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Cultural factors influencing Advance Care Planning in progressive, incurable disease: A systematic review with narrative synthesis

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Running head: Cultural acceptability of ACP

Abstract

Context: Advance care planning (ACP) can improve end-of-life outcomes, but low uptake indicates it is less acceptable to patients of some cultural backgrounds.

Objectives: To explore how cultural factors influence ACP for patients with progressive, incurable disease and how ACP could be made cross-culturally appropriate.

Method: Systematic literature review using narrative synthesis. Protocol registered prospectively (PROSPERO CRD42017060441). Key words and subject headings of six databases (AMED, PsycINFO, Embase, Ovid MEDLINE, CINAHL, Cochrane) were searched without time restrictions. Eligible studies reported original research published in full that included adult participants with progressive, incurable disease or their formal or informal caregivers. Study quality was assessed using the Mixed Methods Appraisal Tool.

Results: 818 studies were screened. 27 were included: 20 quantitative, 4 qualitative and 3 mixed methods. Most (20/30) studies were conducted in the USA, where non-White ethnicity was associated with lower acceptability of formal, documented ACP processes. Cultural factors affecting ACP acceptability included religiosity, trust in the healthcare system, patient and clinician comfort discussing death, and patient attitudes regarding decision-making. Informal, communication-focused approaches to ACP appear more cross-culturally acceptable than formal processes. Clinician education in cultural-competence is recommended. Study limitations included use of un-validated tools and convenience samples, and lack of reflexivity.

Conclusion: Many interconnected cultural factors influence the acceptability of ACP in progressive, incurable disease, although specific mechanisms remain unclear. A communication-focused approach may be valuable in adapting ACP to meet the needs of culturally diverse populations.

MeSH Keywords:

Advance Care Planning; palliative care; culturally competent care; ethnic groups; culture; patient preference; health services accessibility; review

Introduction

Significant advancements in medical technologies and modern biomedical medicine have led to widened availability of life-sustaining treatments(1). However, the use and withdrawal of these treatments pose ethical challenges for all involved in end of life (EOL) care(2-5) and can have adverse impacts on patients and their families(6). In this context, advance care planning (ACP) offers potential to improve patient and family outcomes, through identifying, documenting and enacting patients' EOL preferences.

A recent consensus statement defined ACP as "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", with the goal of helping to "ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness"(7). Documented benefits of ACP include improvements in patient and family satisfaction and well-being(8), improved concordance between preferences for care and delivered care(9, 10), and healthcare savings(11). These benefits are reflected in endorsement of ACP by the Australian(12), British(13) and American(14) medical associations.

Given globalisation and increasing migration, requirements for cross-culturally appropriate EOL care are set to increase(15), as reflected in palliative care policy guidance(16, 17). However, there is evidence of significant disparities in uptake (i.e. acceptance of or engagement with) of EOL decision-making and care-planning support services, including ACP, amongst minority ethnic groups in multi-cultural settings in the UK(18), New Zealand(19), the USA and Australia(20). Despite this, little attention has been given to cross-cultural issues in ACP to date(20).

Understanding ACP's impact in different populations, settings and contexts is needed to maximise the full potential of ACP(21). In particular, if all patients and families are to benefit from ACP, there is a need to better understand how cultural factors influence its acceptability. "*Culture*" can be understood as a system of ideas, rules, meanings, and ways of living and thinking that are built up, shared, and expressed by a particular group of people, often of the same ethnic background(22-24). In 2014, Lovell and Yates published a systematic review examining the influence of contextual factors on the uptake of ACP among adults and identified ethnicity as one of these(25). But research on the influence of ethnicity and culture included in their review was limited to five USA-conducted studies. Another review in this area examined the attitudes of culturally diverse groups towards EOL decision-making(26), but focussed on community-dwelling older adults, who may have varied levels

of health or illness. There is evidence that patients' EOL wishes, such as treatment preferences or desire for truth-telling, are influenced and changed by: time and health state(27), greater experience of illness(28) and extent of available information about advance directives (AD)(29). There is therefore a need to synthesise evidence related to the influence of cultural factors in ACP for patients with progressive, incurable conditions, who are likely to have different needs and views of ACP than healthy adults.

This systematic review aimed to answer the following questions:

1. How, if at all, does patients' and families' cultural background influence the acceptability of ACP for seriously ill patients?
2. How might ACP need to be adapted to make it more cross-culturally appropriate?
3. What cultural factors do clinicians need to be aware of in approaching communication and planning with patients and families about EOL issues?

Methods

Design, protocol and registration

We conducted a systematic literature review with narrative synthesis, a primarily textural approach to synthesising and presenting the findings of multiple mixed-methods studies as a narrative, as outlined by Popay et al(30). Given that the research conducted to date into cultural factors in ACP features both qualitative and quantitative studies, narrative synthesis was an appropriate approach for the first systematic review in this area. The review protocol was registered prospectively with PROSPERO(31).

Inclusion and Exclusion Criteria

Participants: We included studies of adults with progressive, incurable disease and their formal (staff) or informal (family) caregivers. Progressive, incurable conditions included but were not limited to: advanced or late stage (3+) cancer, HIV/AIDS, dementia, Parkinson's, organ failure (including renal and heart failure), chronic obstructive pulmonary disease. Mixed study samples in which at least 50% of participants had incurable, progressive illness were included.

Studies: To reflect the complexity of the concept of culture, we included research that measured, adjusted for, recorded and/or explicitly considered the influence on ACP of 'cultural' factors including: ethnicity/"*race*", religion/spirituality, nationality or country of permanent residence. We operationalised 'culture' in these broad terms, to help ensure

important factors related to the acceptability of ACP were not missed. We define ethnicity as "*the fact or state of belonging to a social group that has a common national or cultural tradition*"(32). "Race" is a more difficult concept to define, often tied to crude categorisation based on skin colour, and is considered scientifically discredited(33); our use of the term in our narrative reflects its use by study authors. We explicitly included research that considered the influence of religion/spirituality on ACP uptake, because religion and spirituality are intimately related to and expressed via culture, and can influence how and whether a patient identifies with a particular culture(34). All study designs were included if inclusion criteria were met and the research was published in full, to achieve a comprehensive understanding of cultural factors in ACP. Only original research was included, as the review aimed to synthesise empirical evidence. Studies were excluded if they met any of the following criteria:

Participants: Children and adolescents (under 18 years of age); cancer survivors (people whose cancer is in remission and who are no longer being treated); elderly populations without progressive, incurable disease; people with chronic but not incurable conditions e.g. diabetes, arthritis; mixed study samples in which <50% had incurable, progressive disease or where the proportion with such disease could not be determined; studies of trainee (unqualified) healthcare providers.

Studies: Studies not reported in English were excluded due to resource limitations. Research studies that did not include consideration of ACP or culture, as operationalised above, were excluded. Reports of studies only available as abstracts or letters to the editor were excluded, as were review articles. Studies were not excluded based on institutional setting or country.

Information Sources and Searches

We searched six electronic databases (Box 1) on the 26.03.2017. Initial keywords of sentinel papers (25, 26, 35-39) and corresponding subject headings were used to identify synonyms for 3 elements of our topic area: [ACP] AND [Cultural factors] AND [Acceptability]. The search strategy (Table 1) was developed in Ovid SP's and adjusted for the CINAHL and Cochrane databases, to reflect the different subject headings.

Study Selection

Titles and abstracts of papers retrieved were screened independently to identify studies that potentially met the inclusion criteria (EM). The full texts were retrieved and assessed for eligibility (EM), with a random sample of 10% independently screened to check consistency

in application of the criteria (LS). Disagreements between EM and LS over the eligibility of studies were resolved through discussion and reference to and refinement of the inclusion and exclusion criteria.

Data Collection Process and Data Items

A standardised, pre-piloted form was used to extract data from the included studies for assessment of study quality and evidence synthesis. Extracted information included: study setting; country; study population; ethnicity/race of participants; details of the ACP intervention; study methodology; findings regarding acceptability of ACP; recommendations regarding ACP and clinical implications; and information for assessment of the risk of bias/limitations (see Table 2). EM extracted data, with LS extracting data independently for a random 10% of studies. Discrepancies at this stage were minor and resolved through discussion.

Risk of Bias

The quality of all included studies was assessed independently by EM and LS using the Mixed Methods Appraisal Tool (MMAT), Version 2011(40). This validated tool was appropriate for this review as it can be applied to qualitative, quantitative (randomised, non-randomised and descriptive) and mixed methods study designs. The tool uses a set of questions specific to study design, converted into 4 possible binary scores (worst to best: 25/50/75/100). Disagreements between the review authors over the quality appraisal of three particular studies were resolved through discussion, without requiring a third reviewer's consultation. No studies were excluded based on quality, but we reflect on the quality of the identified studies in the narrative synthesis.

