Review Article

How Should End-of-Life Advance Care Planning Discussions Be Implemented According to Patients and Informal Carers? A Qualitative Review of Reviews

Alex Hall, PhD, Christine Rowland, PhD, and Gunn Grande, PhD

Division of Nursing, Midwifery and Social Work (A.H., C.R., G.G.), School of Health Sciences, University of Manchester, Manchester; and National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) (A.H., C.R., G.G.), Greater Manchester, UK

Abstract

Context. The goal of advance care planning (ACP) is to help ensure that the care people receive during periods of serious illness is consistent with their preferences and values. There is a lack of clear understanding about how patients and their informal carers feel ACP discussions should be implemented.

Objectives. The objective of this study was to synthesize literature reviews pertaining to patients' and informal carers' perspectives on ACP discussions.

Methods. This is a systematic review of reviews.

Results. We identified 55 literature reviews published between 2007 and 2018. ACP discussions were facilitated by a diverse range of formats and tools, all of which were acceptable to patients and carers. Patients and carers preferred health professionals to initiate discussions, with the relationships they had with the professionals being particularly important. There were mixed feelings about the best timing, with many people preferring to defer discussions until they perceived them to be clinically relevant. ACP was felt to bring benefits including a greater sense of peace and less worry, but it could also be disruptive and distressing. Patients and carers perceived many benefits from ACP discussions, but these may differ from the dominant narratives about ACP in health policy and may move away from the narratives of RCTs and standardization in research and practice.

Conclusion. Researchers and clinicians may need to adjust their approaches as current practices are not aligned enough with patients' and carers' preferences. Future research may need to test implementation strategies of ACP interventions to elucidate how benefits from standardization and flexibility might both be realized. J Pain Symptom Manage 2019;58:311–335.

Key Words

Advance care planning, caregivers, palliative care, patients, systematic review, terminal care

Introduction

The goal of advance care planning (ACP) is to help ensure that the care people receive during periods of serious and chronic illness is consistent with their preferences and values, at a time when they may be unable to communicate their wishes.[1] In health policy, ACP is seen as an "unequivocal good," chiefly because of its ability to preserve patient autonomy,[2] and it is highlighted by the World Health Organization as an indication of high-quality palliative care.[3] It can bring numerous clinical and psychosocial benefits to patients and families, including supporting patient autonomy, increasing compliance with patients' wishes for their end-of-life care, enhancing patient and family

Address correspondence to: Alex Hall, PhD, Division of Nursing, Midwifery and Social Work, University of Manchester, Room 5.322, Jean McFarlane Building, Oxford Road, Manchester M13 9PL, UK. E-mail: alex.hall@manchester.ac.uk

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satisfaction with care, supporting families to make decisions on behalf of patients, and reducing family distress and grieving.[4–6] There is also some limited evidence that ACP can lead to health care savings in certain contexts such as dementia care or nursing homes.[7] Despite these potential benefits, the implementation of ACP in practice is extremely difficult because illness trajectories can be difficult to predict, which makes the timing of ACP intervention hard to identify.[8] It is also conceptually and contextually complex because it encompasses a set of decision-making processes and procedures, together with broader phenomenological experiences of dying and death, all occurring within diverse sociocultural and medicolegal contexts.[8,9] All this means that successful implementation of ACP interventions is likely to require strong health system and organizational policy support, knowledgeable professionals, iterative approaches, and cultural sensitivity.[6]

Despite an abundance of literature reviews synthesizing ACP research,[6] there remains a lack of clear understanding about how patients and their informal carers (i.e., family and friends, rather than professionals) feel ACP discussions should be implemented. There is increased recognition that ACP is a continuous discursive process rather than a one-off bureaucratic exercise, yet most health care systems evaluate ACP implementation by document completion, which is a poor proxy for patient and carer actual experiences of ACP.[10] This is important because the realization of the benefits of ACP depends in part upon implementation approaches that are informed by greater understandings of people's readiness to engage in ACP discussions, their values and beliefs about death and dying, and their expectations about the roles of families, health care professionals, and services within end-of-life care.[11] It is also important to understand what patients and carers do not want because factors that hinder implementation of ACP can be more influential than those that facilitate it.[8] In the present study, we aim to synthesize the research literature pertaining to patients' and informal carers' perspectives on ACP discussions and relate this literature to policy, practice, and research around ACP within end-of-life care. This is important because there is a need to ensure that policy, practice, and research are aligned with patients' and carers' preferences about how ACP should be implemented.

Methods

Research Question, Objectives, and Design

This review was conducted in response to a collaborative end-of-life research priority-setting exercise that involved consultations with informal carers and health care professionals in Greater Manchester, U.K.[12] All stakeholder groups in this exercise identified ACP as one of the most important topics for end-of-life research. Our main research question arising from this exercise was as follows: How should end-of-life ACP discussions be implemented according to patients and informal carers? We focused on the following objectives, informed by the local consultation exercise[12]:

- To describe how ACP discussions are held with patients and carers;
- To explore who patients and carers feel should be initiating ACP discussions;
- To identify when patients and carers feel is the most appropriate time to have ACP discussions;
- To identify the perceived value placed by patients and carers on ACP discussions.

We defined ACP as the process of discussions that people have about their personal values, goals, and preferences regarding future medical care, before they lose capacity to make such decisions themselves.[1] These discussions may include formal documentation, which in some cases may be legally binding.

