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Title

Facilitators and barriers to advance care planning implementation in Australian aged care settings: A systematic review and thematic analysis.

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Article type : Review Article

Facilitators and barriers to advance care planning implementation in Australian aged care settings: A systematic review and thematic analysis

Abstract

Objectives. There are many studies investigating the implementation of advance care planning (ACP) in aged care settings around the world, but few studies have investigated Australian settings. The objective of this study was to determine the facilitators and barriers to implementation of ACP in Australian residential and community aged care.

Methods. Evidence from Australian studies published between 2007 and 30th September 2017 of ACP in residential and community aged care was sourced from four electronic databases using pre-determined search strategies. Data was extracted and synthesised using thematic analysis, and summarised according to themes.

Results. Nine studies described the facilitators and barriers of ACP implementation. Six themes covering the facilitators and barriers of ACP implementation were identified: 'Education and

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Knowledge', 'Skills and Training', 'Procedures and Resources', 'Perceptions and Culture', 'Legislation' and 'Systems'.

Conclusion. A whole of systems approach is necessary to facilitate the uptake of ACP in residential aged care settings. More research is needed to understand the facilitators and barriers to ACP in community aged care.

Key Words

Advance care planning, Ageing, Australia, Nursing homes, Review

Introduction:

Background:

Advance care planning (ACP) refers to "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care"[1]. The process of ACP is iterative and complex, involving the individual, family members, health professionals and aged care workers. It is an ongoing discussion regarding a person's preferences for care, including end of life care, and requires regular review. ACP discussions may lead to documentation of a person's preferences in an advance care directive, or appointment of a substitute decision maker (SDM). Although ACP can be initiated in various settings, there is increased interest in implementation of ACP in aged care where chronic illness means that an older person has a higher risk of losing the ability to make or communicate preferences.

The current body of evidence demonstrates the benefits of ACP. ACP results in higher aged care staff satisfaction[2], reduces unwanted hospitalisation and aggressive treatments[3-5], reduces stress and anxiety for family members in decision making and increases family member's satisfaction with outcomes at death[6, 7]. Documented advance care plans also increase adherence to a person's preferences by health professionals, aged care workers and family[5, 6]. Several studies discuss ACP in residential aged care[6, 8-15], but despite the evidence, uptake remains low in Australia with the prevalence of plans in residential aged care estimated to be as low as 0.2% up to 5-14%[16-19]. The prevalence of advance care plans in the community is less clear, but estimates suggest approximately 14% of adults living in the community have an advance care plan[20]. While the prevalence in people receiving community aged care services in Australia is unknown, those in receipt of these services may benefit from considering ACP because a large number may have chronic medical conditions that require complex care[21, 22]. It may also be advantageous to have

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ACP discussions in community aged care settings because of the familiarity of the home environment[23] and people may be less cognitively impaired than those living in residential care.

Although there are several systematic reviews published on the facilitators and barriers of ACP in residential aged care, there are no reviews examining ACP in Australian contexts, nor any including community aged care.

Aims:

This review aims to determine the facilitators and barriers to ACP in Australian aged care settings. Our objectives were:

1. Characterise facilitators and barriers to ACP in Australian residential and community aged care.
2. Determine how ACP is implemented in community aged care.
3. Identify research gaps requiring further exploration.

Methods:

Search strategy:

We conducted a systematic search of CINAHL, EMBASE, PubMed and PsycINFO. Search terms included key phrases relating to ACP, advance care directives, implementation, intervention, strategies, and residential and/or community care. Filters applied to the search included: English only, abstract published between 2007 and 30th September 2017. Reference lists for full-text articles were examined to find relevant articles. The complete search strategy is found in the appendix.

Eligibility criteria

Study population:

Cohorts in Australian community or residential aged care settings: older people or residents, family members, organisational staff, nurses or doctors.

Study design:

No restrictions on study design.

Outcomes:

Publications that discussed the facilitators and barriers to implementing ACP in residential and/or community aged care services.

Exclusion criteria:

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Studies discussing ACP in specific medical settings, such as in palliative care or in specific diseases were excluded. Reviews including narrative and systematic reviews were excluded.