Analysis

We conducted a narrative synthesis of the studies' findings, following the framework stages proposed by Popay et al(30), namely: developing a preliminary synthesis, exploring relationships in the data, assessing the robustness of the synthesis product and developing a theoretical model of how cultural factors influence the acceptability of ACP. The narrative synthesis was guided by our three review questions and was structured around: study population characteristics, study settings, quality of studies, different cultural factors assessed/arising in the studies, different types of ACP examined in the studies, acceptability of ACP, and clinical implications and recommendations. To develop and present the narrative we used several of the tools suggested by Popay et al(30), including: textural description (noting findings that were unusual or relevant to emerging themes); conceptual

mapping/tabulation (this included quantifying which studies featured different factors/settings/participant types, to ensure appropriate weighting was given to each in the discussion, as presented in figure 2); and thematic analysis (a common technique from qualitative data analysis that involves identifying and exploring the most important and/or recurrent themes or concepts appearing in the literature being reviewed(30)). In our narrative we gave greater weight to the findings and recommendations occurring in the greatest number of individual studies of higher quality.

EM led the synthesis, with regular meetings with LS to review emerging findings and patterns. Researchers' backgrounds inevitably influence interpretative aspects of analysis, particularly in research on cultural factors, and awareness of this contributed to the analysis. EM is a White British Medical and Global Health student who has previously worked non-clinically with a Palliative Care team; LS is a White British academic specialising in qualitative and mixed methods social science, with a PhD in palliative care, experience of cross-cultural research, and an interest in cultural factors in care provision.

Results

Study Selection and Characteristics

818 studies were identified and screened. A PRISMA flow chart(41) detailing each stage of exclusion is shown in Figure 1. The main reasons for exclusion were: not about ACP as defined in our review question (n=478), not original, published research (n=125) and participants that did not have progressive, incurable disease (n=95).

27 studies were included. Of these, 20 were quantitative (8 descriptive, 9 non-randomised cross-sectional, 2 non-randomised cohort and 1 randomised control trial), 4 were qualitative and 3 used mixed methods. The concept map in Figure 2 details the distribution of types of participant, types of ACP, cultural factors measured, and setting by country.

We characterised ACP processes as either 'formal', i.e. involving production of written documentation or completion of legal processes, or 'informal', i.e. involving the broader, holistic process of discussion and decision-making involving patients and/or their caregivers/families and health-care professionals; we use this terminology in the synthesis. The distinction between formal and informal ACP processes has been detailed before (42, 43). Fifteen studies measured formal ACP processes including: do not resuscitate (DNR) orders, advance directives (AD) including living wills (LW) and designated power of attorneys

(DPOA), and formal designation of a surrogate decision-maker/health care proxy. Fourteen of these were conducted in the USA; one was conducted in Japan(44).

The most common features of studies were: patients only as participants (n=17), study of informal ACP only (n=12), and consideration of the cultural factor of ethnicity/race (n=18). 74% of studies (n=20) were conducted in the USA and all studies were conducted in high income countries. A full description of the 27 included studies and their main findings regarding the acceptability of ACP is given in Table 2.

Risk of Bias

On the MMAT, ten studies scored 50, fifteen studies scored 75 and two studies scored 100. Common limitations across studies were use of un-validated tools and convenience samples. For qualitative studies, a common limitation was a lack of reflexivity, i.e. "*appropriate consideration... to how findings relate to researchers' influence*" (question 1.4(40)). Out of the 4 qualitative and 3 mixed methods studies, only one study(45) scored a 'yes' for this question, as it gave a detailed explanation for using race-concordant interviewers. However, even this study did not address other factors, such as the researchers' disciplinary background(s).

Narrative synthesis

The narrative synthesis is structured to reflect our three research questions.

1. How, if at all, does patients' and families' cultural background influence the acceptability of ACP for seriously ill patients?

Formal ACP

***Ethnicity*.** Of the fourteen USA studies measuring formal ACP processes, all but one(46) found that non-White patients had lower levels of completion than White patients. Self-reported ethnicities included in these studies were White American (WA), African American (AA), Hispanic American (HA) and Asian American. For example, in a survey of bereaved relatives (n=540) by Hopp et al (47), white patients were more likely to complete a living will (p=0.001), and to designate a DPOA (p=0.032) than black patients. One AA patient offered this reason for not feeling a need to complete an AD:

> *"Uh, I don't have anything in writing, because when I ask my sisters' that's just like printing it in gold, stacking it in gold. They're going to do it"*(48)

In contrast, Laguna's multivariate analysis(46) found that HA hospice patients were 3.68 times as likely as WA hospice patients to have signed a DNR order ($p<0.01$). However, this unexpected result is likely explained by the hospice setting, in which patients are likely to be more accepting of their poor prognosis. The extent to which formal ACP documentation is binding varies between states (USA)(49) and countries(50), and this may also influence completion rates.

Religiousness. Several studies found evidence that religiousness may be a either a mediating or confounding factor in the association between non-White ethnicity/race and lower levels of formal ACP completion(51-54). A quote from an AA patient demonstrates how these factors could be linked:

> *"You don't have no say. The doctors have no say. Only the master has a say. So, you just wait on it."*(48)

However, two studies which performed adjusted analysis found that religiousness did not explain the association(51, 53). Furthermore, some tools used to assess 'religiousness' were not validated(53, 54) and some response rates were below 60%(51, 54). Further research is needed to determine how ethnicity and religion interact in relation to ACP uptake. Overall, our included studies confirm that formal ACP processes are less acceptable to non-White USA patients.

Informal ACP

Trust. Findings regarding the acceptability of informal ACP processes were more mixed. The most commonly researched aspect of informal ACP was patients' engagement in EOL discussions. In the USA, Hopp et al(47) found that deceased AAs (n=86) were 63% less likely than WAs (n=454) to have had an EOL discussion before death ($p<0.001$). However, this finding may not be generalizable to the general USA population as participants were more likely to be older, male and have lower educational attainment. Additionally, Hopp et al do not specify if discussions were with clinicians or caregivers/family, which may plausibly differ in acceptability to AAs. A commonly hypothesised reason why AAs may be less likely to engage in ACP surrounds the community's widespread mistrust of the health-care system. This mistrust has been attributed to historical events such as the Tuskegee Syphilis Study(55) and AAs' persistently limited access to health-care due to socio-economic/insurance barriers(56). For example, one of the doctors interviewed by Periyakoil et al stated "*some groups feel more marginalized in the community at large and this makes them more distrustful of the medical system as a whole"*(57).

Wallace et al found that 88% of USA-born black physicians versus 35% of white physicians perceived that the Tuskegee experiment had impacted AA medical decision-making (p=0.014), although the sample of black physicians was small (n=8 compared to n=91 white physicians)(58). Contrastingly, Smith et al found that, although AAs rated the quality of their patient-doctor relationships lower than WAs for several measures, difference in level of trust in doctors was not statistically significant(39). However, the authors questioned the validity of the questionnaire used, suggesting it may have been skewed towards encouraging positive/'agree' responses.

Comfort discussing death. In contrast to Hopp et al's(55) finding that AAs were less likely to have had an EOL discussion before death, a small comparative study by Kurella et al found that AA patients were more likely to engage in EOL discussions with healthcare professionals than WAs (70% vs 38%) (n=23, n=21) (p<0.01)(59). However, Kurella et al's use of patient self-reporting creates the possibility of recall bias. The authors suggest that, although unlikely, recall of an EOL discussion could plausibly vary between ethnic groups. One reason for this finding could be that patients' level of comfort discussing death influences how memorable EOL discussions are for them, and therefore likelihood of recall.

There is evidence that patients' and families' attitudes towards frank EOL discussions vary between cultural and ethnic groups. For example, in Ireland, Collins et al found that 78% (n=50) of haemodialysis patients reported being comfortable discussing death(50). Research in other settings/groups assessed clinicians' views of patients' comfort and identified cultural differences. In the USA, doctors commented that:

> *"certain groups feel that honesty and frankness is not good for the emotional outlook"*
>
> *"some cultures approach (conversations about) death as something to be avoided at all costs"* (57)

In New Zealand, healthcare professionals reported that patients and families from Maori and Polynesian/Pacific cultures were reluctant to discuss death(19):

> *"(to them) it's like hastening that possibility of their death"* (Focus group with Maori patients)
>
> *"shows that we don't have faith that this person's going to live"* (Focus group with Pacific patients)

However, the latter findings arose from exploratory research in which n=2 clinicians for each focus group (Maori and Pacific); it is unlikely that data saturation was achieved and therefore transferability is limited.