Given the proliferation of literature reviews of research on ACP, work was needed to synthesize information on patients' and carers' perspectives contained within these existing reviews. We therefore adopted a qualitative review-of-reviews approach. We followed the review-of-reviews methodology of Smith et al.,[13] which we adapted to suit a qualitative approach as follows: we developed a clear search strategy, selection criteria, and process of quality assessment, and we present the results in the following according to the research objectives. However, as our review is not a meta-analysis, we do not have primary outcomes and we do not explore potential duplication of primary studies across the reviews.[13]

Search Strategy

We conducted systematic searches of the Cochrane Database of Systematic Reviews, Web of Science, PubMed, CINAHL, and PsycINFO databases for peer-reviewed literature reviews published in English. We limited the searches to publications since 2007 because ACP started to become more prominent in legislation and policy with a number of countries from the mid-2000s, including the U.K.,[14] Australia,[15] France,[16] and Canada.[17] We also applied a time limit because of the potential for reviews to become out of date.[18] We conducted database searches in December 2017 and updated in July 2018. Our search terms included 1) (advance care plan* OR advance directive* OR advance decision*OR living will*OR end of life decision* OR do not resuscitate OR DNR

OR do not hospitalize OR DNH) AND 2) (review or synthesis). Over the last decade, it has become widely accepted that literature reviews should include a description of the intervention and the type of review in the title.[19] We therefore used MeSH search terms or applied the terms to titles of papers. To complement the database searches, we scanned the reference list of the contemporary overview of reviews of ACP by Jimenez et al.,[6] which followed Cochrane methodology in a synthesis of the full spectrum of ACP research.

Study Selection

All records retrieved from the 2017 database searches were imported into Endnote X8 (Clarivate Analytics, Philadelphia, PA). Duplicate references were identified and deleted. Papers were screened independently by two reviewers (A. H. and C. R.), first by title and abstract, and second by full text. The two reviewers compared screening decisions and resolved disagreements by discussion. Our research questions were likely to be addressed by both quantitative and qualitative research studies that would be synthesized by different types of literature review (e.g., systematic reviews, narrative reviews, scoping reviews, realist reviews),[20] and as such, all types were included in this review. We included papers if they were reviews of primary research, had applied a systematic approach to searching literature, and included information on ACP for adults at end of life. We excluded papers that focused on ACP with children, ACP for conditions that were not related to end of life (e.g., during temporary incapacitation from mental illness), and papers where it was not possible to identify patients' and carers' perspectives on ACP discussions. Records from the updated database searches in July 2018 and the reference list scanning were also added to Endnote X8 if they met our inclusion criteria.

Quality Assessment, Data Extraction, and Synthesis

Papers were assessed for quality by two reviewers independently (A. H. and C. R.), using the AMSTAR tool.[21] Data were extracted by one reviewer (A. H.) with 20% checked for accuracy by a second reviewer (C. R.), using a standardized data extraction sheet. As concordance was high, further checks were not conducted. Disagreements were resolved by discussion. For each review, we collated information about its design and methods (review question/objective; review type; participants/condition if specified; number of databases searched and date range) and descriptive information about the included primary research (number and date range; designs; countries; authors' summary of quality). We extracted and tabulated findings relating to the four research objectives that we developed from the priority-setting consultation exercise in Greater Manchester, U.K.,[12] which are detailed previously.

We also extracted information relating to the review authors' recommendations for practice and research.

This work was an analysis of published literature and did not require ethics approval.

Results

Paper Selection and Characteristics

Initial database searches retrieved 224 unique papers. We excluded 163 papers via title and abstract screening. We reviewed 61 full texts, of which 47 met our inclusion criteria. The July 2018 update yielded a further two papers for inclusion, and the Jimenez et al.[6] overview contributed a further six papers, giving a total of 55 papers. The review process is shown in a flow diagram in Figure 1.

Characteristics and quality appraisals of the included reviews are shown in Table 1. We assessed 29 reviews as being of higher quality (scoring 9/11 or higher on the AMSTAR tool), 20 reviews as being of moderate quality (scoring 6–8/11), and six reviews as being of lower quality (scoring 5/11 or below). Just over half of the reviews ($n = 30$) focused on research questions applicable to ACP in general; of these 30, three explicitly excluded primary research that was condition specific. Just under half ($n = 25$) focused on specific conditions, including dementia ($n = 11$), cancer ($n = 4$), heart disease ($n = 3$), chronic respiratory disease ($n = 3$), renal disease ($n = 3$), frailty ($n = 2$), motor neurone disease ($n = 1$), and severe traumatic brain injury ($n = 1$). Two of these papers focused on multiple conditions (dementia/chronic respiratory disease/heart failure/kidney disease; dementia/frailty/brain injury, respectively). Seven reviews focused on ACP with ethnic minority groups, two focused on ACP with homeless people, and two focused on ACP with people with intellectual disabilities. The majority of primary research synthesized in the reviews was conducted in the U.S. Overall, the review authors appraised the primary research they had synthesized as being broadly of low to moderate quality.

How ACP Discussions Are Held?

Several reviews highlighted the lack of consistent implementation of ACP. Discussions were happening most often with patients who were older, white, female, well educated, and had cancer or comorbidities.[22–26] Engagement in ACP within African American, Latinos/Hispanics, and Asian groups was lower than within whites.[27–32] ACP was seldom occurring for people with intellectual disabilities,[33,34] and a review of ACP with cancer survivors[35] found

