et al., 2019 ($N = 4$)	Reduced hospitalization rates (all primary studies in Wickson-Griffiths et al., 2014; Robinson et al., 2012; Dixon et al., 2018)	No effect found (all primary studies in Bryant et al., 2019)	8.5 10 7.5 8.5
ICU use	Dixon et al., 2018 ($N = 1$)	Reduction (all primary studies)		8.5
Tube feeding	Dixon et al., 2018 ($N = 1$)	Reduction (1/2 primary studies)	No effect found (1/2 primary studies)	8.5
Days spend in hospital	Dixon et al., 2018; Robinson et al., 2012 ($N = 2$)	Reduction (all primary studies in Robinson et al., 2012; 1/2 primary studies in Dixon et al., 2018)	No effect found (1/2 primary studies in Dixon et al., 2018)	8.5 10
Emergency ambulance calls	Dixon et al., 2018; Robinson et al., 2012 ($N = 2$)	Reduction (all primary studies in all reviews)		8.5 10
Hospice use	Robinson et al., 2012 ($N = 1$)	Increase (all primary studies)		10
Life-sustaining treatments	Dixon et al., 2018 ($N = 1$)		No effect found (all primary studies)	8.5
Patient outcomes				
Anxiety	Dixon et al., 2018 ($N = 1$)		No effect found (all primary studies)	8.5
Depression	Dixon, 2108 ($N = 1$)	Reduction (all primary studies)		8.5
General health	Bryant et al., 2019 ($N = 1$)		No effect found (all primary studies)	8.5
Quality of life	Dixon et al., 2018; Wickson-Griffiths et al., 2014 ($N = 2$)	Significant increase (all primary studies in Wickson-Griffiths et al., 2014; 1/2 primary studies in Dixon et al., 2018)	No effect found (1/2 primary studies in Dixon et al., 2018)	8.5 7.5
Decisional conflict	Dixon et al., 2018 ($N = 1$)	Reduction (all primary studies)		8.5
Stability of healthcare choices	Wickson-Griffiths et al., 2014 ($N = 1$)	Increase (all primary studies)		7.5
Satisfaction with care	Robinson et al., 2012; Wickson-Griffiths et al., 2014; Dixon et al., 2018 ($N = 3$)	Increase (all primary studies in Wickson-Griffiths et al., 2014)	No effect found (all primary studies in Robinson et al., 2012; Dixon et al., 2018)	10 7.5 8.5
Carer outcomes				
Decisional conflict	Bryant et al., 2019 ($N = 1$)	Decrease (all primary studies)		8.5
Confidence in treatment decisions made	Bryant et al., 2019 ($N = 1$)	Increase (all primary studies)		8.5
Knowledge of dementia	Bryant et al., 2019 ($N = 1$)		No effect found (all primary studies)	8.5
Comfort with knowledge	Bryant et al., 2019 ($N = 1$)		No effect found (all primary studies)	8.5

(*Continued on next page*)

Table 1 (*Continued*).

Outcome measure	Reviews and studie(s) reporting outcome (N)	Positive outcome (significant result reported)	No change	Study quality score (out of 13)
Emotional distress	Dixon et al., 2018 ($N = 1$)	Decrease (all primary studies)		8.5
Physical distress	Dixon et al., 2018 ($N = 1$)	Decrease (all primary studies)		8.5
Anxiety	Dixon et al., 2018 ($N = 1$)		No effect found (all primary studies)	8.5
Depression	Dixon et al., 2018 ($N = 1$)	Reduction (all primary studies)		8.5
Quality of life	Dixon et al., 2018 ($N = 1$)	Increase (all primary studies)		8.5
Satisfaction with care	Dixon et al., 2018; Robinson et al., 2012; Bryant et al., 2019 ($N = 3$)	Increase (all primary studies in Bryant et al., 2019; Dixon et al., 2018)	No effect found (all primary studies in Robinson et al., 2012)	8.5 10 8.5
ACP knowledge	Wickson-Griffiths et al., 2014 ($N = 1$)	Increase (all primary studies)		7.5
Resource use				
Healthcare costs	Dixon et al., 2018 ($N = 1$)	Reduction (all primary studies)		8.5
Hospital costs	Dixon et al., 2018; Robinson et al., 2012 ($N = 2$)	Reduction (all primary studies in all reviews)		8.5 10
Cost per resident	Wickson-Griffiths et al., 2014 ($N = 1$)	Reduction (all primary studies)		7.5

ACP; advance care planning, DNR; do not resuscitate, ICU; intensive care unit.