As communication is a two-way process, comfort of staff discussing death is equally essential for informal ACP. In the Netherlands, patients reported that most doctors (>80%) did not engage them in EOL discussions about prognosis, the dying process or religious/spiritual beliefs (n=185)(60). These findings suggest that the need, in both formal and informal ACP, to discuss death may be a barrier to acceptability for patients and clinicians from some cultural groups, both within the USA and globally.

Patient attitudes and additional factors. Additional cultural factors influencing the acceptability of ACP that were investigated on a lesser scale/by fewer studies than those discussed above were: caregivers' acculturation level(61); patients' attitude to acknowledging a terminal diagnosis(62); collective (family-centred) vs autonomous (patient-centred) approaches to decision-making in American veterans(48) and New Zealanders(19); and patient preference for who to involve in EOL conversations and decision-making in Japan(63) and Hawaii(64). Two studies suggested how clinicians discuss EOL care might differ depending on patient ethnicity: Sharma et al(65) found Black race was associated with higher odds of hospice discussion, while Mack et al(66) found EOL discussions resulted in increased awareness of illness being terminal among White patients, but not Black patients. Further research into these factors is required before solid conclusions can be drawn about their respective influence on the uptake of ACP.

2. **How might ACP need to be adapted to make it more cross-culturally appropriate?**

Recommendations for a focus on communication in ACP. The wide variety of findings discussed in answer to the first research question, particularly regarding the acceptability of informal ACP, reflect the complex and intricate nature of EOL communications. Many authors of included studies made recommendations for how ACP could be adapted to be more cross-culturally appropriate that emphasised a broader, communication-focused approach to ACP, as opposed to a process focused on formal documentation. For example, Hopp et al concluded that "*ACP needs to be part of a broader strategy of communication with patients concerning EOL care*"(47). Communication-focused interventions were investigated by four of our included papers:

Song et al conducted an RCT with semi-structured interviews to evaluate the SPIRIT (Sharing Patients' Illness Representations to Increase Trust) intervention(67). SPIRIT aims to improve EOL communication between AA end-stage renal disease patients and their chosen surrogate decision-makers and involves a single-session interview with a patient-surrogate dyad. SPIRIT was found to significantly improve communication, reported by both patients and surrogates (n=58 dyads), at 1 week (OR 4.40, p=0.02) and 3 months (OR 3.17, p=0.03), compared to baseline, although these findings are limited by only 54% of patient-surrogate dyads agreeing to be included in follow up(67).

Walczak et al tested the acceptability of two versions of a Question Prompt List (QPL) intervention for patients with advanced cancer, one developed in Australia and one in America(49). The QPL aims to improve prognosis and EOL discussions between patients and clinicians outside of palliative care settings, in turn leading to better understanding of prognosis and more informed decision-making. Interviews and focus groups with patients (n=34) and healthcare professionals (n=13) in both countries found that patient and staff participants from both settings generally endorsed the QPL tool. However, there were contrasts between Australian and USA responses, with USA participants generally more hesitant to discuss sensitive content (e.g. prognosis) and using more euphemisms. These contrasts reinforce the need for population-tailored and culturally-appropriate versions of communication aides such as QPL.

Perry et al conducted an RCT of peer mentoring on EOL decision-making for dialysis patients (n=203)(68). They found that AD completion rate was 35% in the group who received peer mentoring, compared to 12% in the group that received standard printed materials and 10% in the group receiving no specified intervention ($p<0.01$). The greatest increase was among AAs ($p<0.001$), for whom peer mentoring also appeared to improve subjective well-being ($p<0.05$). They suggest that oral, rather than written, EOL education may be more acceptable for AAs. However, the study report is limited in that randomisation and allocation concealment are not described.

Zaide et al conducted a cross-sectional medical chart review over a 9-month period for patients seen by the Palliative Care Consultation (PCC) Service in a tertiary hospital in New York, exploring whether the PCC intervention influenced rates of AD completion for different racial/ethnic groups(69). They found that AD completion rates were higher for both AA (n=142) and WA (n=187) patients following the intervention (pre-PCC: AA 11.3%, WA 25.7%; post-PCC: AA 28.9% and WA 33.7%, $p<0.001$). The difference between the two groups' completion rates appears to be significantly smaller following the intervention (14.4

before vs 4.8 after), suggesting the PCC may "*level the playing field*" regarding acceptability of ADs for WAs and AAs.(69)

In sum, these findings suggest that communication-focused EOL interventions have potential to increase acceptability and uptake of both informal (e.g.(49, 67)) and formal (e.g.(68, 69) ACP processes, particularly for AA patients.

3. What cultural factors do clinicians need to be aware of in approaching communication and planning with patients and families about EOL issues?

Clinician training and education in cultural-competence. Several authors of included studies called for staff training and education on topics including: communication skills(44), initiating discussions with diverse and potentially hesitant patients(45, 69), careful use of language and avoidance of medical jargon(57), the potential influence of religiousness/spirituality at EOL(51, 54) and more general promotion of staff's 'cultural competence' and sensitivity(47, 57, 63, 70). Wallace et al(58) suggested that clinicians should incorporate existing culturally-sensitive guidelines, such as the USA Federal Cultural and Linguistic Appropriate Services (CLAS)(71), into their EOL care.

Avoiding stereotyping. Another common recommendation was that clinicians working cross-culturally should aim to avoid stereotyping patients and caregivers based on racial/ethnic or cultural group and not lose sight of the individual. Some studies mentioned this explicitly; for example, Braun et al suggested that clinicians "*should not stereotype a patient into a specific decision-making variant based on their ethnicity/race*"(48) and should only engage with ethnicity/race when "*clinically relevant*"(70) (e.g. to EOL decision-making). Similarly, Frey et al caution that healthcare professionals should not make "*blanket judgements*" about an individual's level of interest in ACP based on cultural background(19). Hopp et al highlight the importance of considering the variations within, as well as between, racial/ethnic groups with regard to "*beliefs, behaviours and decisions related to health care at the end of life*"(47).

The importance of not losing sight of the individual patient when working cross-culturally links to the recommendation of 'cultural competence' training. For example, Wallace et al suggest that clinicians should strive to know their patients as *"individuals within their larger social context"* and that clinician training should go beyond "*simply learning about epidemiologic differences amongst racial and ethnic groups, because this will not capture the subtle variations from person to person*"(58).

Discussion

This is the first review to comprehensively synthesise evidence regarding the cultural acceptability of ACP. We found that most research to date in this area has been conducted in the USA. The main cultural factor examined by researchers was ethnicity/race and the main types of ACP studied were formal, documented processes. The included studies indicate the influence of a wide range of interconnected cultural factors on the acceptability of ACP for patients and caregivers/families. A common finding was that, for seriously ill patients in the USA, non-White ethnicity was associated with lower acceptability of formal ACP processes. Greater levels of religiosity appear to be a factor in this association, although further investigation is required to confirm and define this relationship.

Additional cultural factors thought to influence the acceptability of ACP were patients' degree of trust in clinicians and the wider healthcare system, and their comfort discussing death and EOL issues. Less frequently studied factors included caregivers' acculturation level, collective vs. autonomous approaches to decision-making, patients' attitude to acknowledging a terminal diagnosis and preference for who to involve in EOL conversations and decision-making, and differences in how clinicians discuss EOL care. Further research into these factors, particularly patient attitudes, is required to better understand the nature and mechanisms of their influence on the acceptability of ACP.

Although the concept of culture exceeds ethnic, national, and linguistic boundaries, ethnicity is commonly used as a proxy for culture in research(72), and is recommended as an appropriate proxy for culture(73). A key strength of this review is that we expanded its focus beyond just ethnicity, by including religion/spirituality, nationality or country of permanent residence. Our broad operationalisation of 'culture' will have influenced our findings; for example, including religion/spirituality as a search term will have likely increased the degree to which religion features in the findings, themes and conclusions. However, none of the included papers defined study population solely by religious group – it was always discussed in relation to ethnicity. Our use of narrative synthesis methodology allowed for the inclusion and comparison of quantitative, qualitative and mixed-method studies. Other strengths include our comprehensive search strategy developed using MeSH terms and our use of dual independent quality appraisal and data extraction.

