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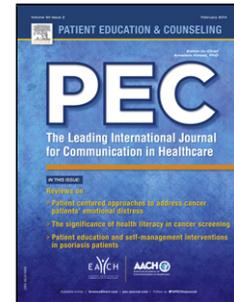
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Authors: Bronwyn Hemsley, Jacqueline Meredith, Lucy Bryant, Nathan J. Wilson, Isabel Higgins, Andrew Georgiou, Sophie Hill, Susan Balandin, Shaun McCarthy



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Views on Advance Care Planning and Advance Care Directives

An Integrative Review of Stakeholder Views on Advance Care Directives (ACD):

Barriers and Facilitators to Initiation, Documentation, Storage, and

Implementation

Bronwyn Hemsley^{*a}, Jacqueline Meredith^b, Lucy Bryant^a, Nathan J Wilson^c, Isabel Higgins^b, Andrew Georgiou^d, Sophie Hill^e, Susan Balandin^f, and Shaun McCarthy^b

* Corresponding author

Author Affiliations

^a The University of Technology Sydney, Australia
Building 7 (Faculty of Science and Graduate School of Health Building)
67 Thomas Street, Ultimo
Email: Bronwyn.Hemsley@uts.edu.au
Lucy.Bryant@uts.edu.au

^b The University of Newcastle, NSW Australia
The University of Newcastle, University Drive, Callaghan, NSW 2308;
Email: jacqueline.meredith@newcastle.edu.au
isabel.higgins@newcastle.edu.au
shaun.mccarthy@newcastle.edu.au

^c Western Sydney University, NSW Australia
Building G10/Office 10, Hawkesbury Campus, Western Sydney University, Locked
Bag 1797, Penrith, NSW 2751;
Email: N.Wilson@westernsydney.edu.au

^d Macquarie University, NSW Australia
Room L6 36, Level 6, 75 Talavera Road, Macquarie University, NSW, 2109;
Email: andrew.georgiou@mq.edu.au

^e La Trobe University, Victoria Australia
School of Psychology and Public Health, College of Science, Health and Engineering,
La Trobe University, VIC 3086;
Email: sophie.hill@latrobe.edu.au

^f Deakin University, Victoria Australia
Deakin University, Melbourne Burwood Campus, 221 Burwood Highway, Burwood,
VIC 3125;
Email: susan.balandin@deakin.edu.au

Views on Advance Care Planning and Advance Care Directives

An Integrative Review of Stakeholder Views on Advance Care Directives (ACD):

Barriers and Facilitators to Initiation, Documentation, Storage, and Implementation

Highlights

- Advance Care Planning and Advance Care Directives are important elements of end-of-life care planning
- Health professionals might avoid discussion of Advance Care Directives and need guidance on initiating the conversation
- An online storage option for Advance Care Directives might help to facilitated documentation
- Further research is needed on implementation of Advanced Care Directives

ABSTRACT

Objective: To examine the views and experiences of patients and their health care providers on developing advance care planning (ACP) and advance care directives (ACD); and determine barriers and facilitators to ACD development, storage, and use, including implications for people with communication disability.

Method: An integrative review of 93 studies, analysed according to their content themes.

Results: Content themes encapsulated the initiation, documentation, and implementation stages of ACP/ACD. Lack of guidance for initiating and supporting ACP/ACD impedes discussions, and both patients and healthcare providers avoid discussions owing to fear of dying and reluctance to think about end-of-life.

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Conclusions: There are several barriers and facilitators to the initiation of ACP discussions, documentation and implementation of ACD, and little research exploring the views of legal professionals on the development, storage, or use of ACP documents. Further research is needed to explore the timing and responsibility of both legal and health professionals in initiating and supporting ACP discussions.

Practice Implications: It is important for healthcare providers to raise ACP discussions regularly so that patients have time to make informed advance care decisions. Storage of the document in an electronic health record might facilitate better access to and implementation of patients' end-of-life care decisions.

KEY WORDS - Advance care planning, advance care directive, end-of-life care, patient views

1. Introduction

Advance care planning (ACP) involves thinking about, discussing, documenting, and storing the types of health care desired at the end-of-life [1, 2]. Advance Care Directives (ACD) are legislated and common-law instruments by which people can (a) appoint or instruct a substitute decision-maker, and (b) document their future preferences for “health, medical, residential and other personal decision-making”. An ACD is distinct from “legislated instruments that allow for decisions about financial and legal matters” (p.9) [3].

Decision-making at the end-of-life is highly emotive and “provides a focal point for conflict within and between patients, families and treating staff” (p.13.3) [4]. Indeed, disagreements over treatment decisions at the end-of-life can jeopardise care often come “to the fore at the end-of-life” (p.490) [5]. Sufficient time spent on ACP discussions at this point could lead to the development of an ACD, diminish subsequent guilt and conflict over later decisions, offer a sense of control for people in the dying process [4], and reduce stress on surrogate decision-makers [6].

Unfortunately, patients who would benefit from engaging in ACP/ACD discussions have high risk of communication disability due to ageing (e.g., hearing loss), acquired health conditions (e.g., dementia, stroke, Parkinson’s disease), or lifelong disability (e.g., cerebral palsy, intellectual disability). There is little information available about how these patients and their family members and health providers develop and use ACP/ACD to inform their decisions at the end-of-life. Therefore, the aim of this review was to examine recent peer-reviewed literature on ACP and ACD to determine: (a) the views and experiences of patients, families, and health providers in relation to ACP and ACDs, (b) barriers and facilitators to developing, storing, or implementing an ACD, and (c) the extent to which patients

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with communication disability have been included in ACP/ACD research. This information could be used to inform policy and practice in relation to (a) developing communication supports for participation in ACP/ACD processes, (b) the use of new digital technologies such as personally controlled e-health records to support development, storage of and access to ACDs, and (c) future research examining ways to remove barriers and enhance facilitators to ACP and ACDs that foster the inclusion of adults with communication disabilities in discussions about these matters.

2. Method

2.1. Search terms and inclusion criteria

This integrative review [7] examined literature on the views and experiences of patients, family members, and health professionals, on ACP and ACD. In December 2016 and March 2018, the second and third authors searched for peer-reviewed literature in 11 legal and health scientific databases, using various combinations and permutations of the terms ‘Advance Care Plan/ning’, ‘Advance Care/Directive/s’, and ‘Advance Health Care Directive/s’, for peer reviewed journal articles published since 2010, written in English, and reporting the views and experiences of key stakeholders in relation to ACP or ACD.

2.2. Study review and selection

Titles and abstracts were screened for exclusion by the second and third authors with any disagreements resolved by consensus with the first author. Full texts were retrieved for a final decision on exclusion using the same method. In total, 69 full texts met the inclusion criteria, and their reference lists were reviewed for further inclusions. This yielded 24 relevant studies and a total of 93 articles addressing

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ACP/ACD. The process of searching, retrieving, and excluding studies is presented in a PRISMA (see Figure 1).