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For more information, visit www.prisma-statement.org.

Fig. 1. PRISMA flow diagram of included reviews and primary articles.

Table 2
Experiences of and perspectives on ACP.
Results of the thematic synthesis of reviews and primary studies.

Themes	Subthemes	Reviews	Quality score reviews (all out of 13)	Primary studies	Quality score primary studies	Example
Tailoring the approach and timing to the needs of PwD	Communication	Piers et al., (2018)	10	Tilburgs et al., 2018a, 2018b	8/10	Adjust communication to the needs of the PwD (e.g. severity of dementia)
	Informal conversations	Tilburgs et al., 2018a, 2018b; Ryan et al., 2017; Petriwskyj, 2014 (qual); Brooke, 2014	9.5 7 6.5 2.5	de Vries, 2018; Asthon, 2016	8/10 8/10	Informal conversations between PwD, carers and/or HCP happen frequently and are preferred by PwD and carers
	Individual approach	Piers et al., 2018; Petriwskyj et al., 2014 (qual); Jones et al., 2016; Petriwskyj 2014 (quant)	10 6.5 10 5	Sinclair, 2016;	7/10	HCP should consider the specific situation of the PwD and carer
	Initiation	Brooke, 2014; Ryan et al., 2017; Jones et al., 2016; Van Der Steen et al., 2014b; Mignani et al., 2017; Piers et al., 2018; Dening et al., 2011; Petriwskyj et al., 2014 (quant); Tilburgs et al., 2018a, 2018b; Beck, 2017	2.5 7 10 8.5 10 10 8 5 9.5 6.5	Jung, 2017; McGlade, 2017; Sinclair et al., 2016; Tilburgs et al., 2018a, 2018b; Beck, 2017	4/8 5/10 7/10 8/10 4/8	Concerns about when to initiate ACP is a barrier
	Timing	Piers et al., 2018; Dening et al., 2011; Petriwskyj et al., 2014 (qual); Jones et al., 2016; Van Der Steen et al., 2014b	10 8 6.5 10 8.5	Sinclair et al., 2016; Tilburgs et al., 2018a, 2018b; McGlade et al., 2017; Beck, 2017	7/10 8/10 5/10 4/8	ACP conversations should be held on varies occasions
Variability in capacity and willingness to engage in ACP	Decision-making capacity	Beck, 2017; Read et al., 2018; Tilburgs et al., 2018a, 2018b; Jethwa, 2015; Dening et al., 2011; Brooke, 2014; Piers et al., 2018; Ryan et al., 2017; Westenhaver et al., 2010; Mignani et al., 2017	6.5 10 9.5 5 8 2.5 10 7 2.5 10	McGlade et al., 2017; Beck, 2017; Gilissen et al., (2018)	5/10 4/8 6/8	Professionals worry about (diminishing) decision-making capacity and so do carers. PwD believe they are able to express their future support needs.
	Willingness to engage, carers	Petriwskyj et al., 2014 (quant); Petriwskyj et al., 2014 (qual); Mignani et al., 2017; Van Der Steen et al., 2014b; Ryan et al., 2017; Dening et al., 2011; Westenhaver et al., 2010; Brooke, 2014; Arcand, 2015; Tilburgs et al., 2018a, 2018b; Jones et al., 2016	5 6.5 10 8.5 7 8 2.5 2.5 2 9.5 10	Ashton, 2016; Jung et al., 2017; de Vries, 2018; Lo et al., 2017; Sinclair et al., 2016; Tilburgs et al., 2018a, 2018b; Givens, 2018	8/10 4/8 8/10 8/8 7/10 8/10 6/8	For carers, decision making can be positive, but also a stressful and challenging task. Views of carers vary greatly. Low IQ, low social status, strong religious beliefs, ethnic minority status, carer burden and guilt are barriers for ACP. Earlier ACP experiences are facilitator for ACP.