A researcher's own cultural background inevitably shapes the research they conduct, as our understanding of the world is inherently shaped by our cultural assumptions(74). In the context of this review, our cultural backgrounds influenced our interpretations of findings, which underpinned the narrative synthesis we produced. Whilst accepting this influence,

particularly considering the topic of the review, we took steps to minimise unconscious bias by utilising concept mapping to give greatest weight to common findings reported by most studies. Additionally, we were mindful to iteratively ground all our conclusions and interpretations in the included studies' empirical data. However, as with any synthesis, our interpretations are limited by being 'a step removed' from the context and participants of the original studies, therefore relying on how studies were reported. While participants' characteristics were generally well described, several studies lacked reflexivity, omitting to consider the potential influence of setting or of the researchers themselves. In some cases, this limited the interpretation of authors' conclusions, which is reflected in our synthesis.

Finally, although a systematic approach was taken in our search strategy, the possibility remains that some relevant papers may have been missed. Our exclusion of papers not written in English was a limitation, given that we were searching for global research surrounding culture. However, only two papers were excluded for this reason, one written in French and one in Hungarian. Nevertheless, research conducted in European countries is under-represented in our review, so these papers could have been potentially valuable.

Findings from this review suggest that firstly, formal ACP processes (ADs, LWs, DPOAs) need better evaluation for cultural sensitivity, as some forms of formal ACP are not acceptable to some cultural groups, and secondly, more informal, discussion-based ACP may be more acceptable in some cultural groups. Research with patients and caregivers has resulted in similar recommendations that ACP should move "*beyond ADs*" towards a broader decision-making process involving patients, surrogates and clinicians(75). The importance of communication is already at the heart of palliative care ethos(76). However, given that EOL care and ACP are often delivered by non-specialist clinicians(77), staff outside the speciality should be encouraged and supported to follow suit in their approach. Common recommendations for how ACP could be adapted to become more culturally-sensitive related to shifting towards a more communication-focused approach to EOL care and ACP. Research into communication-focused interventions found promising results in increased acceptability and uptake of both informal and formal ACP processes(49, 67-69).

Many of the included studies called for clinician training and education in 'cultural competence', including how cultural background might influence patients' views on EOL issues and ACP. Where absent, this education should be integrated into existing training and curricula. Established initiatives such as the End of Life Nursing Education Consortium (ELNEC) (www.aacnnursing.org/ELNEC), which provides training adapted for many different cultural groups, also play an important role. However, criticisms have been levelled at some current approaches to clinical cultural competence, including in EOL care. For example,

Tervalon and Murray-Garcia suggest that the traditional idea of medical competence as "*detached mastery*" is not appropriate to the inevitable complexity of cross-cultural care and should instead be replaced with 'cultural humility'.(78) The complex reality of cross-cultural care is also reflected in Gunaratnam's suggestion that current approaches to cultural competence marginalise the "*role of the non-rational and visceral*" (79). Gunaratnam argues that that these marginalised aspects should be recognised in policy and education that aims to promote cultural competence. There is clearly a need for clinicians, educators and researchers to reflect on what 'cultural competence' really means in EOL care(80).

Many authors highlighted a further, related complexity of cross-cultural care: avoiding stereotyping or losing sight of the individual patient. Recognising the importance of culture must not lead to cultural essentialism. These complexities and criticisms should be engaged with as the concept of cultural competence becomes adopted into EOL care education for non-specialists.

Further research is needed into the cultural acceptability of ACP in countries other than the USA: the UK, other European countries and developing country settings are under-represented. A recent study from Singapore, published after our literature search, illustrates the benefits of examining ACP in different cultural settings(81). The study highlights the need for a nuanced approach to ACP that considers the family network in multicultural, family-centric communities. Further research into cultural adaptations of ACP is needed. To build on research conducted in the USA, studies are needed to determine causal and directional relationships between religiousness, non-White ethnicity and lower levels of formal ACP completion, and the mechanisms involved. The role of discomfort or fear of discussing death as a barrier to ACP also warrants further research. Although beyond the scope of the current review, some included studies discussed the influence of a clinician's own cultural background on ACP and EOL care delivery(44, 57, 58, 63, 70). Given that EOL communication is a two-way process, the influence of clinicians' cultural background is another area which requires evidence synthesis. Future research into communication-focused ACP interventions and solutions to overcome resource barriers to their implementation would also be valuable. The volunteer-led peer mentoring intervention trialled by Perry et al(68) may be a useful model here. More generally, research on the cultural acceptability of ACP would benefit from improved study designs and reporting. Qualitative and mixed methods researchers should reflect on their cultural background and discipline, as well as the characteristics of those collecting data, in line with the MMAT guidance(40) and COREQ checklist(82).

Conclusions

Many interconnected cultural factors influence the acceptability of ACP. Although causal relationships and mechanisms of action remain unclear, non-White ethnicity is associated with lower acceptability of formal ACP, at least in the USA. ACP does need to be adapted to meet the needs of culturally diverse populations. A less formal, communication-focused approach to ACP may be valuable in this regard.

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Authorship: LS conceived of the review and led protocol development and registration on PROSPERO. EM conducted each stage of the systematic review, with LS carrying out 'second rounds' as detailed in the methodology. EM led the narrative synthesis, with regular meetings with LS to review emerging findings and patterns. EM wrote the first draft of the paper, with LS providing important intellectual content and critical review. Both authors approved the paper prior to submission and take responsibility for its content.

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Legend

Box 1: Databases searched

Figure 1: PRISMA Flow Diagram

Figure 2: Concept map

Table 1: Search Strategy

Table 2: Description of Included Studies

Box 1: Databases searched

Via OvidSP:

AMED (Allied and Complementary Medicine) 1985 to March 2017
PsycINFO 1806 to March Week 4 2017
Embase 1974 to 2017 March 26
Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily, Ovid MEDLINE and Versions (R),

Individually:

CINAHL
Cochrane Library

Figure 1: PRISMA Flow Diagram showing stages of study selection

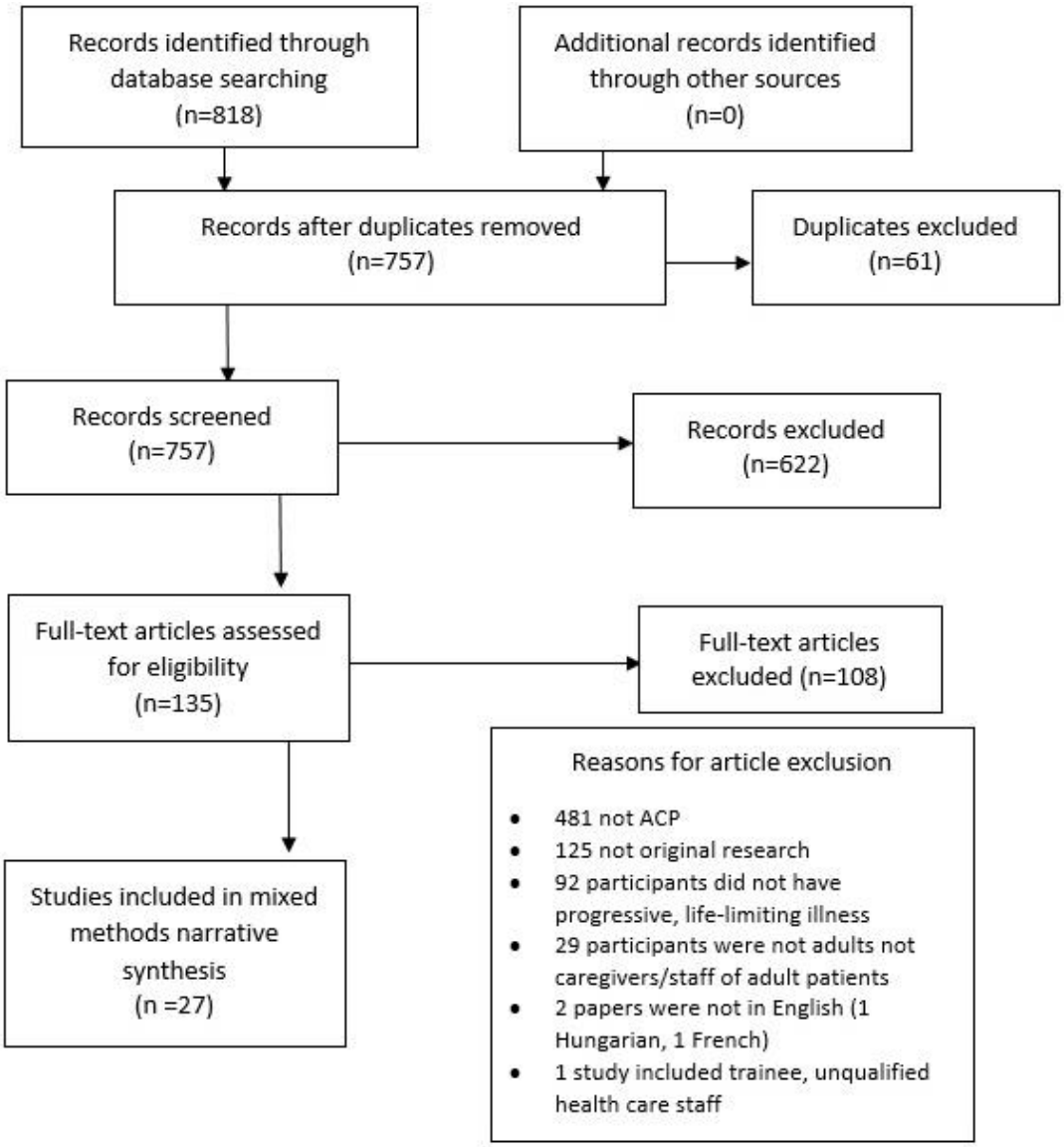

Figure 2: Concept map

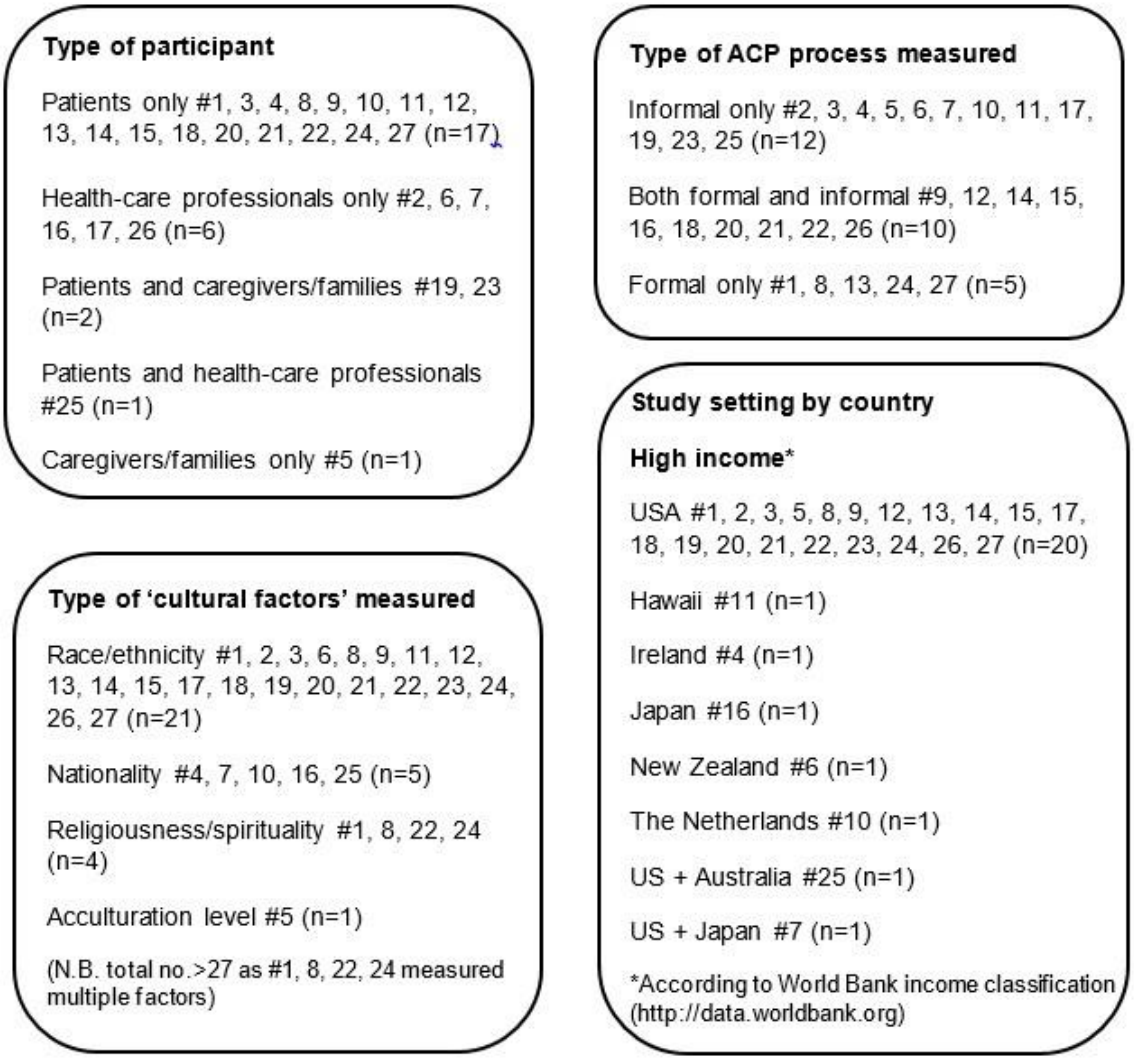

Table 1: Search strategy

	'Advance Care Planning'	**'Cultural factors'**	**'Acceptability'**
Ovid SP: AMED, PsycINFO, Embase, Ovid MEDLINE, CINAHL, Cochrane	(exp Advance Care Planning/) or (advance care plan*.tw.) or (care plan.tw.)	(exp Ethnic Groups/ or exp cross-cultural comparison/ or exp cultural characteristics/ or exp cultural diversity/)	(exp Patient Preference/eh, px [Ethnology, Psychology]) or (exp "Patient Acceptance of Health Care"/eh, px, sn [Ethnology, Psychology, Statistics & Numerical Data]) or (exp Attitude to Death/) or ((acceptability or acceptable or uptake or engage or engagement or preference or preferences).tw.)
CINAHL	(MM "Advance Care Planning") OR TI ("care plan" or "advance care plan") AND AB ("care plan" or "advance care plan")	(MH "Ethnic Groups+") OR (MH "Ethnological Research") OR (MH "Culture+") OR (MH "Cultural Diversity") OR (MH "Cultural Values")	(MH "Patient Satisfaction") OR "Patient Acceptance of Health Care" OR (MH "Attitude to Death") OR (MH "Attitude to Medical Treatment") OR TI (acceptability or acceptable or uptake or engage or engagement or preference or preferences) AND AB (acceptability or acceptable or uptake or engage or engagement or preference or preferences) OR TI patient preference AND AB patient preference
Cochrane Library	MeSH descriptor: [Advance Care Planning] explode all trees OR advance care plan*:ti,ab,kw (Word variations have been searched) OR care plan:ti,ab,kw (Word variations have been searched)	MeSH descriptor: [Ethnic Groups] explode all trees OR MeSH descriptor: [Cross-Cultural Comparison] explode all trees OR MeSH descriptor: [Cultural Characteristics] explode all trees OR MeSH descriptor: [Cultural Diversity] explode all trees	MeSH descriptor: [Patient Preference] explode all trees OR MeSH descriptor: [Patient Acceptance of Health Care] explode all trees OR MeSH descriptor: [Attitude to Death] explode all trees OR acceptability or acceptable or uptake or engage or engagement or preference or preferences:ti,ab,kw (Word variations have been searched)

Table 2: Description of included papers

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology*	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
1	(Balboni et al, 2007)(51)	Religiousness and Spiritual Support Among Advanced Cancer Patients and Associations With End-of-Life Treatment Preferences and Quality of Life	US - 8 cancer centres/hospitals/PC centres/oncology departments/veteran health-care centre in CT, NY, TX, MA, NH	n=230, advanced cancer patients with failure of first-line chemotherapy, aged >=20, with adequate stamina to complete interview, without dementia or delirium, spoke English or Spanish, + unpaid caregiver	White 140 (61%), Black 44 (19%), Hispanic 39 (17%), Asian 5 (2%), Other 2 (1%). Of 100 participants from southern institutions 61% were non-White; of 130 from north-eastern institutions 22% non-White (self-identified)	QUAN – descriptive - survey, hospital chart data and statistical analysis (McNemars test, linear regression, univariate models, multivariate analysis, logistic regression)	LW, DPOA, DNR	Greater religiousness /spirituality is associated with lower levels of formal ACP completion	50 (4.2) sample not representative of the population under study and (4.4) less than 60% response rate (42% 230/538)
2	(Braun et al, 2010)(70)	The physician's professional role in end-of-life decision-making: voices of racially and ethnically diverse physicians	US - Texas Medical Centre, Houston	n=26, internists and specialists (doctors) who commonly treated patients in end-stages of disease, purposively sampled to include ethnic minority doctors, 7 racially/ethnically-homogenous focus groups + moderators	3 focus groups with Caucasian patients n=11, 2 focus groups with African American patients n=8, 2 focus groups with Hispanic patients n=7 (self-identified)	QUAL– descriptive - focus groups, semi-structured interviews and questionnaire and thematic analysis using grounded theory	Doctor's EOL discussion and decision-making style and valuing of addressing patient's religious/spiritual needs	Doctors felt that patient ethnicity/race is clinically relevant to some aspects of informal ACP. Concordance/discordance of clinician' and patient' ethnicity/race was thought more important by AA than Caucasian doctors.	75 (1.4) no consideration of how findings relate to researchers influence