Study selection:

Articles were imported into Covidence (Covidence systematic review software, Veritas Health Innovation, Melbourne, Australia.) and duplicates were removed. One author (xx) screened the title and abstract and sourced relevant full text articles based on the eligibility criteria. Full text articles were independently assessed by two authors (xx, xx). Conflicts regarding the eligibility of articles were discussed until consensus was reached. The final list of articles in the study was quality assessed.

Quality assessment of studies:

Quality was assessed as follows:

- For qualitative studies, the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used[24]. The COREQ checklist has 32 items, organised into three domains: 'Research team and reflexivity', 'study design' and 'analysis and findings'.
- For studies involving surveys, the SUrvey Reporting GuidelinE (SURGE) checklist was used[25].
- Intervention studies were assessed using the checklist for assessment of the methodological quality of healthcare interventions[26].

Quality assessment was conducted by two authors (xx, xx) independently using the relevant checklist. Discrepant views regarding the quality were settled by a third author (xx).

Data extraction:

Data extracted included: objectives, setting and location, participants, and the findings related to facilitators and barriers to ACP.

Data synthesis:

Deductive thematic analysis was used to synthesise major themes relating to facilitators and barriers[27]. Each article was read independently by two researchers (xx, xx). Both researchers manually coded and extracted the major themes. The two researchers then agreed on the final themes in conjunction with a third author (xx).

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Results:

Summary of studies:

The search identified 291 studies. Following abstract screening, 30 articles were extracted for full text review. Three additional articles were identified from reference lists. From the 33 articles, 24 were excluded, leaving nine that met inclusion criteria (Figure 1). The reasons for exclusion are listed in Figure 1.

The nine studies included seven qualitative studies[21, 28-33] and two intervention studies[34, 35], summarised in Table 1. The majority of qualitative studies used interviews as their primary data source, and one used a descriptive survey[21]. One article described the facilitators and barriers to ACP in community aged care[21]. Two studies were from an older person and/or family member's perspective[29, 31], two described a nurse's perspective[28, 30], two described general staff perspectives[34, 35], and three described management's perspective[21, 32, 33].

The average COREQ checklist score amongst the qualitative studies was 12/32, indicating low reporting quality. The descriptive survey[21] scored 16/28 on the SURGE checklist, indicating medium quality. The two intervention studies scored 12[34] and 8[35] out of 26 on the methodological checklist for health care interventions, indicating low quality.

Thematic Analysis:

Six themes related to facilitators and barriers to ACP in residential and community aged care were identified. These were: Knowledge and Education, Skills and Training, Procedures and Resources, Perception and Culture, Legislation, and Systems.

Knowledge and education:

Lack of knowledge and understanding of ACP reduced the confidence of staff to facilitate ACP conversations with residents[32, 34, 35].

There was low awareness of ACP amongst community-dwelling older Australians, residents of aged care facilities and their families[34]. Providing education improved uptake of ACP and supported family members to consider their own advance care plans[34]. Lack of written material about ACP was one reason for not initiating ACP with service users[21]. Complex terminology in written material was seen as confusing for residents and family members[31]. In contrast, having health professionals and aged care workers clarify ACP empowered residents and family members to undertake ACP[30, 31, 34].

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Skills and Training in ACP facilitation:

Two intervention studies reported that training for nursing staff increased the uptake of ACP post-intervention[34, 35]. These studies focused on identifying illness trajectory[34], or training nurses using a co-ordinated systematic approach to ACP[35]. Key enablers included: communication, leadership and critical thinking skills[28]. Conversely, a lack of training for health professionals and aged care workers was associated with poor uptake of ACP[21, 32, 33].

Procedures and resources:

Having dedicated ACP policies [29] and systematic ways to store and retrieve plans supported staff to implement ACP[21, 32].

Accessibility and transferability of documents across care settings were seen as imperative [35]. The lack of a central electronic registry, and standardised documents, was identified as a barrier to ACP[32].

Time constraints were identified as a barrier in both residential and community aged care settings[21, 30, 32].

Perception and Culture:

There were different perceptions about ACP from residents' and relatives' perspective. One study found that residents were open to ACP, as it allowed autonomy regarding future medical treatment decisions[31]. Residents worry that future wishes would not be followed by health professionals or relatives, and were concerned about relatives being "paternalistic"[31, 32]. From a nurse's perspective, relatives were seen as sometimes demanding treatment that a nurse believed the resident would not want[30].