(*Continued on next page*)

Table 2 (*Continued*).

Themes	Subthemes	Reviews	Quality score reviews (all out of 13)	Primary studies	Quality score primary studies	Example
	Willingness to engage, PwD	Dening et al., 2011; Petriwskyj et al., 2014 (quant); Petriwskyj et al., 2014 (qual); Westenhaver et al., 2010; Jethwa, 2015; Tilburgs et al., 2018a, 2018b; Read et al., 2018; Migani, 2017; Ryan et al., 2017; Van Der Steen et al., 2014b	8 5 6.5 2.5 5 9.5 10 10 7 8.5	Lo et al., 2017; Jung et al., 2017; McGlade et al., 2017; Tilburgs et al., 2018a, 2018b	8/8 4/8 5/10 8/10	PwD show no distress before or after an ACP conversation, are not always keen on having a conversation, but find ACP important. Strong religious beliefs are a barrier to engage in ACP. Older age, higher education, being single and having an active coping strategy are facilitators to engage in ACP.
Roles & responsibilities of healthcare professionals	Healthcare system	Arcand, 2015; Beck, 2017; Jones et al., 2016; Petriwskyj et al., 2014 (quant); Piers et al., 2018; Ryan et al., 2017; Van Der Steen et al., 2014b; Tilburgs et al., 2018a, 2018b; Wickson-Griffiths et al., 2014	2 6.5 10 5 10 7 8.5 9.5 7.5	Jung et al., 2017; McGlade et al., 2017; Tilburgs et al., 2018a, 2018b; Beck, 2017	4/8 5/10 8/10 4/8	HCP fear they cannot comply to future wishes because of (changes in) the healthcare system
	HCP; professional views	Arcand, 2015; Beck, 2017; Dening et al., 2011; Jethwa, 2015; Ryan et al., 2017; Tilburgs et al., 2018a, 2018b	2 6.5 8 5 7 9.5	Lo et al., 2017; McGlade et al., 2017; Tilburgs et al., 2018a, 2018b; Beck, 2017	8/8 5/10 8/10 4/8	Being unsure who's role it is to initiate ACP is a barrier
	HCP; attitudes	Brooke, 2014; Beck, 2017; Tilburgs et al., 2018a, 2018b; Jones et al., 2016; Ryan et al., 2017	2.5 6.5 9.5 10 7	Beck, 2017; Tilburgs et al., 2018a, 2018b	4/8 8/10	Taking initiative, time and a positive attitude are facilitators. Fear of causing fear, anxiety or distress is barrier for ACP
The impact of relationships on ACP	Carers and PwD	Jethwa, 2015; Petriwskyj et al., 2014 (qual); Petriwskyj et al., 2014 (quant); Piers et al., 2018; Dening et al., 2011; Beck, 2017; Mignani et al., 2017; Arcand, 2015; Van Der Steen et al., 2014b; Tilburgs et al., 2018a, 2018b	5 6.5 5 10 8 6.5 10 2 8.5 9.5	Givens et al., 2018; McGlade et al., 2017; Tilburgs et al., 2018a, 2018b; Beck, 2017	6/8 5/10 8/10 4/8	Complex family dynamics is a barrier
	Carers and HCP	Arcand, 2015; Dening et al., 2011; Piers et al., 2018; Tilburgs et al., 2018a, 2018b; Petriwskyj et al., 2014 (qual); Petriwskyl, 2014 (quant) Ryan et al., 2017; Van Der Steen et al., 2014b	2 8 10 9.5 6.5 5 7 8.5	Ashton, 2016; McGlade et al., 2017; Beck, 2017; Tilburgs et al., 2018a, 2018b	8/10 5/10 4/8 8/10	Trusting relationship between carers and professionals is a facilitator for ACP

(*Continued on next page*)

Table 2 (*Continued*).