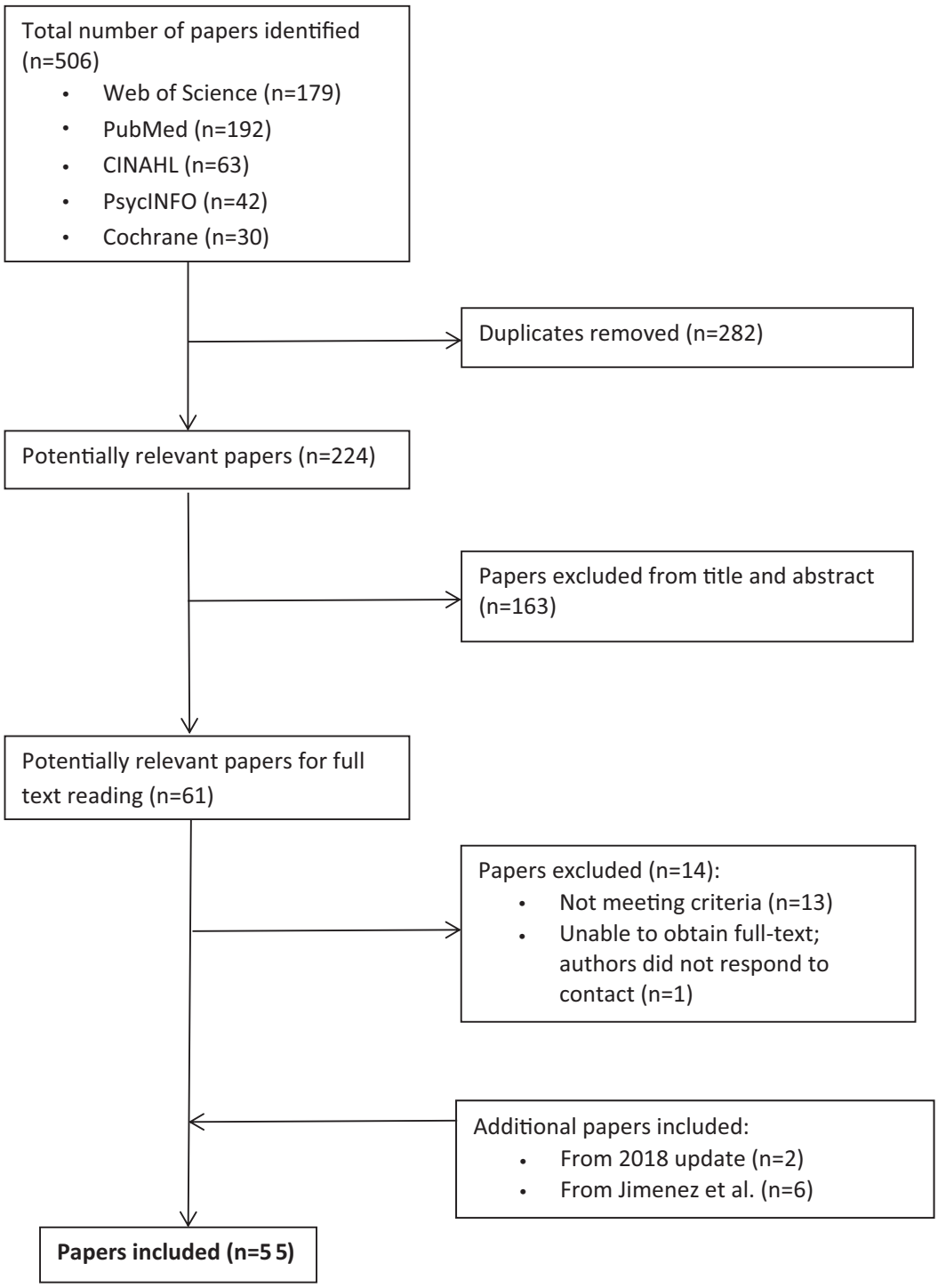

Fig. 1. Flow of papers through the review process.

no papers meeting the inclusion criteria, suggesting that ACP was not happening at all for this group. However, the complexities in defining what constitutes ACP (and thus perception of whether it has occurred) were highlighted by patients in primary care settings perceiving a lower frequency of ACP initiatives than had been reported by health care professionals.[36]

ACP discussions were facilitated by a diverse range of decision aids and tools, including print, video, and computerized formats, which could be self-guided or professionally supported.[37–42] The duration of ACP discussion varied from five to 90 minutes, and the most common topics addressed were treatment options and preferences.[37] Quantitative evidence

Table 1
Characteristics of Included Reviews

Review	Aim/Objective	Review Method[a]	Population or Condition	Number of Databases Searched (Date Range)	Number of Studies Included (Date Range)	Designs of Studies	Countries of Studies	Quality Appraisal
Adams et al. 2011[69]	To analyze the literature concerning nurses' roles and strategies in EoL decision making in acute care environments	Systematic	Unspecified	2 (1996–2011)	44 (unclear)	32 qualitative, 7 quantitative, three mixed methods, two literature reviews	USA (22), U.K. (4), Canada (4), Australia (3), Finland (2), New Zealand (2), Norway (2), Sweden (2), Belgium (1), Spain (1), Pan-European (1)	Moderate
Barker et al. 2017[52]	To explore the evidence on the decisional support needs of informal carers of people with end-stage dementia	Rapid scoping	Dementia	6 (2000–2016)	40 (2000–2016)	29 primary studies (6 of which purely qualitative), one literature reviews	U.K. (16), USA (10), Canada (5), Belgium (2), Australia (1), Germany (1), Ireland (1), Japan (1), Netherlands (1), Norway (1), Spain (1)	Moderate
Barnes et al. 2012[56]	To identify existing interventions of patient-professional communication developed for life-limiting conditions and explore the applicability of interventions developed within a cancer framework to other diagnostic groups	Systematic	Unspecified	10 (up to 2010)	16 (1995–2009)	Seven controlled trials, three uncontrolled intervention studies, three qualitative, three tool development	USA (10), U.K. (4), Australia (2)	Moderate
Bernacki & Block 2014[57]	To review the evidence and describe best practices in conversations about serious illness care goals; to offer practical advice for clinicians and health care	Systematic	Cancer, COPD, heart failure, CKD/end-stage renal disease	1 (2006–2014)	Unclear (unclear)	Unstated	Unstated	Lower

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Table 1
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Review	Aim/Objective	Review Method[a]	Population or Condition	Number of Databases Searched (Date Range)	Number of Studies Included (Date Range)	Designs of Studies	Countries of Studies	Quality Appraisal
	systems about developing a systematic approach to quality and timing of such communication to assure that each patient has a personalized serious illness care plan							
Birchley et al. 2016[47]	To understand challenges in securing good EoL care	Scoping	Dementia, frailty, severe traumatic brain injury	6 (up to 2015)	49 (1997–2015)	18 qualitative or mixed methods, 15 observational, 9 epidemiological, five intervention/quasi-experimental, two case series	USA (17), U.K. (12), Netherlands (5), Canada (3), Hong Kong (2), Belgium (2), Pan-European (2), Australia (1), Germany (1), Israel (1), Italy (1), Japan (1), Ireland (1)	Higher
Cardona-Morrell et al. 2017[37]	To describe the range of decision aids available to enable informed choice for older patients at the end of life and assess their effectiveness or acceptability	Systematic	Unspecified	7 (up to 2015)	17 (1999-2014)	Six RCT, one quasi-experimental, one prospective, seven before-and-after, two qualitative	USA (13), Canada (3), Australia & Canada (1)	Higher
Cogo & Lunardi 2015[58]	To analyze the scientific literature regarding advance directives both in Brazil and in other countries, as they applied to the terminally ill	Integrative	Unspecified	4 (up to 2014)	44 (unclear)	Unstated	Brazil (13); North America (13), Europe (11), Asia (4), South America (1)	Moderate
Conelius 2010[59]	To examine the literature related to research on	Systematic style (but unstated)	Heart disease	7 (1990–2008)	Unclear (unclear)	Unstated	Unstated	Lower