Insert Figure 1 about here

2.3. Data analysis

The first three authors read and discussed the articles to develop an inductive coding framework to guide further detailed analysis of each study in the review. This framework was based on the main aims of the studies and results pertaining to different stages and processes in ACP/ACD: (a) the views and experiences of key stakeholders in the ACP/ACD on: (i) the initiation stage, (ii) the documentation stage, and (iii) the implementation stage; and (b) barriers to and facilitators for ACP/ACD, at any of these stages. Directions for future research were also extracted.

3. Results

As study terms varied, we use ACP/ACD when both of these issues were the topic of the article, and either ACP *or* ACD if these were considered individually.

3.1 Characteristics of included studies

The included articles comprised 74 original research papers, 12 discussion articles, 1 instructional paper [8], and 6 review papers; from 14 countries.

Characteristics of the 74 original research articles are presented in Table 1; the focus areas of each of the articles is presented in Table 2; and quotes illustrating these focus areas are presented in Table 3.

<Insert Tables 1, 2, 3 about here>

This research synthesised the views and perspectives of doctors, nurses, healthcare providers, family members, or patients and others; but no studies related to legal professionals. Only two studies reported on the views or experiences of people

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with communication disability - one study focused on people with Parkinson's disease [9] and one on people with intellectual disability [10]. The major themes in the results are illustrated in Figure 2. Owing to the fact that storage of ACD in personal e-health record systems is now possible, Figure 2 also includes contextual factors as impacting ACP/ACD, notably health literacy, legal, and ethical issues affecting the use of personal e-health records for online storage of health information [11-13].

<Insert Figure 2 about here>

3.2. The initiation stage of ACP or ACD

3.2.1. *Personal factors: emotions, culture, and beliefs*

Cultural factors [14-19], including “social and personal taboos” associated with discussing dying (p.662) [20] and a prevailing “don't go there” culture (p.171) [21], impede end-of-life planning [17, 21-27]. A greater public awareness and openness towards discussing death and end-of-life issues is needed to improve uptake of ACP and ACD [28]. Health professionals fear that discussing ACP may erode a patient's hope [29-33], or upset them and their families [33] and these negative attitudes towards death and dying impede ACP discussions [20, 22, 34], particularly if professionals believe that their attention should focus on prolonging life [18, 30] (e.g., 23, 32, 35, 36). However, engaging in ACP discussions does not change patients' sense of hope, hopelessness, or anxiety [37] and healthcare providers need to address their own beliefs and attitudes towards ACP to facilitate more comfortable conversation and engage their patients in the process [38].

Healthcare professionals view avoidance of ACP discussions arises from conflict between a patient's family members [33], or a patient's reluctance to ‘burden’ a surrogate with decision-making responsibility [22]. They also considered that

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patients who believed the ACP could not be changed or revoked avoided ACP discussions for fear of losing control over their dying process [22, 39]. Emphasising that ACD can be altered or revoked could reduce the intimidation or confusion that patients may experience when faced with preparing this legal document [20].

Older patients' interest and reluctance to engage in ACP was affected by their "general level of scepticism about the ability of ACP to overcome bureaucratic obstacles to having wishes followed" (p.310) [40]. Reluctance on the part of patients [20] and family members [26] also stemmed from ACP processes being conflated with either euthanasia or assisted suicide, and possible concerns from older patients that promoting ACD reflects an ageist motivation to restrict the provision of healthcare as a cost-cutting measure [41, 42].

Accordingly, patients, their family members, and healthcare providers acknowledge the need for sensitivity when approaching the subject of ACP [21, 24, 36]. Nurses reported that their involvement in ACP was supported and justified when they were able to create a sensitive communication environment that enabled older people to document their wishes [21]. Sensitivity to the patient's family improved ACP outcomes, as the family is potentially affected by the implementation of any ACP or ACD [40].

3.2.2. Roles or responsibilities

While health professionals agree that a medical consultation is needed for effective ACP, they are not clear on whether a medical practitioner is responsible for initiating ACP discussions [43, 44]. Guidance on professional responsibilities for supporting and promoting ACP and ACD is lacking [22, 43] contributing to ongoing avoidance of the task and delays in its completion [45] by nurses [21] and physicians

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[46]. A preference amongst medical professionals that “somebody else” (p. 58) [46] initiate and engage in end-of-life planning might result from a lack of preparedness for the discussion [21, 46]. The majority (74.5%) of patients with Parkinson’s disease surveyed in the USA emphasised the importance of patients raising the ACP and ACD discussion [9]. Yet, patients may wait for doctors [20, 47], healthcare providers may wait for the patient or family members, and general practitioners (GPs) may wait for specialists to commence ACP or ACD discussions.

While some patients and carers are eager to discuss their future medical and care treatment [45], researchers in the UK [48], Australia [45], Italy [49], the USA [50] and Canada [51] report that most older people who had engaged in ACP had not discussed this with a health professional. Only 12 percent of patients enrolled in a palliative care program had received medical input into the development of their ACD [50]. Advanced cancer patients in Canada often discussed their ACD with family or a lawyer, but few sought assistance from healthcare providers [51]. These findings are at odds with the notion that ACP should involve ongoing discussion with health professional to ensure the individual’s wishes are clear and understood [25, 52].

Clarification of professionals’ roles surrounding ACP would facilitate more timely initiation of these discussions [43, 53] and the provision of support to patients for decision about their end-of-life care [22]. In particular, nurses need to play an active role in ACP, promoting communication and a values-based discussion [46, 54]. Professional interpreters might also be involved to reduce cultural barriers and increase ACD completion rates for patients from non-English speaking countries [55].

3.2.3. Time for the ACP/ACD discussions

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Health providers have reported lacking time to manage the complexities of ACP [33, 48, 56, 57], as they are not always able to manage their time towards ACP efficiently [58, 59] and some complete these in their personal time [31]. Clinical roles took precedence over ACP discussions, particularly as additional time was needed to sensitively raise the topic [60]. Although this did not impede ACP discussions entirely [21], it required more time than was usually available [20, 29, 56] as reflection time was needed to examine and clarify thoughts, feelings and concerns [21]. Indeed, in one study, 40 African American participants aged 25-84 from the faith community unanimously reported feeling that they would not be prepared to complete an ACD in a six-month time period [17]. Malpas [41] suggested several short consultations would be needed for planning and completing an ACD.

Lack of time to develop and document an ACD has several consequences. Incomplete discussions about treatment options result in ACP documents containing limited guidance for health professionals [61]. Patients and their families reported negative experiences when they were asked to make end-of-life decisions with little warning or time to think, resulting in significant distress [45], poor quality decisions, or suboptimal care [20]. When adequate time was taken for ACP discussions, patients and their families experienced improved satisfaction with care and significantly less anxiety and depression associated with the death of a family member [55, 58].