No (#)	Author (Ref. no)	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
3	(Braun et al, 2014)(48)	Decision-making styles of seriously ill male Veterans for end-of-life care: Autonomists, Altruists, Authorizers, Absolute Trusters, and Avoiders	US - Michael E. DeBakey VA Medical Centre (MEDVAMC) in Houston, Texas	n= 44, "seriously ill" patients (lists included diagnoses in Table1), arranged in 8 racially/ethnically homogenous focus groups, purposively sampled	2 focus groups with African American patients n=14, 3 focus groups with Hispanic patients n=17, focus groups with Caucasian patients n=13 (self-identified)	QUAL – focus groups and inductive thematic analysis, from 'natural-language' answers and coding	EOL decision making style	5 different types of EOL decision-making style (Autonomists, Altruists, Authorizers, Absolute Trusters, and Avoiders) influence acceptability of formal ACP. EOL d-m style was suggested to be associated with different racial/ethnic groups (i.e. no White patients were 'Avoiders') although this relationship was not confirmed.	75 (1.4) no consideration of how findings relate to researchers influence
4	(Collins et al, 2013)(50)	Perspectives on death, dying and advance care planning from patients receiving haemodialysis	Ireland - acute renal unit in Irish hospital	n=50 (67% of eligible pop) individuals receiving haemodialysis >3 months	"Irish patients" - those who weren't 'Irish' (5% of the unit) and those who couldn't speak/ understand English were excluded	QUAN – descriptive – questionnaire and descriptive statistics	Importance of twenty wide-ranging EOL care issues (Table 5)	The majority of Irish dialysis patients wished to know their prognosis if they had <6 months to live (60%) and wanted honest answers from their doctors.	50 (4.2) sample representative of pop understudy and (4.3) validity of instrument used for measurements not known
5	(DeSanto-Madeya et al, 2009)(61)	Associations between United States acculturation and the end-of-life experience of caregivers of patients with advanced cancer	US - four comprehensive cancer centres in the Northeast and two in the Southwest	n=167 identified primary, unpaid, informal caregivers of patients with diagnosed advanced cancer, where both patient and caregiver could speak English or Spanish + neither met criteria for dementia or delirium	White n=79, Black n=8, Asian n=8, Hispanic n=71, Other n=1 (self-reported by caregiver)	QUAN – descriptive – chart review and questionnaire and Descriptive statistics (t test, pearson correlation, logistical regression)	EOL preferences and medical decision-making, physician–caregiver communication including doctor's listening and information provided	Caregivers' level of acculturation influenced their EOL preferences and EOL medical decision-making, for example being less acculturated was associated with being more likely to perceive that doctors had provided too much information.	50 (4.2) reasons for eligible participants not participating are not addressed and (4.4) less than 60% response rate (32% 167/448)

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
6	(Frey et al, 2014)(19)	Advance care planning for Maori, Pacific and Asian people: the views of New Zealand healthcare professionals	NZ - hospitals, general practice, Maori community support services and Pacific and Asian hospital support services	n=40, health and social care professionals with a wide range of knowledge and experience in PC	NZ European (19), Maori ethnicity (3) or membership in a Pacific (3) Asian (5), Southeast Asian (7) or other European (3) (self-reported)	QUAL – individual interviews, focus groups and thematic analysis	ACP defined as "A voluntary process of discussion about future care between an individual and their [sic] care providers, irrespective of discipline"	Maori, Pacific and Asian families/whanau in NZ are reluctant to engage in ACP conversations	50 (1.3) no consideration of how findings relate to context/setting and (1.4) no consideration of how findings relate to researchers influence
7	(Gabbay et al, 2015)(63)	Negotiating end-of-life decision making: a comparison of Japanese and U.S. residents' approaches	US + Japan - two U.S. sites in LA, California (one with predominantly poor, veteran population) and five Japanese sites in Central Honshu, Kyushu, Okinawa	n=347 (103 internal medicine residents in US and 244 general medical practice residents in Japan)	103 US residents, 244 Japanese residents (ethnicity not recorded)	QUAN - non-randomised cross-sectional – questionnaire and descriptive statistics (chi-square tests, and t-tests)	EOL decision making, diagnostic and prognostic disclosures and involvement of family	Differences were found in American and Japanese clinicians' approaches to EOL decision making. Japanese clinicians were more likely to inform the family of diagnosis/prognosis before the patient (44%: 2% p<0.001).	75 (3.3) – they couldn't fully assess for differences between sites in US/Japan and therefore don't control for this

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
9	(Garrido et al, 2014)(52)	End-of-life treatment preferences: A key to reducing ethnic/racial disparities in advance care planning?	US - outpatient clinics in 5 states (Connecticut, Massachusetts, New Hampshire, New York, and Texas)	n=606 patients from the 5 centres who had advanced cancer and spoke English or Spanish and were cognitively able to participate	non-Latino whites n=437, blacks n=93, Latinos n=76	QUAN - non-randomised cross-sectional - baseline interviews and descriptive statistics (Bivariate tests)	DNR order completion	White non-Latino patients were more likely to have a DNR order (45%) than black (25%) and Latino (20%) patients (P<0.001). Individuals with DNR orders had lower levels of positive religious coping than those without DNR orders (30% vs 40%; P=0.048).	75 (3.2) as methods for measuring each preference not validated
9	(Hopp et al, 2000)(47)	Racial variations in end-of-life care	US – older persons living in continental US outside of institutional settings at onset of AHEAD study	n=540 relatives (proxy respondents) for persons who died between 1993 + 1995; including 169 spouses, 247 children, and 124 other relatives.	White n=454, Black n=86 (others excluded as small sample size of respondents)	QUAN – descriptive – secondary analysis of phone or in-person interview data and descriptive statistics (logistical regression modelling)	LW, DPOA and EOL discussion including treatment preferences	Deceased AAs were 63% less likely than White Americans to have had an EOL discussion before death (p<0.001). Ethnicity/race continued to be a significant predictor of ACP uptake even after logistic regression modelling to control for sociodemographic factors.	75 (4.2) sample not representative of population understudy (decedents included in this study were more likely to be older, male, and to have lower educational attainment)

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10	(Janssen et al, 2011)(60)	A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure	The Netherlands - 1 academic and 5 general hospitals	n=185 outpatients with severe COPD (n=105) or chronic heart failure (n=80)	Dutch	QUAN - non-randomised - prospective cross-sectional – survey, home visit, doctor's statement and logistic regression analysis	Discussion of preferences for CPR or MV, prognosis of survival, dying process and PC, according to patient and clinician. Quality of communication.	Doctors reported greater rate of having had ACP communication than patients. Majority of Dutch COPD or heart failure patients were able to indicate their preferences regarding life-sustaining treatments. Doctors rarely discussed prognosis, dying or PC.	50 (3.2) validity of survey tools used not stated and (3.4) less than 60% response rate (for patients with heart failure)
11	(Kataoka-Yahiro et al, 2010)(64)	ACP among Asian Americans and Native Hawaiians receiving haemodialysis	Hawaii - four outpatient dialysis centres in the island of Oahu, Honolulu	n=50 CKD haemodialysis patients of AA or NH ethnicity with ability able to read/ understand English and capacity for informed-consent	62% Asian Americans (AA), 24% Native Hawaiians (NH), and 14% mixed AA + NH	QUAN – descriptive – survey and descriptive statistics (frequencies, percentages, means, and standard deviations)	AD, LW and ACP ("process of communication among patients, families and HC providers addressing EOL care"	Majority of patients' attitudes about ACP were positive however less than half (40%) had completed formal ACP such as AD or LW, despite most having heard of these processes.	50 (4.2) sample not rep. of understudy population and (4.3) as questionnaire tool not validated