Other barriers identified included family members being reluctant to discuss ACP, and struggling to accept "refusal of treatment", and the burden of decision making causing emotional distress[31, 35]. It was identified that relatives may find it distressing to talk about death, may be in denial[30, 35], or do not wish to discuss ACP for religious reasons[32].

Paternalistic attitudes of health-care workers were identified as a barrier to implementing ACP[32]. Health professionals may have the perception that everything must be done to prolong life [30-32], but this can also be an expectation of family members[30, 31].

Legislation:

Uncertainty about the legislation regarding ACP was a barrier to implementation[32, 33]. One study found that there was confusion about the role of legally-appointed SDMs[34].Providing information

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and education on the role of the legally appointed SDM helped to overcome this. Clarification and standardisation of legislation on ACP across jurisdictions was seen as a facilitator to ACP[32].

Systems:

A person-centred approach was identified as a facilitator [28, 29, 31]. Evidence indicated that nurses play an important role in eliciting a person's preferences, values and beliefs[29, 31].

Five papers discussed a multi-disciplinary approach[28-30, 33, 34], involving concerted effort of stakeholders including: family members[28, 33], care staff[33, 34], nurses[28, 34], doctors[28, 29, 33, 34], hospital teams[29, 30, 34], and physiotherapists[34] to support residents in ACP. When this occurred, this facilitated ACP discussions, as each component of the multi-disciplinary team brought their expertise to the process[28-30, 33, 34]. From the perspective of the family, a multi-disciplinary approach relieved decision making burden[30].

Having a standardised approach facilitates ACP in residential aged care, including standardisation of forms[32]. In one study, only one-sixth of residential aged care managers indicated that ACP was systematically approached[33]. Another study described a whole-systems framework to implementing ACP in a residential aged care setting[29]. Specifically, the expertise of nurses, involvement of the multi-disciplinary team, having discussion and providing education, as well as using a person-centred and standardised process was seen as ideal.

Discussion:

To our knowledge, this is the first systematic review to characterise facilitators and barriers to ACP in Australian residential and community aged care. Overall there was a lack of evidence particularly in community aged care settings and no studies that explored facilitators and barriers in cohorts such as culturally and linguistically diverse (CALD) populations, those who identify as Lesbian Gay Bisexual Transgender or Intersex (LGBTI) or those who identify as Aboriginal and/or Torres Strait Islander.

Facilitators common to other settings included improving general awareness about ACP in the community, individual knowledge and attitudes about ACP (older people and their families, as well as health professionals), provision of structured training to staff, clear policy and procedures, and having standardised documentation. [36]. Common barriers included lack of time, attitudes towards

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death and dying and culture within health systems that is geared towards life-prolonging treatment[37].

Our review highlights the importance of a whole-systems ACP approach in Australian residential and community aged care, a theme echoed by international reviews[38-40]. While education and training are important, programs are usually targeted towards staff or an ACP champion[41], whereas it may be more beneficial to include older people and their family members in the education program rather than provide education separately.

Implications for policy:

Our review highlights the role of policy in both residential and community aged care settings and the need for regular review and adaptation. Organisational policy that provides clarity on the expectation of staff, responsibilities and processes, that outlines local procedures regarding documentation, storage and accessibility, as well as the time required to implement ACP effectively can facilitate uptake. To facilitate uptake, local policy must align with other relevant organisations such as primary care, hospital, health and ambulance services. In Australia, the laws governing ACP are state or territory-based[42] and there is evidence that the differences in legislation are a barrier to ACP [32-34].

Implications for research:

This review has highlighted the need for more robust research particularly in community aged care. The included studies were mostly of relatively low quality, limited in number, size and scope and did not include outcome measures that evaulate uptake of ACP in aged-care.

Only one study investigated the facilitators and barriers to ACP in community aged care[21], and this was from the case manager's perspective. There are commonalities between community and residential aged care such as: lack of training, documentation, time and organisational approach[21]. Yet there is no exploration of the potential facilitators and barriers to ACP from a client's or family's perspective. Given the increasing uptake of home care packages in Australia, and the high prevalence of cognitive impairment in aged care residents[43], it is important to understand more about how best to facilitate uptake of ACP in community aged care.