3.2.4. Scope of the ACP/ACD discussion

The scope of ACP or ACD discussions potentially includes values, beliefs, wishes [62], and specific medical treatments [63]. The scope of the discussion also changes over time, and should be revisited when health status changes [8]. In a survey of 1823 people aged over 65 years, Musa et al. [48] found that individuals were unable to perceive their potential future circumstances and changes to their health.

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Similarly, patients diagnosed with diseases with unpredictable trajectories struggled to make firm decisions in relation to an ACD [62].

ACP discussion is facilitated by a focus on the patient's values, goals and beliefs, and how these may be achieved, with the medical knowledge of the healthcare practitioner [20, 29, 55, 64, 65]. Prommer [65] identified a values-based approach to ACP/ACD as a non-threatening way for patients to confront end-of-life planning. This approach ensures that ACP content is guided by the patient's values, and minimises the risk of using ACD to limit medical treatment costs at end-of-life by hastening death [64]. Detering et al. [55] described how framing ACP discussions broadly can ensure that "both notions of individualism (autonomy, informed consent, and truth telling), and familism/collectivism (family sovereignty, familial roles and obligations) can be supported" (p.5).

Although patients requested a wider scope in their ACP discussions (e.g., including goals and values for end-of-life care), palliative care health professionals considered ACDs to be of limited value unless they explicitly addressed specific medical situations [63]. McMahan and colleagues [66] identified the need to expand ACP discussions beyond ACD and decisions about specific medical interventions, to include future planning and the appointment of a surrogate decision-maker. Overall, determining the appropriate scope and content of an ACP discussion is complicated by the differing expectations of patients and healthcare providers [63]. The association between ACP tools (i.e., wills, enduring power of attorney, ACD) indicates that there may be potential to improve the uptake of ACD by reframing the ACP discussion towards future planning. The tendency to discuss ACP only with individuals who may be unwell needs to be changed in order to achieve improved uptake of ACDs [67]. Emphasising that ACDs can be altered or revoked could reduce the intimidation or

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confusion patients may experience when faced with preparing this legal document [20, 39].

3.2.5. Timing of the discussion

Health professionals were not clear on the ideal stage (e.g., of the patient's age or health condition) to initiate ACP discussions [9]. Discussing ACP in abstract terms prior to the onset of severe illness is problematic [30], and delaying ACP discussions may be preferable if the patient struggles to see the relevance of these discussions [22, 46, 57, 68]. Health professionals consider that people with dementia find the point of diagnosis too early to discuss ACP, but there is also a reduced ability to participate in ACP discussions as the disease progresses [43]. If ACP is not initiated at the right stage, the time available for planning and the patient's ability to participate may be reduced, impacting on the quality of care decisions [20, 49] and the overall psychological health of patients and their families [33].

Early discussions about ACP enable a more complete consideration of matters [30, 35, 62, 69], depending on the needs and readiness of individual patients [10, 20, 68]. Sizoo et al. [70] suggested that specific guidance for healthcare practitioners on when to introduce ACP would be helpful. An ongoing conversation embedded within routine visits with the health professionals is useful [8, 20], enabling patients to decline the discussion until they feel ready [9, 36], and to change their ACD as their illness progresses [33]. Despite misgivings of some members of the public about healthcare provider financial reimbursement for time spent on ACP, such funding arrangements could also facilitate early and repeated discussions that are helpful [28, 42].

3.2.6. Inter-personal patient-provider relationships

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Patient-provider relationships are also important to facilitate a collaborative and holistic approach to ACP including all stakeholders [20]. GPs with longstanding and trusted relationships with their patients may be well-placed to engage in ACP discussions [20, 49]. A close relationship between the patient and their health provider may either (a) impede effective ACP discussion either by delaying initiation [71] or because of overly optimistic prognostication [72], or (b) promote effective engagement in ACP discussions [24, 73]. A weak patient-provider relationship can delay discussions [74], and family members attribute a reluctance to discuss end-of-life issues to residents' discomfort with care home staff [24]. Problems in the patient-provider relationship are amplified in acute care settings, where lack of time limits the building of rapport and the effectiveness of advance care discussions [60].

3.2.7. Awareness of ACP and ACD.

Patients and their health professionals lacking awareness and understanding about ACP and ACDs can prevent them engaging in discussions about these matters [27, 29, 51, 75-78]. An Australian survey of 171 older persons from culturally and linguistically diverse (CALD) backgrounds identified that poor awareness of ACP and ACD were the primary barriers faced by these patients when discussing advance care wishes [54]. However, information alone does not increase ACD completion rates significantly, and patients need an opportunity to interact with an expert in the field who will answer queries and offer them assistance [77, 79].

3.2.8. Differing views on the purpose of ACP or ACD.

Some patients making ACD believe the purpose of the documents is to provide explicit instruction for their healthcare providers to follow, while others view it as a tool to guide health professionals in their decision-making [52, 80].

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Misinformation and patients not being clear on the purpose of the ACD in relation to other end-of-life planning documents (e.g., a will [22] or enduring Power of Attorney [67]) may lead to care wishes not being clearly expressed or followed because the correct legal documents are not in place [22]. Specialists and GPs have been unsure about the role of a Power of Attorney, confusing this with an Enduring Guardian or surrogate able to make healthcare decisions [69]. These and other legal and ethical issues surrounding ACP and ACD are outlined in more detail in McCarthy et al. [12].

3.2.9. Lack of education, training, and skills

There is minimal education and training for health professionals who lack the skills [56] and knowledge [31] to talk about ACDs, including the implications and scope of the document and the process required to make a binding directive [22]. In addition to having the confidence to initiate ACP discussions [81], health professionals need to be competent in sensitively and effectively communicating a patient's prognosis and healthcare options [10, 82]. McKenzie et al. [10] identified these communication skills as being of increased importance when discussing ACP with patients with intellectual disabilities and their families. Without adequate skills and knowledge to guide development of an ACD, discussions are likely to lack the detailed and accurate information necessary to ensure the patients' wishes are followed and the ACD is implemented appropriately [32].

3.3. Documentation Stage of ACP or ACD

3.3.1. Quality of ACP/ACD forms

Patients require access to appropriate tools and resources to record their ACD and to ensure ACP/ACD discussions are directed towards relevant content. Limited access to these tools may hamper appropriate documentation, leading to inadequate

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end-of-life care that is not consistent with the patient's choices [22]. Poor quality ACP or ACD documents limit the completion and accuracy of formal documentation of ACD [61, 63, 83]. Luckett et al. [84] identified 14 different ACD template forms to record healthcare wishes, noting a large degree of variation in their structure and content, and language and literacy barriers may further limit access [54]. ACD forms are typically filled with legal and medical terminology that may be misunderstood or misinterpreted by patients, and there are few resources about ACD templates available for patients from non-English speaking backgrounds [84]. Such language and literacy barriers limit access to information to guide appropriate ACP discussions that address all relevant areas of end-of-life care.