	ACP and advance directives particularly in patients with implantable cardioverter defibrillators in place							
Cruz-Oliver et al. 2014[27]	To review current evidence on how to deliver EoL care to Latino elders	Systematic	Latinos	4 (up to 2011)	38 (unclear)	17 qualitative, 16 quantitative, five mixed methods	USA (34) Dominican Republic (1), Argentina (1), South America (1), Spain (1)	Higher
Dening et al. 2011[48]	To examine the facilitators and inhibitors to ACP in people with dementia	Systematic	Dementia	7 (up to 2010)	17 (1991-2008)	11 quantitative, five mixed methods, one qualitative	USA (12), U.K. (3), Australia (1), Netherlands (1)	Higher
Dev et al. 2012[44]	To offer a comprehensive update of current evidence reflecting perspectives of patients and their surrogates regarding ACP and advanced heart failure device therapies	Systematic review approach to generate a structured narrative review	Heart disease	Unstated (unstated)	27 (1995–2011)	14 qualitative, 10 quantitative, two mixed methods, one literature review	USA (20), Canada (2), Ireland (1), Spain (1), Switzerland (1), U.K. (1)	Lower
Flo et al. 2016[49]	To outline the process of implementation of ACP-related communication and EoL conversations discussing care and treatment with patients and relatives	Scoping	Unspecified; excluded studies that focused on specific diagnoses	5 (up to 2014)	16 (1994–2013)	Seven quantitative, six mixed methods, three qualitative	USA (5), Australia (4), U.K. (4), Canada (1), Hong Kong (1), New Zealand (1)	Higher
Fosse et al. 2014[50]	To identify and synthesize qualitative research findings about nursing home patients' and relatives' expectations and experiences on how doctors can contribute to quality EoL care	Meta-ethnography	Unspecified	7 (up to 2012)	14 (1999–2011)	All qualitative	USA (10), Canada (2), Sweden (1), Norway (1)	Higher

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Review	Aim/Objective	Review Method[a]	Population or Condition	Number of Databases Searched (Date Range)	Number of Studies Included (Date Range)	Designs of Studies	Countries of Studies	Quality Appraisal
Frost et al. 2011[22]	To determine which factors are known to influence EoL decision making among patients and health care providers	Systematic	Unspecified	1 (1950–2010)	102 (1986–2010)	All quantitative (excluded qualitative): cohort (64), surveys (32), controlled clinical trials (2)	Unstated	Higher
Glaudemans et al. 2015[36]	To provide an overview of the actual practice of ACP in primary care	Systematic	Unspecified	5 (up to 2013)	10 (1991–2011)	Seven survey, three qualitative	USA (5), Belgium (1), Belgium and Netherlands (1), Belgium, Netherlands, Australia, Denmark, Italy, Sweden, and Switzerland (1), Germany (1), U.K. (1)	Moderate
Hong et al. 2018[28]	To update the current state of knowledge, develop implications for culturally competent practice, and identify further research directions in promoting ACP among ethnic minorities	Systematic	Ethnic minority groups in U.S.	12 (2006–2016)	26 (2006–2016)	Six experimental, 12 cross-sectional, eight qualitative	USA (25), USA & Japan (1)	Moderate
Hubbell 2017[60]	To develop an understanding of homeless EOL planning needs	Systematic	Unspecified	7 (unstated)	9 (2005–2015)	Two RCT, one quasi-experimental, six qualitative	Unstated	Moderate
Jabbarian et al. 2018[61]	To systematically review ACP practice in chronic respiratory disease, attitudes of patients and health care professionals and barriers and	Systematic	Chronic respiratory disease	12 (up to 2015)	21 (1996–2015)	10 quantitative, 11 qualitative	USA (8), U.K. (5), Australia (3), Canada (2), USA/ Netherlands (1), Netherlands (1), Portugal (1)	Higher

	facilitators related to engagement in ACP							
Jain et al. 2015[38]	To evaluate the impact of video decision aids on patients' preferences regarding life-sustaining treatments	Systematic; meta-analysis	Unspecified	6 (1980–2014)	10 (1996–2013)	All RCT	USA (10)	Higher
Jethwa & Onalaja 2015[67]	To assess the factors that affect the clinical use of ACP and palliative care interventions in patients with dementia	Systematic style (but unstated)	Dementia	3 (unstated)	Unclear (unclear)	Unclear	The majority were in the U.S. or continental Europe	Lower
Jezewski et al. 2007[43]	To synthesize the state of the science regarding effectiveness of interventions to increase advance directive completion rates	Systematic	Unspecified	8 (1994–2005)	25 (1994–2004)	14 experimental, three quasi-experimental, eight pre-experimental	USA (22), Canada (3)	Moderate
Johnson et al. 2016[62]	To examine the literature exploring patient, caregiver, and health care professional experiences and perceptions of ACP in cancer care	Systematic	Cancer	5 (up to 2014)	40 (1996–2014)	19 quantitative, 17 qualitative, four mixed methods	USA (19), U.K. (8), Europe (5), Australia (5), Taiwan (1), and 1 study from Canada (reported in two papers)	Higher
Jones et al. 2016[53]	To synthesize the literature on dementia-specific issues concerning EoL care	Scoping	Dementia	6 (up to 2015)	25 (unclear)	10 qualitative, four intervention, three survey, three case review, two epidemiological, one RCT, one cross-sectional, one cohort	USA (7), U.K. (7), Belgium (2), Netherlands (2), Japan (1), Ireland (1), Israel (1), Italy (1)	Moderate
Ke et al. 2017[55]	To understand the experiences and perspectives of older people regarding ACP	Systematic; meta-synthesis	Unspecified; excluded studies that only included specific diagnoses	4 (up to 2014)	50 (unclear)	All qualitative, or qualitative components of mixed methods	USA (27), U.K. (6), Australia (4), Canada (3), Belgium (1), Germany (1), Hong Kong (1), Japan (1), Malaysia (1), Singapore (1)	Higher