Themes	Subthemes	Reviews	Quality score reviews (all out of 13)	Primary studies	Quality score primary studies	Example
The need to equip PwD, carers and healthcare professionals to engage in ACP	HCP training and education	Brooke, 2014; Ryan et al., 2017; Dening et al., 2011; Jethwa, 2015; Arcand, 2015; Jones et al., 2016; Piers et al., 2018; Tilburgs et al., 2018a, 2018b; Beck, 2017	2.5 7 8 5 2 10 10 9.5 6.5	Katwa, 2018; McGlade et al., 2017; Givens et al., 2018; Tilburgs et al., 2018a, 2018b; Beck, 2017;	6/8 8/10 4/8	HCP need education about ACP in general and legal issues specifically; about the dementia disease trajectory; about treatment options, incl. withholding or withdrawing treatment; and about communication skills
	Carer training and education	Arcand, 2015; Dening et al., 2011, Petriwskyj et al., 2014 (quant); Brooke, 2014; Piers et al., 2018;	2 8 5 2.5 10	Beck, 2017; Tilburgs et al., 2018a, 2018b;	4/8 8/10	Carers need education about life-sustaining treatment, the role of a surrogate decision maker, ACP and palliative and end-of-life care.
	PwD training and education	Piers et al., 2018; Van Der Steen et al., 2014b; Brooke, 2014; Mignani et al., 2017; Read et al., 2018	10 8.5 2.5 10 10	Jung et al., 2017; Givens, 2018; Lo et al., 2017;	4/8 6/8 8/8	PwD need training on the dementia disease trajectory and ACP
Lack of resources supporting ACP	Costs	Petriwskyj et al., 2014 (quant); Tilburgs et al., 2018a, 2018b;	5 9.5	Sinclair et al., 2016; Tilburgs et al., 2018a, 2018b	7/10 8/10	ACP consultation time should be reimbursed to HCP, possibly with a unique dossier code
	Tools	Petriwskyj et al., 2014 (quant); Tilburgs et al., 2018a, 2018b	5 9.5	Mitchell, 2018	12/13	Decision-making tools or videos are facilitators for ACP
	Time	Van Der Steen et al., 2014b; Tilburgs et al., 2018a, 2018b	8.5 9.5	McGlade et al., 2017; Tilburgs et al., 2018a, 2018b; Beck, 2017;	5/10 8/10 4/8	Lack of time of HCP is a barrier for ACP

PwD; people with dementia, ACP; advance care planning, HCP; healthcare professionals.

Settings included long-term care ($N = 5$), the community ($N = 3$), hospital ($N = 2$) or primary care ($N = 1$). Three studies included the views of people with dementia, either using surveys (Jung et al., 2017) or via face-to-face encounters (Lo et al., 2017; Tilburgs et al., 2018b), but no studies reported the views of people with severe/advanced dementia. Healthcare professionals involved were general practitioners (GPs), physicians, nursing home managers, nursing home care staff and other professionals caring for people with dementia (e.g. practice nurses, case managers). Carers are family caregivers (e.g. spouses, children), healthcare proxies and surrogate decision makers. Characteristics of the included primary studies can be found in the supplementary file (Table 4e).

4. Quality appraisal

Quality scores for the included reviews (Supplementary file, Table 5e) ranged from two out of thirteen to 10/13. All but one explained the heteroginity of their findings and around half of the included reviews assessed and accounted for Risk of Bias in their manuscripts. Almost none of the included reviews published or drafted a study protocol before starting their studies. Of the primary studies the cluster RCT (Mitchell et al., 2018) fulfilled all but one of the criteria. The intervention was not delivered to blinded groups, however, this was due to the nature of the intervention. Scores for the qualitative studies ranged from 5–8 from a possible total of 10. All studies showed congruity between their chosen methodology and their research question, their methods used and the interpretation of their findings. However, none addressed the potential influence of the researcher on the research conducted. For the cross-sectional papers subjects, setting and statistical analysis were deemed appropriate, however the identification and inclusion of confounders was lacking in most of the studies.