Although a large number of templates are available to patients to support their recording of advance care decisions [84], these templates must be improved to enable all patients to more easily access and record their wishes. An audit of ACD documents in Australian aged care facilities identified that consistent document names and content requirements would improve the overall quality of ACD documentation, and therefore the outcomes of patients at end-of-life [85]. The variation between forms also needs to be addressed to minimise confusion and ensure healthcare providers are able to familiarise themselves with a standard procedure for completing an ACD [43, 85], bearing in mind that this is likely to be country specific.

3.3.2. Disputes or tensions over ACDs

Disagreements or tensions might arise between patients, families, and health professionals over the type of information that should be recorded in an ACD. Bond and Lowton [86] reported that geriatricians preferred ACD to be prescriptive, with explicit information regarding treatments to be provided or withheld in the event of specific medical circumstances. However, documenting a patient's values and goals

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for end-of-life care, with statements that guide the path of treatment rather than explicitly stating treatments may reduce the risk of patients becoming overwhelmed in the process [52].

Although explicit content about preferred medical treatments is beneficial to health professionals, a more flexible approach to recording ideal quality-of-life outcomes for the patient may improve their documentation of ACD [52]. Similarly, Zadeh et al. [8] reported that adolescents and young adults could be supported to document ACDs through personalising the document with quality-of-life outcomes, not being limited to only recording specific medical decisions. The discrepancy in expected content, or tension between specificity and broad statements of values or goals for treatment, were reasons why an audit of ACD documents used in Australian Aged Care Facilities judged many ACDs to be inadequate [85].

3.3.3. Storage of and access to ACD

An ACD needs to be stored in a location known to others where it can be quickly retrieved and referenced by health professionals when faced with decisions about end-of-life care [58, 75]. If storage is not appropriate the most up-to-date version of the ACD might be unavailable at a time when it is needed [22, 42]. Johnson et al. [63] surveyed Australian healthcare providers, and identified that while GPs were well placed to complete an ACD, sharing this information between providers was problematic [22]. The absence of a centralised storage system or register of completed ACD contributed to this problem [22, 53]. Such registries do exist, although information about appropriate methods of storage are not provided on ACD document templates [84]. The lack of instruction may contribute to reluctance

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and confusion when using an electronic record storage system and lower rates of use by GPs [44].

Johnson *et al.* [63] stated that “the greatest hope for embedding ACD across services and jurisdictions is the electronic medical record” (p.158). Electronic health records provide a means of secure storage for medical information, including ACD, while also enabling access to authorised healthcare providers who may need the document to inform care provision [28]. In the US, an implementation trial and document review by Turley *et al.* [87] evaluated the effectiveness of a unified storage tab for storing ACP documents in an e-health record. This led to a significant improvement in ACP documentation, and could improve the confidence of healthcare providers in the availability of ACD when needed [87]. In Australia, the MyHealth record offers online storage of ACD [12]. While uptake to date has been limited [63], improved information about online storage options could facilitate uptake and use for this purpose [84].

3.4. Implementation stage of ACP or ACD

An Australian study on implementation of ACDs found that a culture of “do everything” when delivering treatment at the end-of-life in residential care meant that an ACD may not always be followed (p.170) [21]. Health professionals may be hesitant to act on an ACD, particularly in circumstances where that action is irreversible, for fear of legal action [75]. This fear is greater in some jurisdictions where the law allows for verbal ACD, and health professionals may not be able to verify the expressed end-of-life wishes [41]. Conflict between a documented ACD and surrogate decision-makers’ views can increase the difficulty of providers’ decisions; leading to conservative treatment and the withholding of medical

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intervention [88, 89]. Researchers in the UK reported that nursing staff experience conflict when attempting to promote the healthcare wishes of residents that conflict with the preferences of family members [24]. Providers may object to, and over-rule, an ACD due to reasons of conscience or because of existing policies and procedures, particularly in emergency medicine [75] and in the perioperative setting [90].

Clear policies and procedures will better support healthcare providers to implement ACDs [33]. In a survey of 350 specialists and 650 GPs in Australia, over three quarters reported that they would follow an ACD whatever their own personal opinions regarding treatment; while 13 per cent would not follow an ACD if they disagreed with the patient's decisions [69]. Clear departmental policies about legal and ethical requirements would improve the knowledge and practice of healthcare providers as they integrate the patient's wishes with the medical care they provide [22, 40].

Open lines of communication between all members of the healthcare team and the patient's family facilitate better outcomes for all involved in the patient's dying [60, 63, 91, 92]. When family members are involved in the discussion of implementing an ACD, they report greater satisfaction with the quality of care received by the patient, and reduced anxiety and depression [58]. Additionally, stress is reduced when the surrogate decision-maker is guided by an ACD [6]. Similarly, registered nurses working in residential care settings reported feeling satisfaction, relief, and comfort as a result of upholding a patient's healthcare or end-of-life wishes [21].

3.5. Facilitators to ACP/ACD

3.5.1. Increasing education and training.

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Several studies emphasised the importance of healthcare professionals receiving continuing education about ACP processes [22, 23, 28, 31, 32, 42, 56, 69, 75, 93-95]. Researchers have evaluated education programs aimed improving the skills of doctors [59] and nurses [60, 95] in undertaking ACP discussions with patients. The additional training led to improvements in confidence when initiating discussions about ACP [59, 60]. Patients might also benefit from education about ACP as this facilitates initiating a discussion with the healthcare provider or completing an ACD [96]. Such education can also inform patients of their rights to make their own medical decisions [64]. The myths and misunderstandings surrounding ACP and ACDs have deterred patients from engaging in all stages the process [33].

3.5.2. Improving information on ACP and ACD.

To overcome patients' perceived poor engagement with ACP and lack of access to information [29], more comprehensive and detailed information must be made available. However, the best information to support ACP appears to come from personal exposure and experience in ACP and creating an ACD. Patients [48], caregivers [25], and health professionals [56, 71] report more informed ACP practice after having completed an ACD previously for themselves or a close family member. To improve their knowledge of ACP and ability to communicate this information to patients, Black [56] suggested that health professionals be encouraged to engage in ACP themselves during their professional training. Similarly, patients who had previous exposure to circumstances where ACP was needed and implemented were more able to conceptualise their own ACP [48, 66]. Previous experience may be difficult to provide, but McMahan *et al.* [66] reported that information about 'worst

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case scenario' outcomes may support decision-making by reducing the hypothetical element to discussions.

4. Discussion and Conclusion

The results of this review provide important insights into the broad range of issues to be considered in developing interventions for ACP/ACD processes, particularly at the initiation stage. Under-researched groups include legal professionals, social work or social welfare professionals, adolescents, and adults with lifelong or acquired disability. There is also a need for additional research to be carried out in non-English speaking countries and exploring the views of various CALD populations [48, 55, 79]. Training and educational programs must also address “culturally sensitive” ACP discussions (p.385) [16].