There is also a need for more research into ACP in relation to people from CALD backgrounds. Not only is the proportion of older Australians from CALD backgrounds increasing[44], the aged care workforce consists of increasing numbers of people born overseas[45]. Although one study indicated that cultural considerations are needed[33], no studies were found that investigated facilitators and

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barriers to ACP from CALD perspectives in community or residential aged care. There is also a need for more evidence on the perspectives of Aboriginal and/or Torres Strait Islanders and the perspectives of people who identify as LGBTI.

Implications for practice:

Our review highlights the approaches that support ACP in aged care settings. Multi-disciplinary approaches bring together expertise from health and aged care professionals to facilitate ACP discussions, clarify the medical and legal terms of advance care plans, and reduce burden on family members and residents when the time for decision nears. A person-centred approach is also important, as it reduces the taboo nature of ACP for older people, and empowers them to reflect on their life and make decisions. Our review highlights a gap in research about how ACP is impacted by broader practices within health, such as access to general practitioner services, relationships with local health services and the perceptions and overarching discourse about end of life care in the broader Australian community. There is an opportunity to consider how policies, practices and roles and responsibility of the health and aged care sector impact on uptake and adherence to ACP. This could include investigating the potential role of Aged Care Assessment Teams, who assess access to aged, and the GP, in facilitating early discussions, as well community aged care providers having a more central role. Despite differences in state and territory legislation, aged care providers operate under the Aged Care Act and need to fulfil the same accreditation standards across Australia. There is thus an opportunity to consider drivers for an overarching national framework to guide implementation in this setting.

The provision of time and having the skills to discuss ACP was identified as a key facilitator. There is an opportunity to consider innovation in the delivery of education that is meaningful and logistically possible within environments where staff feel time-poor.

Limitations of the review:

There are some limitations of this review. Our search criteria were restricted to studies published in the last 10 years, which may have limited the number of included studies. Another limitation is that the results of the review may not be generalisable beyond Australia.

Conclusion:

This review highlighted some of the facilitators and barriers to implementation of ACP in aged care. However, more research is needed, particularly in community aged care settings, to determine the effectiveness of interventions that are aimed at increasing uptake of ACP. Future studies should also take into consideration the perspectives of older people, their families and service providers,

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including GPs. Further research is required to identify the facilitators and barriers to ACP in particular cohorts such as those from CALD backgrounds and those who identify as LGBTI or as Aboriginal and/or Torres Strait Islander. Future efforts should focus on the development of a comprehensive framework for ACP in aged care which is person-centred and multi-disciplinary and recognises that legislation varies across Australia. Such a framework should also recognise the interface between primary care, health services and aged care sectors.

Competing interests:

None declared.

Impact statement:

Policy Impact Statement:

To improve uptake of advance care planning, organisations must ensure that policies align with relevant healthcare organisations, and with the laws governing advance care planning in their respective states or territories. Clear policies outlining expectation of staff, responsibilities and processes can facilitate uptake of ACP.

Practice Impact Statement:

The process of implementing advance care planning is complex. Providing education and training for staff can enhance the implementation of advance care planning and raises the awareness amongst older people and their family members. A person-centred approach using a multidisciplinary team is ideal for facilitating ACP.

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Table:

Table 1: Summary of Australian studies included in this systematic review.

No.	Reference	Study quality Score	Study type	Method	Setting	Sample	Aims	Main findings
1	Fernandes, 2008[34]	12/26	Intervention	Intervention study based on a pre-implementation audit and action research	Residential aged care facility, with 57 beds and 107 direct care staff	100 residents and 20 staff members	To evaluate best practice of ACP using an evidence implementation technique in a residential aged care setting.	Initial audit revealed ACP was poorly implemented. Seven barriers were identified and addressed, including: knowledge, education, administration and documentation. After addressing these barriers, ACP compliance increased from 50 to 75%.
2	Lyon, 2007[35]	8/26	Intervention	Intervention study based on a pre-implementation audit and action research	Residential aged care facility with 150 beds	46 residents and 6 staff	To determine whether best practice of ACP was occurring in their facility using an audit tool.	Barriers to ACP identified early in the intervention phase included: lack of staff training, reluctance of GPs to become involved, reluctance of family members to discuss ACP, confusion about the role of Medical enduring power of attorney and lack of time. Facilitators included training staff, education to staff and residents and families, and explaining that ACPs can be updated regularly.