5. ACP definition

A wide range of ACP definitions was used. Some used definitions from national or international health organizations (e.g. WHO, 2011, $N = 2$) or the EAPC white paper definition of Rietjens et al. (2017)($N = 3$). Others used their own definition ($N = 7$, of which 5 were reviews). None of the definitions used was specifically designed for ACP with people with dementia.

Most authors identified ACP as;

1) a multi-stage, voluntary, interactive, continuous, formalized process (Beck et al., 2017a, 2017b; Bryant et al., 2019; de Vries and Drury-Ruddlesden, 2018; Dening et al., 2011; Dixon et al., 2018; Jung et al., 2017; Lo et al., 2017; McGlade et al., 2017; Mignani et al., 2017; Piers et al., 2018; Robinson et al., 2012; Ryan et al., 2017; Tilburgs et al., 2018b, 2018a; Wickson-Griffiths et al., 2014)
2) being a discussion or conversation between either, individuals and healthcare professionals (Ashton et al., 2016; Brooke and Kirk, 2014; de Vries and Drury-Ruddlesden, 2018; Dening et al., 2011; Jones et al., 2016), patient and informal carer (Beck et al., 2017a, 2017b; Robinson et al., 2012; Ryan et al., 2017; Van Der Steen et al., 2014b; Westenhaver et al., 2010) or patient, carer and healthcare professional (Arcand M., 2015; McGlade et al., 2017; Mignani et al., 2017; Piers et al., 2018; Read et al., 2018; Ryan et al., 2017; Tilburgs et al., 2018a, 2018b; Wickson-Griffiths et al., 2014; Givens et al., 2018),
3) about goals and preferences for future care (Arcand M., 2015; Ashton et al., 2016; E. R. Beck et al., 2017b, 2017a; Brooke and Kirk, 2014; Dixon et al., 2018; Jones et al., 2016; Lo et al., 2017; McGlade et al., 2017; Piers et al., 2018; Read et al., 2018; Robinson et al., 2012; Ryan et al., 2017; Sinclair et al., 2016; Tilburgs et al., 2018b, 2018a; Van Der Steen et al., 2014b; Wickson-Griffiths et al., 2014; Givens et al., 2018), future wishes (Bryant et al., 2019; de Vries and Drury-Ruddlesden, 2018), or end-of-life decisions (Jethwa and Onalaja, 2015; Piers et al., 2018; Van Der Steen et al., 2014b),
4) in anticipation of future deterioration (Ashton et al., 2016; Brooke and Kirk, 2014; de Vries and Drury-Ruddlesden, 2018; Dening et al., 2011; Jones et al., 2016; Lo et al., 2017; Read et al., 2018; Sinclair et al., 2016) or awaiting reduced capacity or mental incompetence (Bryant et al., 2019; de Vries and Drury-Ruddlesden, 2018; Dixon et al., 2018; Jung et al., 2017; Mignani et al., 2017; Van Der Steen et al., 2014b).

Some advocated ongoing review of ACPs (Ryan et al., 2017; Tilburgs et al., 2018a, 2018b) or at least some continuing communication (Givens et al., 2018; Sinclair et al., 2016). The benefit of ACP was identified as creating a shared understanding between the person with dementia and their carers and healthcare professionals (Beck et al., 2017a, 2017b; Wickson-Griffiths et al., 2014) and promoting autonomy and choice for the person with dementia (Jethwa and Onalaja, 2015).

6. Effectiveness of ACP

Four reviews (Bryant et al., 2019; Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014) and one primary study (Mitchell et al., 2018), reported the effectiveness of ACP programs for people with dementia or cognitive impairment and their carers. The four reviews included 32 primary articles, of which 26 focused solely on people with dementia and their carers. The included reviews reported on 25 unique primary studies, of which six used a (cluster) randomized controlled trial design, five used a cross-sectional study design, four a retrospective design, four a prospective design, three a before and after design, one a quasi-experimental design, one an evaluation without a control group and one was a feasibility study. Sixteen of these primary studies included in the reviews used patient notes or files as their main source of data-collection. Ten studies also included measures to collect data from the persons with dementia themselves.