The lack of theory development in the literature, and reliance on descriptive research, indicates that a more nuanced understanding of the factors motivating individuals to engage in and move through all stages of the ACP process is needed [67, 97]. Research exploring both the *interrelationship* of an individual's personal experiences and the ACP practices in which they have engaged [56, 67] and the impact of the experiences and practices [43, 63], could inform theory development. In Australia, for example, recording the patient's ACD in the clinical records is a quality and safety standard for accreditation of hospitals [98]. This might be facilitated by both upload of an ACD to an electronic personal health record (e.g., the My Health Record) [12] that connects to hospital electronic medical record systems. Additional clinical research is needed to understand how often ACD are accessed and implemented by healthcare providers [99], and to evaluate the “effects of ACP on clinical outcomes and the fulfilment of patients' wishes” (p.665-666) [20].

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It is important to understand more about which patients prefer to broach the subject and when optimally this should occur [22, 24]. Future research could make better use of the several online resources for eliciting and recording consumers' views and preferences in relation to ACDs [84, 96]. Health systems and policy research is needed to examine the feasibility of a "whole-system ACP model" in which there exists "organizational wide commitment and preparedness for health service reform to embed advance care planning into routine practice" (p.2021) [93]. Rhee et al. [28] identified the need for ACP programs to be implemented systematically in health systems. Research on the effectiveness of online ACD storage options, including the use of personal e-health records [87], could inform policies and practices around the implementation of ACD and personal e-health records.

4.1. Implications

This review provides important insights into the benefits and motivators for individuals to engage in ACP/ACD. These include the desire to exercise personal autonomy [15], improve personal quality-of-life [40], maintain self-sufficiency [15], and minimise decision-making burden on family members [6, 15, 25, 40]. Healthcare policy development is now needed to support both the documentation and implementation of ACDs. Such policies need to support healthcare providers in having the knowledge and confidence to raise ACP discussions regularly during routine clinical interactions so that patients have time to consider and make informed advance care decisions [20, 41]. Policy development on the storage, retrieval, and implementation of ACDs is also required to strengthen the procedures around the development and management of ACDs in the wider healthcare system. Following ACP discussions and documentation of ACD, storage of the document in an electronic health record [12], might facilitate better access for healthcare professionals

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to patients' clearly documented end-of-life care decisions and facilitate ACD implementation [63, 87] for better outcomes [60, 63, 91, 92].

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Figure Captions

Figure 1: Systematic search process for literature identification, review and exclusion

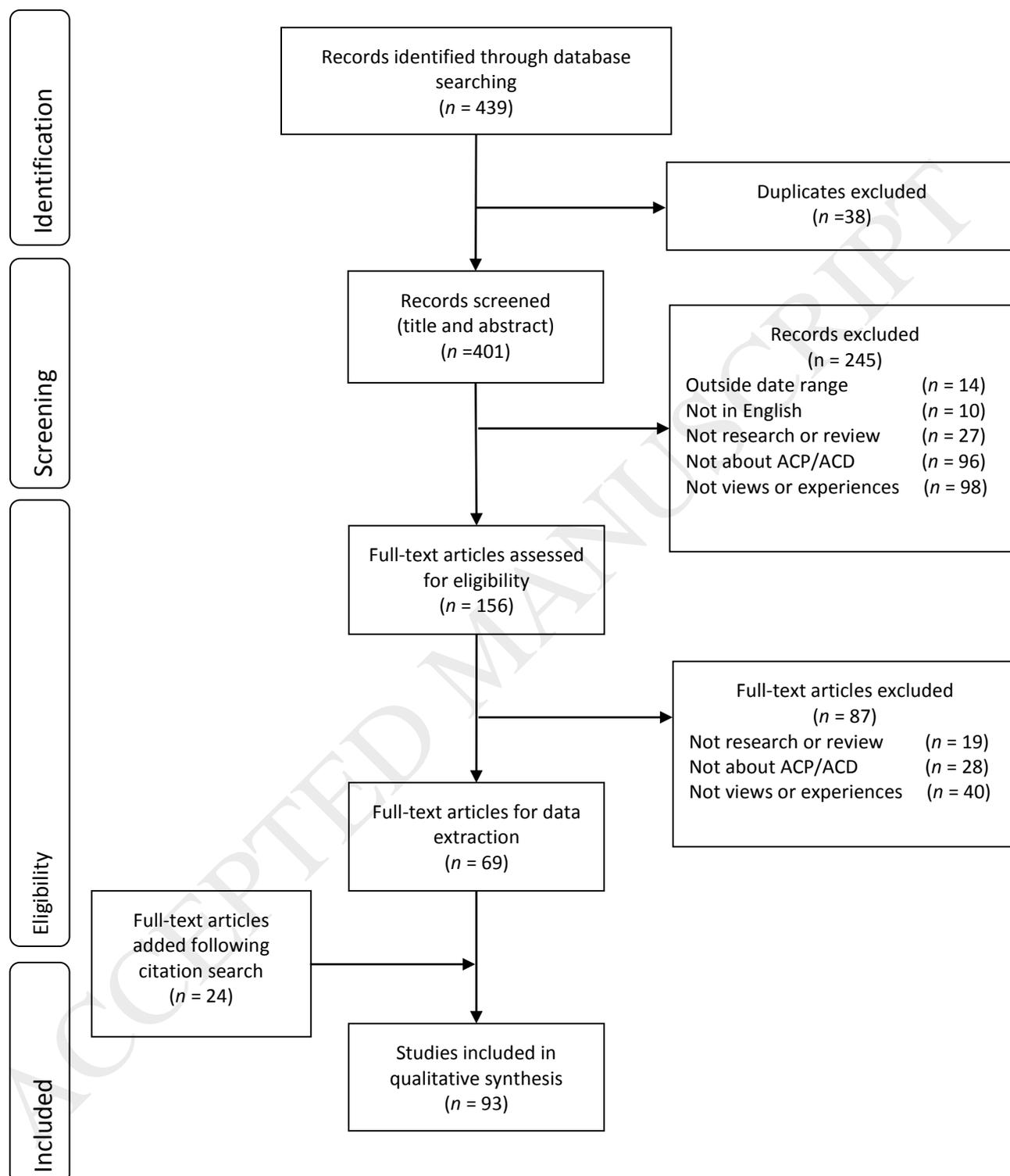
(adapted from Prisma diagram)

Figure 2: Barriers, facilitators, and other factors in stages of ACP and ACD:

Initiation, documentation, and implementation

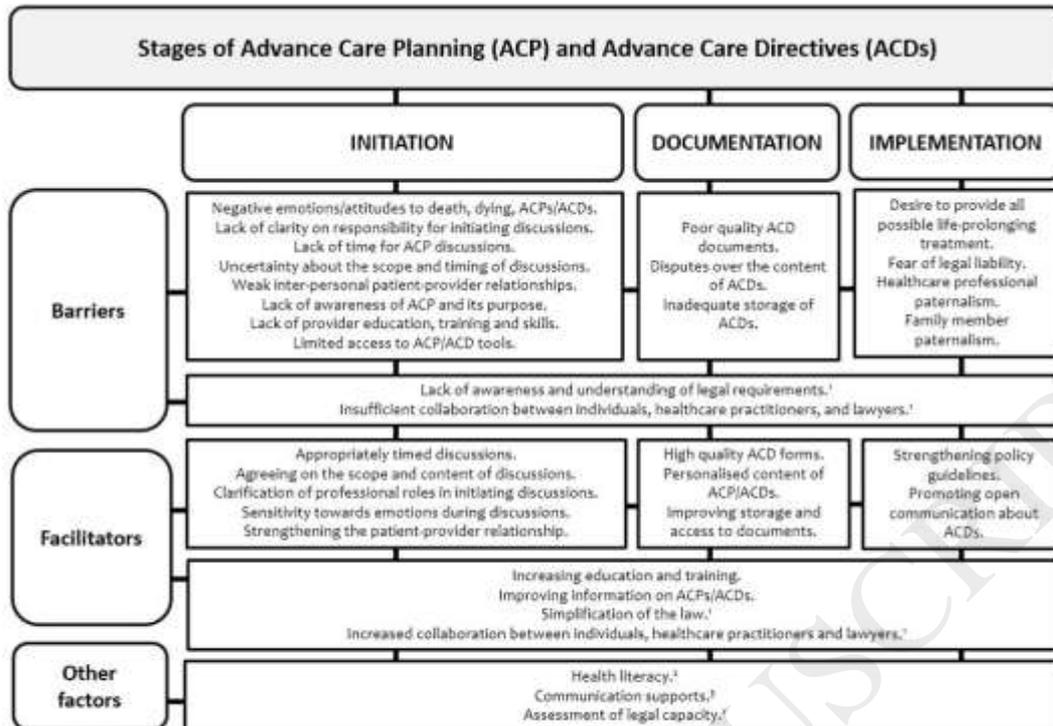
ACCEPTED MANUSCRIPT

Figure 1: Systematic search process for literature identification, review and exclusion (adapted from Prisma diagram)



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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¹ Factors revealed in legal and ethical studies (9, 10)² Factors revealed in health literacy studies (11)³ Factors revealed in communication disability studies (9)

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Table 1*Characteristics of original research in the included studies*

Focus	First author	Year	Ref no.	Country¹	Research method/type	Participants included in the study
Discussion of ACP/ACD	Arnett	2017	53	USA	Survey	Health professionals (n = 118) including physicians (53%), practice nurses (18%), nurses (11%), other (25%)
	Baughman	2012	71	USA	Survey	Community-based long-term care providers (n = 182)
	Boddy	2013	22	AU	Focus groups	Hospital practitioners (n=41)
	Boucher	2017	19	USA	Interviews	Older community-dwelling adults of Dominican (n = 23) or Puerto Rican (n = 28) descent
	Brown	2012	45	AU	Interviews	Pts with advanced COPD (n=15)
	Detering	2015	55	AU	Intervention	Hospital inpatients aged 65 or above who spoke Greek (n=25), Italian (n=24) or English (n=63)
	Green	2015	37	USA	Randomised control trial	Pts with advanced cancer (n = 200)
	Hutchison	2017	57	Ca	Interviews	Pts with renal failure (n = 9), their family members (n = 7) and clinicians (n = 9)
	Ingravallo	2018	49	ITL	Interviews	Nursing home residents (n = 30) and family members (n = 10)
	Jeong	2011	21	AU	Multi-methods case study	Registered Nurses (n=13)

¹ Key: AU = Australia, BE = Belgium; Ca = Canada, Ch = China, Ger = Germany, IRE = Ireland, ISR = Israel, ITL = Italy, KOR = Korea, LTU = Lithuania, ND = Netherlands, NZ = New Zealand, SUI = Switzerland, Sw = Sweden, UK = United Kingdom, USA = United States of America; ACD = Advance Care Directive, ACP = Advance Care Planning, COPD = Chronic Obstructive Pulmonary Disease, HIV = Human Immunodeficiency Virus, pts = patients, RACFs = Residential Aged Care Facilities, SNFs = Skilled Nursing Facilities

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Jeong	2015	54	AU	Survey	Older community-dwelling individuals from culturally and linguistically diverse backgrounds ($n=171$)
Liberman	2016	23	USA	Intervention	Families of children with a complex chronic medical condition ($n=20$)
Lotz	2017	36	Ger	Interviews	Parents of deceased children ($n = 11$)
MacPherson	2012	62	UK	Interviews	Pts with severe COPD ($n=10$)
McKenzie	2017	10	NZ	Interviews and document review	People with Intellectual Disability and life-limiting conditions ($n = 4$), family members ($n = 3$), disability support workers ($n = 4$)
Michael	2014	25	AU	Focus groups and interviews	Primary and secondary caregivers of pts with lung and gastrointestinal tumor ($n = 18$)
Musa	2015	48	UK	Survey/ questionnaire	Persons aged 65 or over ($n=1,823$)
Pfeil	2015	46	Ger	Interviews	Physicians ($n=12$) and nurses ($n=6$) working at the Department of Haematology/Oncology at the University Hospital in Munich
Sanderson	2016	35	USA	Survey	Paediatric physicians ($n = 107$) and paediatric nurses ($n = 159$)
Sinclair	2016	74	AU	Survey	GPs ($n = 70$)
Song	2017	92	USA	Interviews	Bereaved surrogates of dialysis patients ($n = 24$)
Stewart	2011	24	UK	Interviews	Care managers ($n=33$), Nurses ($n=18$), Care assistants ($n=29$), Community nurses ($n=10$), and families ($n=15$)
Tuck	2015	9	USA	Survey	Pts with Parkinson's Disease ($n=267$)
Ulrich	2010	99	USA	Survey	Nurses ($n=422$)
van Eechoud	2014	26	BE	Interviews	Family members of pts in geriatric settings aged 70 or older with a limited life expectancy ($n = 21$)
West	2012	17	USA	Focus groups	African Americans aged 25-84 from the faith community ($n=40$)