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Table 1
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Review	Aim/Objective	Review Method[a]	Population or Condition	Number of Databases Searched (Date Range)	Number of Studies Included (Date Range)	Designs of Studies	Countries of Studies	Quality Appraisal
Kirkendall et al. 2017[33]	To describe the current state of the literature on decision making for individuals with an intellectual disability at the end of life, identify gaps in our understanding of this issue, and make recommendations for further development of protocols to increase the involvement of individuals with an intellectual disability in EoL decision making	Systematic	Intellectual disabilities	10 (2000–2014)	12 (2005–2014)	Six conceptual, one literature review, three qualitative, two quantitative	USA (all six conceptual + one qualitative), Netherlands (two qualitative + two quantitative)	Moderate
Lee et al. 2014[75]	To examine the empirical evidence about ACP and advance directives in Chinese populations from Eastern and Western cultures	Systematic	Chinese and Chinese North Americans	5 (up to 2013)	15 (Eastern cultures 2000–2012; Western cultures 1996–2001)	Seven quantitative, six qualitative, two mixed methods	Eastern: Hong Kong (7), Singapore (2), China (1); Western: USA (4), Canada (1)	Moderate
Lewis et al. 2016[63]	To determine whether advance care documentation encourages health care professionals' timely engagement in EoL discussions	Systematic	Unspecified	7 (2000–2015)	24 (2003–2013)	10 qualitative, eight mixed methods, six quantitative	U.K. (8), USA (6), Finland (2), Australia (2), Japan (2), Israel (1), Germany (1), Netherlands (1), Switzerland (1)	Higher
LoPresti et al. 2016[29]	To conduct a systematic review examining	Systematic	African Americans, Hispanic/Latin Americans, Asian	4 (up to 2014)	25 (1996–2013)	20 quantitative, five qualitative	USA (25)	Moderate

	ethnic/racial disparities in EoL care for cancer patients		Americans; Cancer					
Lord et al. 2015[74]	To identify 1) barriers and facilitators to carer proxy decision making and 2) interventions designed to help carers make proxy decisions and their effectiveness	Systematic	Dementia	1 (up to 2014)	30 (1993–2013)	20 qualitative, 10 quantitative	Unclear	Moderate
Lovell & Yates 2014[23]	To identify the contextual factors influencing the uptake of ACP in palliative care	Systematic	Unspecified; excluded studies evaluating a novel intervention, tool or model of ACP because they tend to be condition and population specific	3 (2008–2012)	24 (2008–2012)	13 qualitative, 11 quantitative	USA (10), U.K. (8), Australia (4), Belgium (2), Netherlands (1), China (1), Taiwan (1)	Higher
Luckett et al. 2014[39]	To identify what interventions have been developed, piloted, and evaluated; identify which measures have been used in intervention and other studies; establish evidence for the efficacy of interventions; and inform understanding of barriers and facilitators to implementation, as well as stakeholders' perceptions of ideal approaches	Systematic integrative	CKD	6 (up to 2013)	55 papers reporting 51 studies (1989–2013)	48 quantitative (seven intervention), six qualitative	USA (35); unclear (16)	Higher
Mignani et al. 2017[46]	To systematically search and synthesize qualitative studies exploring the perspectives of older people living in long-	Systematic; thematic synthesis	Unspecified	3 (2000–2015)	9 (2008–2015)	All qualitative or qualitative components of mixed methods	Belgium (2), Norway (2), U.K. (2), USA (2), Australia	Higher

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Table 1
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Review	Aim/Objective	Review Method[a]	Population or Condition	Number of Databases Searched (Date Range)	Number of Studies Included (Date Range)	Designs of Studies	Countries of Studies	Quality Appraisal
	term care facilities and of their family members about ACP discussions							
Mitchell et al. 2014[24]	To identify factors that facilitate the establishment of enduring powers of attorney, and those that create a barrier to their establishment	Systematic style (but unstated)	Unspecified	3 (unstated)	13 (unclear)	Unstated	Unclear	Lower
Murray & Butow 2016[70]	To summarize what is known about the prevalence, predictors, content (including timing, format, documenting), patient/caregiver benefits, health care professional awareness/ acceptance, and health care outcomes associated with ACP in the MND setting	Systematic	MND/ALS	4 (unstated)	16 (1991–2011)	12 quantitative, four qualitative	USA (63%), Europe (37%)	Higher
O'Caoimh et al. 2017[35]	To summarize the evidence for the inclusion of ACP decisions and advance care directives within survivorship care plans among older cancer survivors	Systematic	Cancer	2 (up to 2017)	0 (n/a)	n/a	n/a	Moderate[b]
Oczkowski et al. 2016 (ambulatory care)[40]	To determine, among adults in ambulatory care settings, the effect of structured	Systematic; meta-analysis	Unspecified	5 (up to 2014)	67 (1991–2014)	46 RCT, 21 observational	North America (62) Asia (2), Europe (2), Australia (1)	Higher

	communication tools for EoL decision making on completion of ACP. Concordance between patient wishes and medical orders and care received.							
Oczkowski et al. 2016 (intensive care)[41]	To determine the impact of communication tools for EoL decision making in the ICU on the following outcomes: the number and quality of EoL discussions between shared decision makers and health care providers; the documentation of code status; and decisions to withdraw or withhold life-sustaining treatments	Systematic; meta-analysis	Unspecified	5 (up to 2014)	19 (1995–2014)	5 RCT, 14 observational	USA or Canada (16), France (3)	Higher
Petriwskyj et al. 2014[51]	To identify and appraise existing knowledge about family involvement in decision making for people with dementia living in residential aged care	Systematic; meta-synthesis	Dementia	15 (from 1990)	16 (2000–2011)	All qualitative	Unstated	Higher
Rahemi & Williams 2016[30]	To critically analyse the research concerning EoL preferences among older adults of underrepresented groups	Integrative	Unspecified	4 (2000–2015)	21 (2005–2015)	15 quantitative, four qualitative, two mixed methods, one longitudinal descriptive	USA (19), Australia (1), U.K. (1)	Higher
Ryan et al. 2017[66]	To undertake a synthesis of the qualitative	Systematic; thematic synthesis	Dementia	3 (2007–2015)	5 (2008–2014)	Five qualitative	U.K. (4), USA (1)	Moderate