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
12	(Kurella Tamura et al, 2009) (59)	Preferences for dialysis withdrawal and engagement in advance care planning within a diverse sample of dialysis patients	US - University of California San Francisco Mt. Zion Haemodialysis Centre and the San Francisco Veterans Affairs Medical Centre Haemodialysis Centre	n=62 end-stage renal disease (ESRD) patients who were fluent in English and without an active psychiatric disorder including schizophrenia and dementia or a learning disability (about 23% of the clinic did not meet these criteria)	n = 23 Black, n = 7 were Latino, n = 21 White, n = 10 Asian, (1 ppt failed to complete questionnaire and was excluded) (self-reported)	QUAN – descriptive - questionnaire + medical chart review and Fisher's exact test	EOL discussions, AD, DNR/DNI	Rates of engagement in informal ACP (EOL discussion) were generally higher than for formal ACP (documentation). Racial/ethnic minorities were not less likely to engage in EOL discussions: AAs were more likely to engage in EOL discussions with health-care professionals than Whites (70% vs 38%) (p<0.01).	75 (4.2) sample not rep. of understudy population (only recruited English-speaking participants)
13	(Laguna, 2014)(46)	Racial/ethnic variation in care preferences and care outcomes among united states hospice enrolees	US - 657 hospice-providing agencies in the US	n= 3,661 Medicare hospice patients (representing 788,872 patients) (Medicare is 82% of hospice care in US)	White, Black, and Hispanic (as reported on charts)	QUAN – descriptive - retrospective analysis of NHHCS hospice care survey and statistical analysis (F-statistics, chi-squared tests, ANOVA)	AD, DNR, HC proxy	Black hospice patients were less likely to complete an AD than Whites (80%:93%) (p=0.004). Hispanic hospice patients were 3.68 times more likely to have signed a DNR order than Whites (p<0.01) and 3.67 times as likely as Blacks (p<0.001).	75 (4.3) "unique" un-validated variable of emergent care use

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
14	(Loggers et al, 2013)(62)	Predictors of Intensive End-of-Life and Hospice Care in Latino and White Advanced Cancer Patients	US - 8 cancer centres/hospitals/PC centres/oncology departments/veteran health-care centre in 5 states	n=292 stage IV cancer patients with metastatic disease refractory to first-line chemotherapy	Latino (n = 58) and white (n = 234) (self-reported)	QUAN - non-randomised cohort – prospective longitudinal analysis of interview data from Coping with Cancer (CWC) study and statistical analysis (stratified logistical regression models)	EOL discussion, DNR	Latino patients were less likely to acknowledge their condition was terminal than Whites (19%:47.4%, AOR 0.18) (p=0.0001) and less likely to have DNR orders than Whites (22.4%:50.4%, AOR 0.23) (p=0.0003). No differences in the rate of positive religious coping, EOL discussions, or preferences for life-extending care among Latino and White patients.	100
15	(Mack et al, 2010)(66)	Black-White Disparities in the Effects of Communication on Medical Care Received Near Death	US - 8 cancer centres/hospitals/PC centres/oncology departments/veteran health-care centre in 5 states	n=332 advanced cancer patients who participated in and died during the CWC study	White (n=261) and Black (n=71) (self-identified)	QUAN - non-randomised cohort - prospective longitudinal analysis of interview data from CWC study and statistical analysis (stratified logistical regression models, bivariable and multivariable)	EOL discussion regarding "wishes about care would want to receive if dying", achievement of communication goals, DNR orders	Similar rates of EOL discussions in Black and White patients (35%:38%) (N.B. p=0.65 not statistically significant so excluded from our analysis). EOL discussions associated with achieving some communication goals among Blacks, including placement of DNR orders (AOR 4.25, p=0.04), but this did not translate into a reduction of life-prolonging care, as occurred with Whites.	100

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
16	(Nakazawa et al, 2013)(44)	Palliative care physicians' practices and attitudes regarding advance care planning in palliative care units in Japan: A nationwide survey	Japan - 99 palliative care units (PCUs)	n=99 doctors working in PCUs in Japan who responded to survey request	Japanese doctors/residents, ethnicity not recorded	QUAN – descriptive – survey and descriptive statistics (chi-square test, Fisher exact test)	AD: "directions recorded by competent individuals to allow them to influence treatment decisions in the event of serious illness and subsequent loss of competence" and ACP: "making decisions about patient's future healthcare by a patient in consultation with health care providers, family members, and important others, should they become incapable of medical treatment decisions"	86.9% of doctors agreed that "ACP is an effective way for patients to influence their medical treatment should they lose competence" however many failed to implement aspects of ACP such as recommending completion of ADs and designation of health care proxies or implementing existing ADs.	50 (4.2) sample not rep. of understudy population as self-selecting participants and (4.4) less than 60% response rate (49%)

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17	(Periyakoil et al, 2015)(57)	No Easy Talk: A Mixed Methods Study of Doctor Reported Barriers to Conducting Effective End-of-Life Conversations with Diverse Patients	US - two large training hospitals in California (Stanford Hospital and Clinics and the VA Palo Alto)	n=1040 multi-specialty doctors who care for seriously ill patients (n=8 didn't identify any barriers so didn't then participate, n=1032 remaining), development cohort n=29, validation cohort n=966	Caucasian n=485, Latino-American n=58, AA n=34, Asian n=335, Mixed ethnicity/race n=84 (presumed self-reported in survey, although this not clearly stated)	MIXED METHODS - Sequential exploratory design: survey then grounded theory analyses and coding validation cohort	EOL conversations	99.9% doctors reported barriers to conducting EOL conversations with patients, especially those of different ethnicity/race, including language, religious/spiritual beliefs, health literacy and cultural differences in truth handling and decision making. Dr's ethnicity did influence their level of reported barriers (Chi-Square = 12.77, DF = 4, p=0.0125).	75 (5.3) no triangulation or consideration of divergence of qualitative/quantitative results and (1.4) no consideration of how findings relate to researchers influence
18	(Perry et al, 2005)(68)	Peer Mentoring: A Culturally Sensitive Approach to End-of-Life Planning for Long-Term Dialysis Patients	US - 21 dialysis centres across Michigan	n=203 dialysis patients	38% were African American	QUAN - controlled randomised – RCT and generalized least squares estimation for multilevel binomial models	Intervention: peer mentoring on EOL decision making - dialysis patients trained to help other patients through 8 contacts over 2-4-month period, semi-structured, detailed on p113 of paper	Peer mentoring intervention increased completion of ADs (P<0.001), comfort discussing ADs (P<0.01) and improved subjective well-being (P< 0.05) among African American patients compared to printed materials and control group. (These effects did not occur for White patients although printed materials did decrease reported suicidal ideation in Whites (p<0.05).	75 (2.2) no description of allocation concealment from researchers or participants

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
19	(Phipps et al, 2003)(45)	Approaching the End of Life: Attitudes, Preferences, and Behaviors of African-American and White Patients and Their Family Caregivers	US - patients from cancer centres, tumour registries, or recruited through oncologists/ doctors	n=68 patients with stage III-B or IV lung or stage IV colon cancer and n=68 patient-designated family caregivers (of 159 eligible) (of 198 identified but 38 died before time of contact)	AA n=38, White n=30	MIXED METHODS – interviews and medical records review and statistical analysis and coding of qualitative data	LW, completion of a HC proxy directive, DPOA for healthcare and EOL discussions	White patients were more likely than AA patients to have completed formal ACP including: DPOA (34%:8%, -p=0.01) and LW (41%:11%, p=0.004).	75 (5.3) no triangulation or consideration of divergence of qualitative/quantitative results and (4.4) less than 60% response rate (42% 68/159)
20	(Sharma et al, 2011)(65)	Documentation of information and care planning for patients with advanced cancer: associations with patient characteristics and utilization of hospital care	US - Johns Hopkins Hospital and Sidney Kimmel Comprehensive Cancer Centre, Baltimore	n= 238 deceased patients with advanced cancer, primarily Medicaid, who died between 2 and 15 months after diagnosis and had at least 3 hospital visits	White n=151, Black n=76, Other n=11	QUAN - retrospective cross-sectional - hospital chart review and descriptive statistics (multivariate logistic regression, chi-squared tests, ANOVA)	AD, DPOA, DNR order, hospice discussion, hospice referral	Rates of ACP documentation were generally low. Black patients had a higher odds of hospice discussion than White patients in the multivariate analysis (AOR 2.11; 95% CI 1.18 to 3.76) (p=0.01).	75 (3.1) participants not recruited in a way that minimizes selection bias (all from one specialist cancer hospital so not representative of other settings)