ACP- Advance care planning, ACD- Advanced care directive, GP- General practitioner, RACF- Residential aged care facility

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3	Jeong et al., 2007[28]	12/32	Qualitative	Case study methodology: field notes, observations, document analysis and semi-structured interviews with staff and residents.	Three residential aged care facilities	3 RACFs– 8 nursing staff	To determine the use of ACP and advance care directives in residential aged care facilities, and the scope of the clinical nurse in facilitating ACP and ACD's.	Nurses have a good understanding of ACP and advance care directives, and have specialised skills in facilitating ACP to residents and their families.
4	Jeong et al., 2011[31]	11/32	Qualitative	Case study methodology: field notes, observations, document analysis and semi-structured interviews with staff and residents.	Residential aged care facility	20 high-care residential facilities (plus 710 hospitals) – total of 1335 high-level care beds for people 65 years or over	To investigate the experiences of residents and family members involved in ACP and ACDs.	Older people/family experiences fall into three phases: pre-transition, transition and post-transition Older people are often concerned that their wishes may not be followed. Needs to be an understanding that ACP/ACDs are followed no matter where the person is – it transitions with the older people from residential care to hospital.
5	Jeong et al., 2011[30]	11/32	Qualitative	Case study methodology: field notes, observations, document analysis and semi-structured interviews with staff and residents.	Residential aged care facility	3 RACFs – 13 registered nurses (including the clinical nurse consultant)	To report on the experiences of registered nurses with ACP and ACDs	Barriers included: lack of time, need to follow up, culture of using all available resources, influence of families' wishes and the taboo topic of death.
6	Jeong, et al., 2010[29]	10/32	Qualitative	Case study methodology: field notes, observations, document analysis and semi-structured interviews with staff and residents.	Residential aged care facility	20 high-care residential facilities (plus 710 hospitals) – total of 1335 high-level care	Investigate the implementation process of ACP and the use of ACDs Investigate the outcomes of ACP and experiences of people	Four main elements (input, throughput, output and feedback) and 20 sub-elements were identified as requisites for nurses to initiate and implement ACP in a whole-systems approach. The role

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						beds for people 65 years or over	involved in ACP and ACDs. Determine the extent of nursing participation and scope of practice for nurses in the use of ACPs and ACDs.	of the nurse in facilitating quality end of life discussions with strong education and training for nursing staff and resident was emphasised.
7	Rhee et al., 2012[32]	17/32	Qualitative	Semi-structured interviews	Community and residential aged care facility	23 representatives of various organisations and healthcare professionals with experience and interest in aged care, end of life issues and ACP	To explore expert health professional views on issues relating to uptake of ACP and implementation of ACPs in Australia	Low level of uptake of ACP in Australia is due to: personal preference to not do ACP, lack of community awareness and understanding and reluctance to discuss end-of life and generally poor procedures to execute ACP. Health professionals should be involved in promotion of ACP but lack time, experience and training to facilitate end of life discussions. A system-wide implementation of multi-faceted interventions is needed to improve uptake of ACP, including: awareness campaigns, incorporating ACP as routine in everyday healthcare, adequate resources and effort to support change, standardised approaches and a patient centred approach.
8	Sellars et.al., 2015[21]	16/28	Qualitative	Descriptive survey	Community aged care facilities	120 service managers and 178 case managers across Australia	To explore the current attitudes, knowledge and practice of ACP among home care package service managers and case managers.	There some organisational support for ACP in some organisations including ACP training. Most case and service managers believed it was their responsibility to discuss ACP. Most case managers had engaged in ACP discussion in the previous 12 months of

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									the study, however a small number of discussions resulted in documentation of wishes. Most case managers believed ACP was not done well within their organisation.
9	Shanley et.al., 2009[33]	13/32	Qualitative	One-on-one telephone interview	Residential aged care facilities	Managers from 41 residential aged care facilities from South Western Sydney.	To understand how ACP is understood and approached by managers of residential aged care facilities.		Most facilities do not have a systematic approach to ACP. ACP discussions is often initiated late in a resident's illness. There were variations regarding when ACP discussions was initiated with residents. A continuum model of ACP implementation described with four broad approaches with five domains (Initiation, scope, follow-up, documentation and organisational leadership), that can be used as a practical tool for ACP implementation and review.