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Table 1
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Review	Aim/Objective	Review Method[a]	Population or Condition	Number of Databases Searched (Date Range)	Number of Studies Included (Date Range)	Designs of Studies	Countries of Studies	Quality Appraisal
	research undertaken within the field of ACP and dementia with an emphasis on experiences, barriers and facilitators							
Sanders et al. 2016[31]	To understand factors impacting ACP among African Americans and explore their interactions, to guide further research and intervention development	Systematic integrative	African Americans	3 (up to 2016)	52 (1993–2014)	38 quantitative, 14 qualitative	All USA	Higher
Sharp et al. 2013[45]	To undertake a systematic review and narrative synthesis of the literature concerning the attitudes of the public and health care professionals to discussions about EoL care with frail and older individuals with no overriding diagnosis	Systematic	Frail and older adults with no diagnosis	4 (1991–2012)	26 (1991–2012)	14 qualitative, eight questionnaire, two mixed qualitative and questionnaire, two record review	USA (19), U.K. (5), Canada (1), unstated (1)	Higher
Skinner et al. 2014[25]	To explore electronic ACP models for community-dwelling older people and whether electronic information sharing for this population was effective	Realist; meta-synthesis	Unspecified	8 (1990–2012)	17 (1990–2012)	Nine quantitative, eight qualitative	USA (13), U.K. (3), Japan (1)	Moderate

Sumalinog et al. 2017[73]	To summarize and evaluate the evidence surrounding ACP, palliative care, and EoL care interventions for homeless persons	Systematic	Homeless people	8 (up to 2015)	6 (2006–2015)	Two RCT, two cohort, two qualitative	Canada (3), USA (2), Sweden (1)	Higher
Tilburgs et al. 2018[54]	To determine the barriers and facilitators faced by GPs related to ACP with people with dementia	Systematic integrative	Dementia	5 (1995–2016)	16 (2004–2016)	10 qualitative, six quantitative	U.K. (7), USA (4), Belgium (2), Germany (1), Netherlands (1), Singapore (1)	Higher
Tong et al. 2014[64]	To describe the perspectives of patients and family caregivers on the illness trajectory encompassing decisions not to initiate or to withdraw from dialysis therapy and for EoL care in chronic kidney disease	Systematic; thematic synthesis	CKD	4 (up to 2013)	26 (1988–2012)	All qualitative	USA (12), Canada (4), U.K. (4), Sweden (2), Australia (1), Ireland (1), Netherlands (1), Thailand (1)	Higher
van der Steen et al. 2014[26]	To identify factors associated with initiation of ACP regarding EoL issues in dementia	Systematic	Dementia	5 (up to 2013)	33 papers reporting 29 studies (1995–2013)	21 qualitative, 11 quantitative, one mixed methods	USA (19), U.K. (6), Netherlands (2), Belgium (2), Canada (2), Australia (1), USA & Netherlands (1)	Moderate
Voss et al. 2017[34]	To gain more insight into what is known about the use and effects of ACP in palliative care for people with intellectual disabilities	Systematic	Intellectual disabilities	6 (up to 2016)	14 (2003–2016)	Seven quantitative, three qualitative, four mixed methods	Netherlands (5), USA (4), Switzerland (3), U.K. (2), Belgium (1)	Higher
Walczak et al. 2016[71]	To assess and synthesize the available evidence for interventions targeting both EoL communication and any or all stakeholders in such communication	Systematic	Unspecified	3 (1950–2014)	45 (unclear)	17 RCT, 28 quasi-experimental	USA (31), Australia (3), U.K. (3), France (2), Canada (1), Germany (1), Hong Kong (1), Italy (1), Japan (1), Netherlands (1)	Higher

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Table 1
Continued

Review	Aim/Objective	Review Method[a]	Population or Condition	Number of Databases Searched (Date Range)	Number of Studies Included (Date Range)	Designs of Studies	Countries of Studies	Quality Appraisal
Wallace 2015[72]	To examine the current state of empirical literature on the relationship between family communication and decision making about EoL care, to identify gaps, and to discuss implications for policy, practice, and future research	Systematic	Unspecified	8 (up to 2013)	Unstated (unstated)	Unstated	Unstated	Lower
Wicher & Meeker 2012[32]	To examine and synthesize the state of the science from published research focused on EoL preferences and the influences on those preferences among African Americans	Garrard's matrix method	African Americans	4 (1985–2010)	46 (1990–2010)	14 qualitative, five mixed methods, 11 data set analysis (e.g. medical records), 16 quantitative	USA (all)	Moderate
Wickson-Griffiths et al. 2014[42]	What are the impacts of programs used to promote ACP in long-term care homes and do the programs include a consideration of the values that are important to persons with dementia and their family members?	Systematic	Dementia	4 (1990–2013)	6 (2000–2010)	All quantitative with a control group	Unstated	Higher
Wong & Gottwald 2015[65]	To map the perspectives that influence ACP discussions in the context of COPD	Scoping	COPD	3 (2003–2013)	11 (2004–2013)	All qualitative	Unstated	Moderate