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Awareness of ACP/ACD	McMahan	2013	66	USA	Focus groups	Pts from primary care clinics, cancer support groups, and senior centres ($n=38$) and Surrogate decision-makers ($n=31$)
	Cartwright	2014	69	AU	Survey	GPs ($n=650$) and medical specialists ($n=350$)
	Michael	2013	82	AU	Interviews	Pts aged over 25 with lung or gastro-intestinal tumour ($n=18$)
	Rhee	2012	28	AU	Interviews	Healthcare professionals and representatives of organisations with experience in aged care, end-of-life issues and ACP ($n=23$)
	Silvester	2013	61	AU	Survey	12 aged care organisations (representing 19 RACFs), 12 RACFs, and 45 staff (from 19 RACFs)
	Tripken	2018	78	USA	Survey	Older adults over 55 years ($n = 77$)
	Tripken	2018	27	USA	Survey	Young adult university students ($n = 310$)
	Zhou	2010	33	USA	Survey	Oncology Advanced Practice Nurses ($n=89$)
Education in ACP/ACD	Colville	2012	60	UK	Interviews	Nurses attending an ACP study day ($n=16$)
	Detering	2014	59	AU	Training evaluation	Doctors ($n=148$)
	Lesperance	2014	31	USA	Training evaluation	Providers from oncology practices ($n=11$)
	McGlade	2017	95	IRE	Training evaluation	2 Long term care nursing homes and 1 community hospital
	Radhakishnan	2017	77	USA	Focus groups	South Asian Indian American adults ($n = 36$), family carers ($n = 10$), physicians ($n = 4$)
	Reinke	2011	96	USA	Intervention	Pts with severe to very severe COPD ($n=7$)
Skills or attributes	Black	2010	56	USA	Mixed methods - focus groups, questionnaire	Geriatric case managers ($n=148$)
	Peicius	2017	76	LTU	Survey	Health care professionals including nurses, physicians and pharmacists ($n = 478$)
Motivators for ACP/ACD	Ho	2013	15	Ch	Multi-methods – ethnography, interviews	Terminal cancer pts ($n=18$)

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	Levi	2010	40	USA	Focus groups	Senior centre attendees ($n=16$) and breast cancer support group attendees ($n=7$)
	Rhee	2011	80	AU	Interviews	Healthcare professionals and representatives of organisations with experience in aged care, end-of-life issues and ACP ($n=23$)
Purpose of ACP/ACD	Willmott	2013	52	AU	Mixed methods – expert reference group, interviews and focus groups, survey	A critical reference group consisting of representatives from legal and advocacy organisations, medical practitioners, and a social worker; interviews with doctors, professionals who have assisted in ACD form completion, and principals ($n=18$); surveys completed by principals and doctors ($n=37$)
Storage	Turley	2016	87	USA	Document review	ACD documentation rates of Pts in an integrated care delivery system aged 65 years and older ($n=57,058$)
	Dillon	2017	44	USA	Interviews	Health providers with high or low rates of ACD documentation ($n = 13$)
Usage	Blackford	2012	92	AU	Mixed method action research – document audit, interviews	Community palliative care services ($n=3$)
	Chen	2015	50	USA	Case control cohort pilot intervention	Pts in a Palliative Care Homebound Program ($n=54$)
	de Caprariis	2013	100	USA	Record review	Review of Pts' charts ($n=182$)
	Guo	2010	72	USA	Record review	Cancer pts with <i>Metastatic Spinal Cord Compression</i> ($n=88$)
	Lu	2011	16	USA	Record review	Nursing homes residents ($n=10,023$)
	McDonald	2017	51	Ca	Survey	Advanced cancer patients ($n = 193$)
	Pockett	2010	81	AU	Record review	Review of medical records ($n=310$)

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	Schellinger	2011	101	USA	Record review	Pts with a primary or secondary heart failure diagnosis ($n=1,894$)
	Silveira	2010	102	USA	Survey	Persons aged 60 or older who died between 2000-2006 ($n=3,746$)
	Van Leuven	2011	103	USA	Mixed-methods – interviews, observations	Persons aged 75 and over ($n=18$)
	Van Leuven	2012	104	USA	Multi-method - Chart review, observation	Pts residing in three SNFs ($n=272$)
	White	2014	67	AU	Survey	Australian adults ($n=2,405$)
Content	Kim	2017	39	KOR	Survey	Cancer patient-caregiver pairs ($n = 80$)
	Luckett	2015	84	AU	Document review	Review of online ACD templates ($n=14$)
	Silvester	2013	61	AU	Document audit	RACFs ($n=19$)
Implementation	Bond	2011	86	UK	Interviews	Geriatricians ($n=10$)
	Bump	2011	83	USA	Observational cohort study, mixed methods – survey, observation, record review	Internal medicine interns ($n=24$)
	Escher	2014	88	SUI	Survey	Generalists and Internists ($n = 853$)
	Escher	2015	89	SUI	Survey	Generalists and Internists ($n = 853$)
	Jeong	2010	64	AU	Multi-methods case study - observation, interviews, document review	Residents, families, and registered nurses in teaching hospitals ($n=2$) and high-care facilities ($n=20$)
	Jones	2012	94	AU/ Ca/ Sw	Record audit	Pts who received a medical emergency team call ($n=518$)
	Robinson	2013	43	UK	Multi-methods - Focus groups, interviews	Participants from 1 Primary Care Trust, 2 acute National Health Service Hospital Trusts, 1 Ambulance Trust, 1

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						Local Authority, and voluntary organisations and the legal sector (<i>n</i> =95)
	Schweda	2017	18	USA/Ger/ ISR	Focus groups	Religious and secular adults (<i>n</i> = 82) from USA (<i>n</i> = 23), Germany (<i>n</i> = 29) and Israel (<i>n</i> = 30)
	Sizoo	2012	70	ND	Survey/ questionnaire	Physicians and relatives of deceased high-grade glioma pts: GPs (<i>n</i> =71); nursing home specialists (<i>n</i> =21); clinical specialists (<i>n</i> =9); Deceased pts' partners (<i>n</i> =41); parent (<i>n</i> =3); and sibling (<i>n</i> =1)
Outcomes	Detering	2010	58	AU	Prospective RCT	Medial inpatients aged 80 or more (<i>n</i> =309)
	Johnson	2015	63	AU	Survey	Healthcare practitioners working in Palliative Care Services (<i>n</i> =60)

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Table 2*Primary focus of articles included in the review*

Stage	Focus	Primary focus ²	Secondary focus	Total
Initiation	Discussion (Total)	35	17	33
	- Emotions/Attitudes	19	6	15
	- Initiation/Responsibility	11	5	11
	- Scope of Conversation	7	3	10
	- Timing	8	5	8
	- Relationship	2	4	4
	Awareness	9	8	9
	Education (Healthcare Practitioners)	5	4	8
	Skills/attributes (Healthcare Practitioners)	2	5	6
	Motivators	3	2	4
	Access to ACP tools	0	3	3
Purpose of ACD	1	0	1	
Documentation	Usage	13	6	16
	Content	3	5	4
	Storage	2	1	1
Implementation	Implementation (Before Death)	12	6	15
	Outcomes (After Death)	3	5	7

² Some studies were assigned dual primary/secondary codes.