Thirty-nine different outcomes were reported, with limited consensus on core outcomes. Outcome measures used in the reviews and the primary study (RCT), fell into five categories; 1) ACP and end-of-life outcomes, 2) healthcare utilisation, 3) patient outcomes, 4) carer outcomes and 5) resource use. All results are reported in Table 1. Either positive associations with ACP, or no change from the intervention was found for most outcomes for people with dementia and their carers. However, all reviews stated the quality of the included studies was of variable quality. Despite concerns that talking about dying and future wishes could be distressing, none of the reviews or the primary study identified any negative association with ACP. The most frequently reported outcomes are summarised in the text.

6.1. ACP and end of life outcomes

The completion of ACP documents was used as an outcome in three of the four included reviews and in the primary study (Bryant et al., 2019; Mitchell et al., 2018; Robinson et al., 2012b; Wickson-Griffiths et al., 2014). Most reported a significant association between ACP interventions and an increase in ACP documentation (Mitchell et al., 2018; Robinson et al., 2012b; Wickson-Griffiths et al., 2014). In three reviews, concordance between subsequent care and stated wishes was found to increase significantly where there had been an ACP intervention (Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014).

6.2. Healthcare utilisation

Hospitalisation rate was measured in all included reviews (Bryant et al., 2019; Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014), of which three showed a significant decrease in hospital use related to the presence of an advance care plan.

6.3. Patient and carer outcomes

People with dementia's satisfaction with care was measured in three reviews (Dixon et al., 2018; Robinson et al., 2012; Wickson-Griffiths et al., 2014). One review, in the nursing home setting, showed significant positive associations with ACP (Wickson-Griffiths et al., 2014), the other two found no effect. Two of the three reviews that reported carer satisfaction with care found a significant increase post ACP interventions (Bryant et al., 2019; Dixon et al., 2018), the other found no effect (Robinson et al., 2012).

7. Experiences and views of ACP

We identified six discrete themes, with 19 different subthemes. Supporting evidence can be seen in Table 2. All themes were based upon input from people with dementia, carers and healthcare professionals. No differences were identified between different settings (home, nursing home, hospital).

Theme 1 'tailoring the approach and timing to the needs of people with dementia' The difficulties of knowing the best time to initiate ACP discussions with the person with dementia and their family carer was a recurring theme and concerned, timing, initiation, communication, informal conversations and individualised approach. Recommendations for tailoring ACP to be suitable for people with dementia and their carers included, reflecting a commitment to personalized care, a recognition that ACP was likely to be an ongoing, repeated process over time, and communication approaches that fit with the style and level of the person with dementia. Some carers and healthcare professionals stated that immediately post diagnosis would be a suitable time to discuss ACP, others argued that a person should be given some time to become familiar with the dementia diagnosis and some felt that a decrease in the general health status of a person with dementia (e.g. pneumonia, broken hip) would be the right point to initiate ACP. Ryan et al. (2017) described finding the right moment as a balancing act between an individual's understanding of the implications of a dementia diagnosis and their diminishing decision-making capacity. As well as routine discussions as part of doctors' appointments ACP can involve informal, spontaneous conversations.

T*Theme 2 'variability in capacity and willingness to engage in ACP'* highlights the differences between how people with dementia and their carers engage in ACP. People with dementia appeared to show little distress about engaging in ACP conversations whilst carers often found the decision-making tasks stressful and challenging. The diminishing decision-making capacity of people with dementia is a concern for both healthcare professionals and carers. However, studies found people with dementia are able to consistently express their future wishes and discuss values and healthcare decisions. Instances when people with dementia and carers were reluctant to engage in ACP related to a lack of familiarity with the process and the specific content of ACP and concerns about the future. Personal factors, such as strong religious beliefs, low social status and low IQ can also influence how people with dementia and carers engage in ACP.

Theme 3 'roles and responsibilities of healthcare professionals'. Healthcare professionals agreed that ACP is important for people with dementia, but consistently identified barriers including fear of causing stress and anxiety for people with dementia and carers, and not being able to comply with future wishes because of (possible) changes in the healthcare system. Healthcare professionals also identified a lack of clarity around whose role it is to initiate ACP. However, healthcare professionals are consistently identified by both themselves, as well as people with dementia and their carers, as the most appropriate party to initiate ACP conversations.