Zager & Yancy 2011[76]	To review, evaluate, and synthesize the evidence concerning the utilization of culturally sensitive advance directives with respect to cultural values and beliefs	Systematic style (but unstated)	African Americans, Asian Americans, European Americans, Hispanic Americans, Native Americans	3 (Cochrane and PubMed limited to 2008-2011; Google Scholar first three pages reviewed)	10 (2001-2008)	Five quantitative, three qualitative, two qualitative review	USA (all)	Moderate
Zwakman et al. 2018[68]	To synthesize and describe the research findings on the experiences with ACP of patients with a life-threatening or life-limiting illness	Systematic with iterative method	Unspecified	4 (up to 2016)	20 (1998–2016)	19 qualitative, one mixed methods	Canada (6), U.K. (5), USA (4), Austria (3), Denmark (1), Germany (1)	Higher

EoL = end of life; ACP = advance care planning.
[a]All narrative or qualitative approach to synthesis unless otherwise stated.
[b]The review by O'Caoimh et al. found no studies that met its inclusion criteria, and thus, some items on the AMSTAR were not applicable.

showed that patients and carers found all formats acceptable; they led to small increases in knowledge of prognosis and knowledge of ACP and increased completion rates of documentation such as advance directives, although the strength of the evidence was weak.[37,38,40,41,43]

Family carers appeared to have a strong influence on whether and how ACP discussions were carried out. Family carers often mediated between patients and health care professionals in a "decision making triad".[25] Where patients had spoken with someone about ACP, it was more likely to be with family or friends than health care professionals.[44,45] Some reviews highlighted that ACP could be difficult if family carers were unwilling to engage.[45,46] This was particularly apparent in the context of dementia and long-term care, where families often become proxy decision makers; they may face uncertainty around legalities and patient wishes and are often unprepared for involvement in ACP.[47–51] Families and health care professionals may disregard the patient's ability to consent, or their preferences for end-of-life care[50]; family carers were also likely to be guided by health care professionals and may not have had conversations with the person with dementia.[52,53] However, patients and carers would prefer all stakeholders to be involved in ACP discussion.[54] In the context of dementia, patients and carers both felt financial issues and Power of Attorney must be included in ACP discussion.[54] Similarly, in other contexts, some patients had thought more about practical arrangements after death (e.g., finances and funerals) than end-of-life care.[25,46,55] This suggested that some people were more ready to engage in discussions about nonhealth "administrative" issues than in their thoughts about health care options.

Initiation of ACP Discussions

Overall, there was a preference among patients and carers for health care professionals to initiate ACP discussions.[25,26,28,36,39,45,46,49,50,52,54–65] Some reviews revealed that there were preferences for the physician or medical team to initiate ACP discussion,[39,45] rather than informal carers. Perceived power differences seemed to influence some preferences for initiation. For example, some homeless people preferred initiation of the discussion by doctors, but others struggled to trust doctors that they perceived as controlling[60]; in other contexts, some patients and carers preferred initiation by doctors because of their seniority, but others preferred initiation by nursing staff because of the closer relationships that they had with these practitioners.[49,58] Other reviews also highlighted the importance of relationships, with preferences for ACP to be initiated by professionals who are familiar with the patient's history and who know the patient

and family well,[46,59,62] and who are well trained in ACP facilitation.[56,65] Literature in nursing homes highlighted that while patients and carers wanted health care professionals to initiate ACP discussions, they were concerned about whether the professionals had the capacity to engage in these discussions because of staff shortages.[50]

Timing of ACP Discussions

Patient and carers held a broad range of views on the optimum timing for ACP discussions. Some reviews indicated preferences for earlier initiation of discussions,[57] particularly among patients and carers facing dementia[48,52,54,66] who recognized a time-sensitive need to discuss ACP while the patient retained capacity. Yet in a dementia context, optimum timing may depend on a complex array of factors including the readiness of patients and carers to begin ACP discussion, the acceptance of the diagnosis, the knowledge of patients and carers about dementia, and carers overcoming their own reluctance arising from fear, guilt, and lack of knowledge.[26,54,66] People lacked knowledge about the terminal nature of dementia, and it was hard for patients with dementia to imagine future scenarios.[53,67] Reviews with other patient groups highlighted mixed perceptions, with some patients and carers preferring earlier discussion, and some preferring to wait until deterioration in health.[39,45,46,55] In the context of cancer, patients and carers preferred to delay ACP discussion until treatment options had been exhausted.[62] Although some research indicated preferences for earlier discussion, other research found that patients may lack readiness to think about ACP and need time to cope with the initial shock of a diagnosis.[68] For COPD and respiratory illnesses, a lack of knowledge among patients about the terminal nature of COPD could present a challenge to identifying when best to begin ACP discussions.[61,65]

Some reviews showed that patients and carers recognized that ACP discussions may be recurring events rather than one-off exercises. This seemed to be particularly relevant in the context of heart disease,[44,59] where patients may wish to discuss their options at specific transitions in their care and revise their opinions on the use of implantable defibrillators. Other reviews that did not focus on a particular health condition also found preferences for recurring ACP discussion.[36,43,49,50,56,58] In long-term care, patients and carers wanted health care professionals to anticipate illness trajectories and use this to judge the level of information provided to them to help them make decisions.[50]

Perceived Value of ACP Discussions

Patients and carers generally viewed ACP discussions as positive and worthwhile, but the picture was complex and equivocal. Patients valued honest discussions about prognosis,[57,58] and after ACP discussions, patients and carers reported benefits such as feeling more confident about end-of-life issues, worrying less about the future, feeling more at peace and in control, and having better communication.[47,49,66,69–72] ACP was also found to help allay specific concerns unique among homeless people such as fear of dying violently, alone, or unnoticed.[60,73]

Alongside these positive findings, many reviews also highlighted the complex emotions that ACP discussions could raise for patients and carers, which seemed related to the changing nature of disease trajectories, and emphasized sometimes conflicting perceptions of value of ACP between patients and carers. Patients could feel respected and heard through ACP but also disrupted and distressed, and some were reluctant to be open with health care professionals as ACP could expose family tensions.[68] In the context of kidney disease, patients felt generally positive about ACP, but one of the main topics of discussion for this group—decisions about dialysis—was complex and challenging.[39,64] These patients were vulnerable and fluctuated between wanting survival and wanting death; deciding to discontinue dialysis was difficult as some feared being labeled cowardly or upsetting their families.[64] Several reviews in the context of dementia and long-term care pointed to the influence of carers' opinions on the perceived value of ACPs. Patients and carers both gained some feelings of protection and relief from ACP but also had concerns about its value given that preferences might change, the future is unpredictable, and decisions made during ACP might not be feasible.[54,66,68] In long-term care settings, carers were more ambivalent than residents about the value of ACP,[46] and sometimes preferred life-saving treatment where residents did not.[50] Family values about death and end-of-life care could be particularly important, and carers sometimes overruled ACP decisions based on their perceptions in the moment, which were more influential than the advance wishes and past attitudes of the patient.[47,51] Where carers tried to honor the prior wishes of a person with dementia, they found that the person may be resistant,[74] which raised questions about the perceived value of ACP in this context.