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
21	(Smith et al, 2007)(39)	Differences in the Quality of the Patient–Physician Relationship Among Terminally Ill African-American and White Patients: Impact on Advance Care Planning and Treatment Preferences	US - patients recruited through local physicians in 6 sites	n=803 terminally ill patients	African American (n=115), White (n=688) (no distinction between Hispanic or non-Hispanic) (self-reported)	QUAN non-randomised cross-sectional - analysis of Commonwealth–Cummings Project data (nationwide survey) and bivariable sequential statistical analysis	ACP defined as "the patient reporting on one or more of the following: a living will, a health care proxy, or having talked with family or physician about plans for end-of-life care" (i.e. LW, HC proxy, EOL discussion)	AAs were less likely than Whites to have an ACP (ARR =0.66, 95%CI=0.52–0.84) (p<0.001). AAs' ratings of the quality of their patient-doctor relationships were found to be poorer than those of White Americans for several measures but the difference was not statistically significant for level of trust in doctors.	50 (3.1) participants not recruited in a way that minimizes selection bias (recruited through Dr's who may be more likely to recruit patients with whom they had good relationship) and (3.2) poor validity of tool used (q's about dr-pt relationship were skewed towards 'agree')
22	(Smith et al, 2008)(38)	Racial and Ethnic Differences in Advance Care Planning Among Patients With Cancer: Impact of Terminal Illness Acknowledgment, Religiousness, and Treatment Preferences	US - 8 cancer centres/hospitals/PC centres/oncology departments/veteran health-care centre in 5 states	n=449 patients with advanced cancer (clinician's estimate that the patient would live<6 months and failure of first-line chemotherapy) and had an unpaid caregiver	312 non-Hispanic white, 75 non-Hispanic black, and 62 Hispanic patients (self-identified)	QUAN non-randomised cross-sectional – analysis of CWC interview data and statistical analysis (chi-square test, Fisher exact test, modified Poisson approach)	ACP defined as "patient's report of LW or DPOA/HC proxy), completed DNR order (not measured in above study), or having discussed wishes for EOL care with their physician" (i.e. LW, DPOA/HC proxy, DNR order, EOL discussion)	Compared with Whites, Blacks and Hispanics were less likely to have an ACP (W 80%; B 47%; H 47%). Compared with Whites, Blacks and Hispanics were more likely to consider religion very important (W 44%; B 88%; H 73%) (p<0.001). Although Black and Hispanic patients were less likely to consider themselves terminally ill, this factor did not explain observed disparities in ACP.	75 (3.2) – unknown validity of measurements used (e.g. religiousness scale)

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23	(Song et al, 2009)(67)	Randomized Controlled Trial of SPIRIT: An Effective Approach to Preparing African-American Dialysis Patients and Families for End of Life	US - 6 out-patient dialysis clinics in western Pennsylvania	n= 58 dyads: African Americans with end-stage renal disease and their chosen surrogate decision makers	all AA n=58	MIXED METHODS - sequential explanatory design – RCT, surveys, interviews. Statistical analysis (Fisher's exact test, Mann-Whitney U) and thematic analysis qual data.	Intervention: Sharing Patients' Illness Representations to Increase Trust (SPIRIT) involving: identifying and exploring concerns, creating conditions for discussion and conceptual change about death/dying, introducing replacement information, encourage future discussions, assess need for additional support	SPIRIT intervention was well received by both patients and surrogates. SPIRIT was found to increase quality of communication scores reported by patients: intervention vs control at T2 (1 week) (U = 283.50, p=0.03) and T3 (3 months) (U = 165.00, p0<0.01) and by surrogates: intervention vs control at T2 (U = 95.00, p<0.01) and T3 (U = 139.00, p=0.03).	50 (5.3) no triangulation or consideration of divergence of qualitative/quantitative results and (1.3) no consideration of how context/settings could influence findings and (1.4) no consideration of how findings relate to researchers influence and (2.3) outcome data completed below 80% (54% participants agreed to be included in follow up data)

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
24	(True et al, 2005)(54)	Treatment Preferences and Advance Care Planning at End of Life: The Role of Ethnicity and Spiritual Coping in Cancer Patients	US - patients from cancer centres, tumour registries, or recruited through oncologists/ doctors	n=68 patients with an advanced stage of lung or colon cancer	AA n=38, White n=30 (self-defined)	QUAN non-randomised cross-sectional – secondary analysis of medical records and interviews using coding and statistics (fisher's exact test)	LW	AAs more likely than Whites to report belief in divine intervention (rs=0.27, p=0.02) or that their fate was in the hands of higher power (rs=0.25, p=0.04). Patients who reported divine intervention belief less likely to have a living will (p=0.007).	50 (3.2) unknown validity of measurements used and (3.4) less than 60% response rate (42% 68/159)

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
25	(Walczak et al, 2013)(49)	A question prompt list for patients with advanced cancer in the final year of life: Development and cross-cultural evaluation	Australia + US - 1 US and 2 Australian treatment centres	n= 34 oncology patients with advanced cancer (LE <12 months as assessed by doctor) and n=13 health professionals treating patients	patients: Australia n=15, US n=19 ... health-care profs: Australia n=7, US n=6	QUAL – interviews, focus groups and questionnaire and coding and thematic analysis	Intervention: question prompt list (QPL) - booklet containing categorised lists of useful questions patients can ask their clinician	Both the US and Australian versions of the QPL intervention were well accepted and endorsed by patients and health-care professionals. Differences in Australian + US approaches to EOL and prognosis discussions emerged in the interviews.	50 (1.3) no consideration of how findings relate to context and (1.4) no consideration of how findings relate to researchers influence
26	(Wallace et al, 2007)(58)	Physician Cultural Sensitivity in African American Advance Care Planning: A Pilot Study	US - 3 major teaching hospitals in NY	n= 183 convenience sample of all physicians in attendance at medicine grand rounds on one specified day	White (n=92), Asian (n=48), and black Americans (n=8) and non-U.S.–born Black (n=21)	QUAN non-randomised cross-sectional – questionnaire and statistics (Student's t test, chi squared)	Clinician knowledge and perceptions of African American patient preferences, cultural competence (measured by awareness of differences between ethnic groups in: AD completion rates, knowledge of ACP, trust in clinicians)	72% of doctors agreed that different racial/ethnic groups have distinct attitudes towards ADs. 58% acknowledged lack of familiarity with end-of-life preferences of AA patients although this was more commonly reported amongst White doctors than Black doctors. 88% of US-born Black doctors (7/8), vs 35% of White doctors (32/91) and 26% (5/19) of non-US-born Black doctors, perceived that the Tuskegee experiment has impacted African American medical decision-making (p = 0.014).	50 (3.1) participants not recruited in a way that minimizes selection bias (recruited from grand round participants, to ensure high response rate, however limited generalisability) and (3.3) differences between groups being compared not accounted for (small groups so multivariable analysis for potential confounders, e.g. level of training, not possible)

No (#)	Author	Title	Country/ Setting	Population	Ethnicity/race of patients	Methodology	ACP process studied	Main finding regarding acceptability of ACP	Quality appraisal score and missing items
27	(Zaide et al, 2013)(69)	Ethnicity, race, and advance directives in an inpatient palliative care consultation service	US - Long Island Jewish (LIJ) Medical Centre, an academic tertiary hospital in New Hyde Park, New York	n=400 patients who took part in a PCC at LIJ during the 9 month study period where chart had complete documentations of AD variables (533 total, 133 didn't have full data recorded)	white n=187, AA n=142, Asian n=44	QUAN non-randomised cross-sectional – longitudinal hospital chart review and descriptive statistics (t test, Mann Whitney test, chi squared, Fisher's exact test, Bonferroni-adjusted pairwise comparisons)	Intervention: Palliative Care Consultation (PCC) with multi-disciplinary team to develop a plan of care including pain/symptom relief, establishing goals of care, integration of psychological and spiritual aspects of the patient and family experience and offering support to the family during the patient's illness and the bereavement period. Outcomes: completion of AD defined as DNR or DNI	White patients completed more ADs than did non-White (AA, Asian, Hispanic) patients before the intervention (25.67% vs 12.68%) (p=0.021). Further analysis showed AAs differed from whites in the likelihood of AD execution rates pre-PCC, but not post-PCC. PCC Intervention significantly reduced differences between Whites and AAs in completing ADs.	75 (3.4) outcome data below 80% (75% 400/533)

*Methodology = Qualitative (QUAL), Quantitative (QUAN) or Mixed Methods (combining qualitative and quantitative methods)

Abbreviations: EOL=End of life, AD=Advance Directive, DNR=Do Not Resuscitate, LW=Living Will, DPOA=Durable power of attorney, HC proxy= Healthcare proxy, DNI=Do Not Intubate, CPR=Cardiopulmonary Resuscitation, PCC=Palliative Care Consultation, AA=African American, NZ=New Zealand, COPD=Chronic obstructive pulmonary disease, AOR=adjusted odds ratio