Theme 4 'impact of relationships on ACP' highlights that complex family dynamics can hinder ACP conversations, while a trusting relationship between carers and healthcare professionals can facilitate ACP conversations. The latter is especially important when the person with dementia is in the advanced stages of dementia. The quality of the healthcare professional-carer relationship depends on a range of interpersonal and contextual factors. How this can be assessed however, was not discussed in the evidence reviewed.

Theme 5 'the need to equip people with dementia, carers and professionals to engage in ACP'. Education and training were identified as important in preparing and enabling people to engage in ACP. For people with dementia an understanding of the dementia disease trajectory and of what ACP can achieve are facilitators. Carers of people with dementia could also benefit from training on these themes, as well as education on life-sustaining treatment, the role of a surrogate decision maker, ACP and palliative and end-of-life care. Training and education for healthcare professionals on ACP, the dementia disease trajectory, treatment options and communications skills were found to be facilitators when initiating conversations about ACP with people with dementia and their carers.

Theme 6 'lack of resources supporting ACP' captures the time, skills and access to training materials that staff often require to be confident in ACP and achieve quality conversations. More time for healthcare professionals to spend with individuals would facilitate ACP. Furthermore, financial resources for professionals would stimulate initiation of ACP conversations. Lastly, research has shown that decision-making tools and videos can be facilitators for ACP conversations with people with dementia and their carers.

8. Discussion

We identified 19 reviews including 163 unique studies, and an additional 11 primary studies on ACP for people with dementia. The results suggest that ACP can be implemented with and for people with dementia resulting in increased ACP documentation, greater concordance between care and an individuals' wishes, and increased satisfaction with care from both the point of view of people with dementia and their family carers. Furthermore, there is some evidence that the use of ACP is associated with decreased hospitalization rates of people with dementia. The effectiveness reviews and primary studies included in this review showed either positive associations with ACP, or no change from the interventions for people with dementia and their carers. What emerged from the thematic analysis was the variety of individual and organizational factors that impacted the way healthcare professionals and people with dementia and their carers engaged in ACP. Although there were many commonalities, for example positive relationships were a facilitator, views about the appropriate timing of ACP varied. There remains a lack of consensus on which ACP definition should be used for people with dementia. None of the current definitions focus specifically on people living with dementia (Van Der Steen et al., 2014a).

Outcome measures identified in this review could be clustered into five categories; 1) ACP and end-of-life outcomes, 2) healthcare utilization, 3) patient outcomes, 4) carer outcomes and 5) resource use. These categories are similar to those agreed in a recent international Delphi study on ACP (Sudore et al., 2017b). This might suggest that outcomes of relevance to the general population are also likely to be relevant to people with dementia. However, it is also possible that researchers choose these outcomes based on previous research in populations of people without dementia or cognitive impairment. There is a need for outcome measures that specifically reflect the needs of people with dementia. This might include focusing more on people's sense of control and autonomy (Jimenez et al., 2018), or adjusting measures to closely match the impact of ACP conversations on feelings of security, mood and hope (Van den Block, 2019). Furthermore, both short and longer-term effects of ACP conversations on people with dementia and carers should be evaluated (Van den Block, 2019).

In terms of experiences and views of ACP for people with dementia, we found that there was a shared recognition that ACP conversations should be person-centred and communication and timing should be tailored to the level and wishes of the person with dementia. As with all conversations about death and dying, decisions about initiating ACP conversations were hampered by concerns about when to initiate and who should initiate (Goodman et al., 2015). The high likelihood of diminishing decision-making capacity for people with dementia exacerbated this feeling of uncertainty for both healthcare professionals and carers. However, our results suggest that people with dementia are able to express their future support needs and also find it important to do this.