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Table 3*Quotes supporting the focus areas*

Stage	Focus	Quote, source, page number	
Initiation	Discussion	Emotions/ Attitudes	<p>“I’ve made a will and a power of attorney but I haven’t done anything about the medical things because it’s too scary.” (Community-dwelling older person) (p.372) [48].</p> <p>“I’d sort of thought about it, and you think, if I fill that out now, that could be the end of me.” (Patient with advanced COPD) (p.406) [45].</p> <p>“I don’t even want to think about it. I have a hard enough time dealing with now. I can’t plan for what might happen.” (78-year-old with post-polio syndrome and a history of breast cancer) (p.11) [103].</p> <p>“I suppose I’ll live a long life because my mother did. So I guess that means I’ll have a lot of pain and misery. But that’s not something I want to think about it. I don’t think it’s appropriate to even talk about it.” (78-year-old female with hypertension and osteoarthritis was three years post lumpectomy for breast cancer) (p.11-12) [103].</p>
		Timing	<p>“It’s not something you’d want to dwell on whilst you’re enjoying the day to...think about cancer, cancer, cancer all the time” (Female organising end-of-life care in relation to considering ACP when initially diagnosed) (p.2198) [82].</p> <p>“Discussion early on would be broad, hopeful, and not too much detail. As the disease progresses, those same topics would be discussed at a deeper, more immediate level.” (Patient with Parkinson’s disease) (p.70-71) [9].</p>
		Relationship	<p>“It’s the relationship you build...it’s not fair that I hardly know them and I go in and say ‘where would you prefer to die?’” (District Nurse) (p.332) [24].</p>
		Initiation/ Responsibility	<p>“I do not see myself as somebody who goes to the room and actively starts speaking of death; if the patient wants this, I would take this up.” (Physician) (p.58) [46].</p> <p>“Nobody knows what to do or whose role it is to do it, how they’re going to do it and I think it’s just something that’s overlooked...” (Voluntary sector professional) (p.405) [43].</p>

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		<p>“You don’t often have a lot of time, the more time you spend doing it the better and you get more of a sense about that person and then you can say back to them, ‘well my impression from what we have talked about, I get the sense that you’re really, you make decisions this way or that way’ or something like that. And they can agree or differ or they might think about that until the next meeting. (Registered Nurse) (p.170) [21].</p>
Scope of Conversation		<p>Most participants wanted more information about how their disease would progress, and more discussion about the future (p.268) [62].</p>
Awareness		<p>“they [patients] don’t understand what they [advanced directives] are so they don’t understand the consequences of not having one”. (Nurse) (p.40) [22].</p>
Education	(Healthcare Providers)	<p>“I get confused about the terminology about advance care and advance directive and that and one’s legally binding and one isn’t and it all becomes a bit of a blur.” (General Practitioner) (p.404) [43].</p>
Skills/ attributes	(Healthcare Providers)	<p>“...they can’t talk about the palliative care or the end-stage processes. They don’t feel at all educated enough or confident enough to do that discussion” (in reference to health professionals discussing ACP with their patients) (Manager of a care organisation) (p.100) [28].</p>
Motivators		<p>“I’d be more hesitant to do something if it was going to be more of a disadvantage to my family than an advantage to myself.” (p.309) [40].</p> <p>“If you’re just laying there, don’t know nobody, don’t know your kids, unconscious, don’t know nothing. And you’re on the machine...That’s terrible.” (Older person) (p.309) (13).</p>
Access to ACP tools		<p>“Where can we get these documents?” (65-84 year old African American) (p.133) [17].</p> <p>“Online availability of ACD templates, guidelines and other materials has several advantages. The user-led nature of online materials is consistent with ACP’s original philosophy of patient autonomy. The internet allows consumers to complete ACD at a time and place convenient to themselves and their families, providing an opportunity for promotion and uptake of ACP for people who do not regularly access formal healthcare. It also provides an opportunity to access</p>

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		additional information that consumers may require to inform their decision-making about various medical conditions and treatments” (p.553) [84].
	Purpose of ACD	“I do get a lot of people telling me that they don’t need an advance directive because it’s all covered in their will, and when you explain to them what the difference is and what an advance directive is they just say ‘oh no that’s all covered in my will’. (Social worker) (p.40) [22].
Documentation	Usage	<p>“People have discussions about it with their family but unless it is actually written down in a way that meets the requirements of being valid so it needs to be specific and applicable to their situation and unambiguous. Then there can be no misunderstandings.” (RACF nurse) (p.200-201) [80].</p> <p>“I would strongly prefer he writes it [ACP decisions] down, as I always tell in my lectures about advance directives, when you do not know or it isn’t written down, or as in most cases hasn’t been decided yet, it causes a lot of complications... When written down, it clarifies things. Additionally, if he, for example, lapses into a coma, I will need a paper to prove his wish [termination of life]. If it happens now, I will have to depend on the good will of the physicians.” (Son of patient aged over 70 with a limited life expectancy) (p.881) [26].</p>
	Content	<p>“There are difficulties around a very specific advance directive. The directive won’t necessarily have force when those kinds of circumstances might not exist, or if the directive is too general that’s not helpful either because if it applies to all possible events it is usually too vague to give any help” (Consumer representative) (p.101) [28].</p> <p>“...talk people through the ramifications of what they’ve written. Sometimes it is written in language that isn’t clear enough. You’ve got to try and get language that’s as clear as possible”. (Professional society representative) (p.101) [28].</p> <p>“What we actually want is guidance ... my experience is that families who are making most of the decisions ... even when I have an AHD [for the patient], which I totally respect, I usually cannot apply it in the situation in which the patient is in ... I still have to ask the health attorney for agreement of the decision.” (Doctor) (p.42) [52].</p>

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Storage	<p>“...we speculate that a single easily accessible location for these documents may engender confidence among clinicians that the effort required to obtain them will be well spent because advance care planning documentation will be available when needed.” (p.47) [87].</p>
Implementation Implementation (Before Death)	<p>“We might write that down in our notes but then you might have a locum in who might go to another practice. It might be an agency nurse. It’s written in the notes and no-one ever knows it’s there” (Health Department officer) (p.101) [28].</p> <p>“How can the lay public understand all the intricacies of what we decide? They won’t understand basic science, they don’t understand interventions, they can’t understand lots of issues” (Consultant geriatrician) (p.452) [86].</p> <p>“If you make an Advanced Care Directive and you’ve got it in writing and you are admitted to hospital, there are doctors there to save lives, what are they going to do? You know there is still that issue. People are letting their wishes be known and yet they are still being kept alive. So there is always something, it is not going to happen overnight.” (Registered Nurse) (p.170) [21].</p>
Outcomes (After Death)	<p>“I think, so much of this stuff can be just tokenism ... my father, when I filled in something for him...about his life...but then I didn’t hear anything about it after that.” (Son of a recently deceased resident of a nursing home) (p.332) [24].</p>