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Appendix:

Appendix I: Search strategy to identify relevant articles based on key words.

CINAHL Complete search strategy		
ID#	**Search terms**	**Studies found**
#1	ACP OR advance care plan(tiab)	1,435
#2	advance care directive OR advance health directive OR advance directive OR advance care directives OR advance health directives OR advance directives (tiab)	2,202
#3	#1 OR #2	3,360
#4	Implementation OR implementing OR intervention OR strategies(tiab)	453,272
#5	Residential care OR residential aged care OR residential aged care facility OR residential aged care facilities OR nursing home OR nursing homes OR assisted living OR long-term home OR long-term care home OR aged care OR long term facility OR long term facilities OR community care OR community aged care OR community care facilities OR community aged care facility OR community care facility OR community aged care facilities OR older people OR elderly people OR elderly (tiab)	125,854
#6	#3 AND #4 AND #5	194
#7	#6 AND filters: English, abstract available, published in the last 10 years	**120**

EMBASE search strategy		
ID#	**Search terms**	**Studies found**
#1	ACP OR advance care plan(tiab)	2564
#2	advance care directive OR advance health directive OR advance directive OR advance care directives OR advance health directives OR advance directives (tiab)	4083
#3	#1 OR #2	6042
#4	Implementation OR implementing OR intervention OR strategies	>10000
#5	Residential care OR residential aged care OR residential aged care facility OR residential aged care facilities OR nursing home OR nursing homes OR	356200

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	assisted living OR long-term home OR long-term care home OR aged care OR long term facility OR long term facilities OR community care OR community aged care OR community care facilities OR community aged care facility OR community care facility OR community aged care facilities OR older people OR elderly people OR elderly (tiab)	
#6	#3 AND #4 AND #5	263
#7	#6 AND Filters; English, abstract, pub in last 10 years	**191**

PUBMED search strategy		
ID#	**Search terms**	
#1	ACP[Title/Abstract] OR advance care plan[Title/Abstract]	1814
#2	(advance care directive[Title/Abstract] OR advance health directive[Title/Abstract] OR advance directive[Title/Abstract] OR advance care directives[Title/Abstract] OR advance health directives[Title/Abstract] OR advance directives[Title/Abstract])	3288
#3	#1 OR #2	4629
#4	implementation[Title/Abstract] OR implementing[Title/Abstract] OR intervention[Title/Abstract] OR strategies[Title/Abstract]	>100000
#5	residential aged care facility[Title/Abstract] OR residential aged care facilities[Title/Abstract] OR nursing home[Title/Abstract] OR nursing homes[Title/Abstract] OR assisted living[Title/Abstract] OR long-term home[Title/Abstract] OR long-term care home[Title/Abstract] OR aged care[Title/Abstract] OR long term facility[Title/Abstract] OR long term facilities[Title/Abstract] OR community care[Title/Abstract] OR community aged	257,546

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	care[Title/Abstract] OR community care facilities[Title/Abstract] OR community aged care facility[Title/Abstract] OR community care facility[Title/Abstract] OR community aged care facilities[Title/Abstract] OR older people[Title/Abstract] OR elderly people[Title/Abstract] OR elderly[Title/Abstract]	
#6	#3 AND #4 AND #5	200
#7	#6 AND Filters: English, Abstract available, published in the last 10 years	131

PsycINFO search strategy		
ID#	**Search terms**	**Studies found**
#1	ACP OR advance care plan(tiab)	700
#2	advance care directive OR advance health directive OR advance directive OR advance care directives OR advance health directives OR advance directives (tiab)	1223
#3	#1 OR #2	1731
#4	Implementation OR implementing OR intervention OR strategies	432,626
#5	Residential care OR residential aged care OR residential aged care facility OR residential aged care facilities OR nursing home OR nursing homes OR assisted living OR long-term home OR long-term care home OR aged care OR long term facility OR long term facilities OR community care OR community aged care OR community care facilities OR community aged care facility OR community care facility OR community aged care facilities OR older people OR elderly people OR elderly (tiab)	74,852
#6	#3 AND #4 AND #5	79
#7	#6 AND Filters; English, abstract, pub in last 10 years	**50**