The fear of causing stress and anxiety for people with dementia and carers is a persistent barrier that might be linked to the stigma and social dread associated with dementia (WHO, 2012). Evidence indicates that this can be mitigated by relationship continuity. When there are trusting and open relationships between carers and healthcare professionals, ACP conversations are more likely to occur. Recent research argued that these supporting relationships help overcome difficult emotions such as anxiety and stress for carers of people with dementia (Parkinson et al., 2017). The growing interest in initiatives to promote dementia awareness and community engagement with people with dementia (OECD, 2018) could also support conversations about living and dying with dementia that extend beyond the individual-professional encounter, for example during informal conversations and discussions within the family (de Vries and Drury-Ruddlesden, 2018) or a social (peer) group. However, few of the primary studies or reviews discussed how initiatives to promote community engagement and the inclusion of people with dementia could change how living and dying with dementia is discussed in wider society.

The lack of training for difficult conversations, awareness of the dementia trajectory and confidence in what services could be provided at the end of life were barriers repeatedly identified in this umbrella review. Therefore, training and education for all parties involved is recommended in many of the included papers. Research has shown that ACP training is associated with improved outcomes in nursing homes (Aasmul et al., 2018), confidence in undertaking ACP conversations with people with dementia (Katwa et al., 2018), and a reduction in uncertainty in decision-making (Brazil et al., 2018). However, merely educating healthcare professionals might not be sufficient to create real change for people with dementia. As Gilissen and colleagues showed in a recent paper (Gilissen et al., 2018), overall cultural change is needed to embed ACP conversations in standard care.

9. Strengths and limitations

The rapid increase in research on ACP for this population means that a review of reviews that synthesizes the evidence from qualitative, quantitative and mixed-methods reviews provides a resource of what is known and a platform for future work. Furthermore, by including a search on recent primary studies, this paper offers a comprehensive overview of the existing knowledge, methodological approaches and how people with dementia can be involved in research on ACP. Thirteen of the 19 included reviews used articles with direct data from people with dementia, as well as three of the primary studies.

We assessed the quality of included reviews using a modified version of the AMSTAR-2 (Shea et al., 2017). It is possible that these modification may have impacted the validity of the tool. However, since we did not exclude articles based on the quality appraisal, the results of this review have not been altered by these adjustments. Another limitation is the wide range of outcome measures found in the included studies. The lack of agreement on which primary outcome to use, ultimately leads to a lack of strong evidence on the effectiveness of ACP for people with dementia. Some outcome measures however, were found in multiple studies, increasing the likelihood of impact of these measures. Lastly, identifying differences in outcomes between different settings is difficult from reviews, therefore this could not be explored indepth. We would therefore recommend a focus on differences between context in future research.

There is no consensus about what ACP for people with dementia should include or the best outcomes to use when testing ACP effectiveness for people with dementia. Sudore et al. 2017b, have advocated for further research to identify ACP outcome measures and validate them for use in research. We strongly underline the latter, since many of the theoretical assumptions in the included papers were implicit or not validated for people with dementia. Furthermore, the primary studies included in the reviews were of variable quality, leading to further difficulties in identifying the best outcomes for people living with dementia.

10. Conclusions

This review of reviews found ACP interventions to be acceptable for people with dementia and their carers and to be associated with improved outcomes. The consistent findings across the reviews and the primary studies of the challenges faced by both healthcare professionals and carers would suggest that there is a limited need for further descriptive research on barriers and facilitators. Future studies should focus on how to involve people with dementia in decision making, the impacts of different approaches to ACP and the most appropriate timing for the initiation of ACP. To further align this research, we would advocate for the consistent use of an ACP definition, specifically targeting ACP for people with dementia. Furthermore, we believe future work could consider if ACP as a standalone activity reflects the experience and preferences of people with dementia or whether it could be integrated into ongoing decision making activities that recognize the intrinsic uncertainty of living (and dying) with dementia reflecting preferences and priorities for everyday care and service availability (Goodman, 2018).

Authorship

Aims and search strategy: AW-vD, FB, JL, CG
Screening of the articles: AW-vD, FB, JL
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All the authors contributed to drafting the review or revising it critically for important intellectual content. All the authors have approved the version to be published and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Conflict of Interest

None.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ijnurstu.2020.103576.

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