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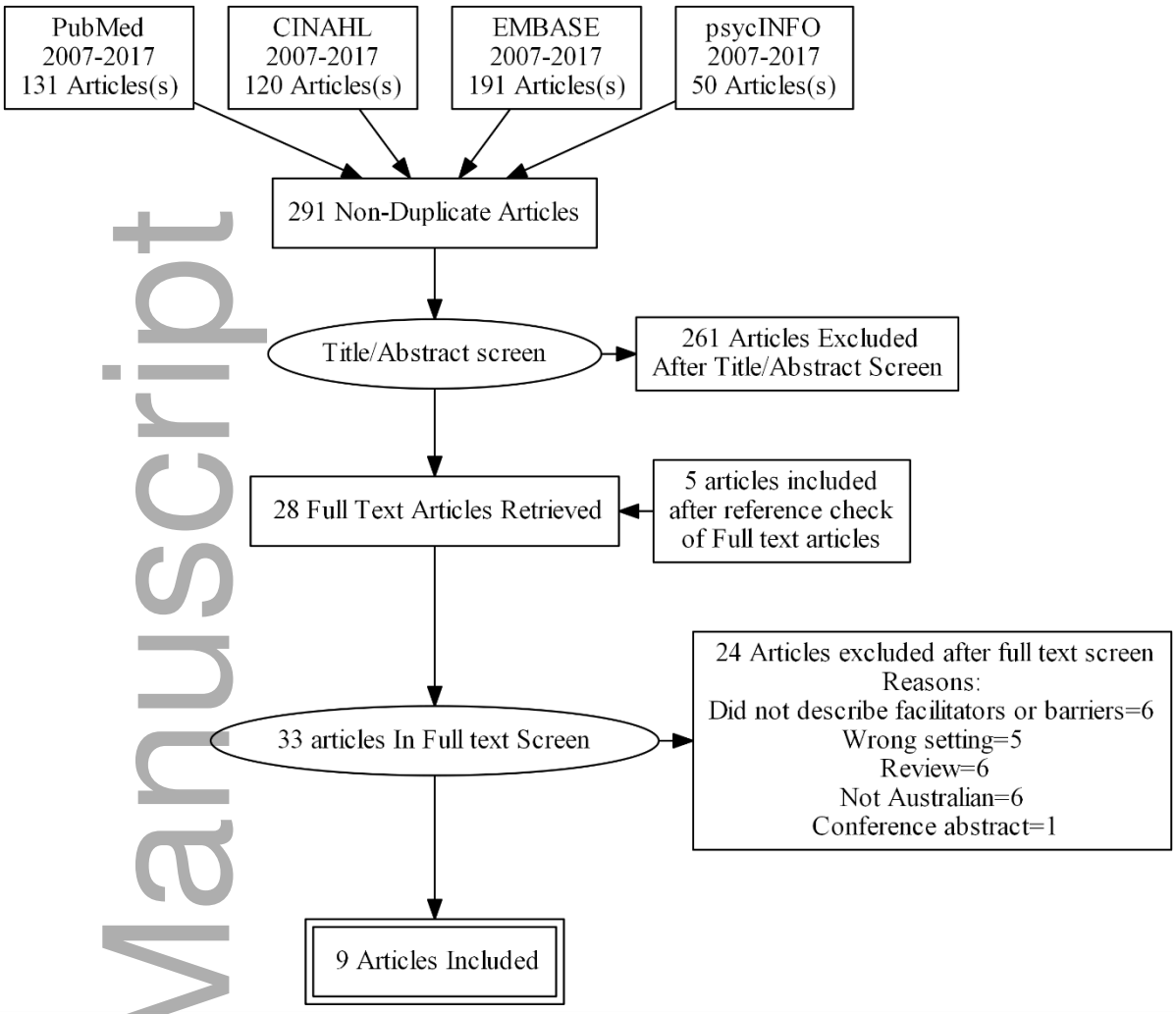

Figure 1: Flowchart of the search strategy to find relevant articles.

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