Some older people did not see much value in ACP discussions because they had passive expectations that "somebody else" would make decisions, including God, their families, or health care professionals.[45] The influence of families and religion on the perceived value of ACP came more sharply into focus with cultural diversity.[27–32,55,75,76] The roles of religion and spirituality were important for African Americans and Latinos/Hispanics, with fatalistic beliefs reducing the perceived value of ACP and leading to a

preference for aggressive treatment.[27–32] There were fears among African Americans that written advance documentation would limit health service provision,[29,32] and among Latinos, fears that such documents were immutable,[29] casting suspicion about their usefulness and value. It was apparent that African Americans in particular showed a mistrust of health services,[28–32] but African Americans also valued discussions of their spirituality with physicians.[30] Family-centered decision making was also an important factor in the perceived value of ACP among African American, Latino, and Asian ethnic groups.[28,30,32,55,72,75] Family-centered decision making could affirm relationships but was also challenging.[72] The concept of filial piety (duty to one's family) may have a dual meaning, emphasizing both the need to preserve life but also to ensure patient wishes and comfort.[30] In Asian cultures, Chinese people tended not to question the authority of the physician and feared making the wrong decision for their families.[75] Older people saw value in ACP to enable their wishes to be respected, but worried about creating family conflict.[55]

Overall, the influences of sociocultural beliefs were particularly strong at end of life.[76] These findings all highlighted how the emphasis on individual autonomy that is fundamental to Western notions of ACP may not be valued by all cultures. However, it may also not be ubiquitous among Western populations. In the context of cancer, ACP could provoke fear and distress, and the behaviors and choices of patients, carers, and health care professionals may be heavily influenced by institutional cultures and their previous experiences of health care and the dying process.[62] Johnson and colleagues suggested that patients emphasized ACP in terms of its social, psychological, and emotional value, rather than viewing it as a means to preserve their own autonomy over treatment decisions.

Recommendations for Practice

After considering patients' and carers' perspectives on ACPs, practice recommendations made by review authors highlighted a tension between standardization and flexibility. Some reviews called for better standardization of ACP practice, including the development of guidelines for the initiation of ACP in primary care,[36] clarification of roles, and standardization of documentation to facilitate continuity of information flow[49,61,67] and attention to ethical issues and informed consent.[49] One review[57] recommended the use of a systematic, multicomponent intervention that would involve training of clinicians, identification of patients and appropriate timing, use of a conversation guide, structured documentation, and performance measurement.

Many reviews recommended the need to approach ACP in flexible ways that respected patient and carer preferences. This included the acknowledgments that ACP is not a set of concrete skills but rather may require creative communication approaches, collaboration between different professionals, and the need to match the kind of ACP intervention to the individual patient's needs and circumstances, which all may be unique. These reviews were heterogeneous, including a range of health conditions, cultural groups, and populations.[22,26,28,29,33,34,39,44,51,53,54,56,60,62,64,66,68,73,75] In the context of dementia, ascertaining the views of people with dementia rather than reliance on proxies should be of primary concern.[48] This meant that health care professionals would need more training in ACP processes and prognostic implications of dementia to be able to confidently discuss with people with dementia and their carers. Similarly, in long-term care settings, there was a need for clinicians to be able to recognize illness trajectories to be able to facilitate individualized ACP,[50] and a need for ACP to include nonmedical issues.[46]

Recommendations for Research

In addition to general calls for higher-quality research into the benefits of ACP, meaning larger-scale randomized controlled trials with clearly defined outcomes, several reviews made recommendations specifically relevant to patients' and carers' perspectives on ACP.

Some reviews recommended exploratory research to gain deeper understandings of patients' and carers' perspectives. Several of these calls were made regarding ACP in dementia, including research into the acceptability and feasibility of ACP from the perspectives of people with dementia[48]; how and when to initiate ACP with this population[26,46,50,51,69]; longitudinal exploration of change over time, agreement and disagreement between carers and people with dementia[48]; and the lack of equivalence given to antecedent and contemporary decisions.[52] In a range of different contexts, there were calls for further exploration of patient and carer understandings of ACP, understandings of patients' illnesses and their end-of-life wishes, and how family relationships affect decision making.[31,32,55,59,72,75] Research on ACP for individuals with intellectual disabilities will need to overcome the methodological complexities in involving this group.[33,34]

Other reviews focused on intervention development and evaluation, particularly on formats and timing of ACP. These included research into decision aids that incorporate patient values and social implications,[37] the effectiveness of video aids in increasing congruence of care with patient wishes,[38] communication intervention development and evaluation,[56] and

evaluation of early initiation of ACP.[57] For homeless people, research into the effectiveness of individual versus group interventions[60] and into the effects of advance directive completion on patient outcomes and delivery of care[73] were needed.

Finally, some reviews called for more systems-level exploration and evaluation, including how to incorporate palliative care into dementia care pathways,[52] and of the ethical frameworks in which ACP is implemented.[62] Some recommended whole systems approaches rather than RCTs of single aspects of ACP,[39,41] but with a need to avoid conflating different aspects of ACP under the same umbrella term.[43]

Discussion

In this review of reviews, we have synthesized evidence regarding patients' and carers' perspectives on ACP discussions. We focused on how ACP discussions were held; who patients and carers felt should initiate these discussions; when they felt they should occur; and the value that they placed on them. Overall, there was a large amount of research that included exploration of patients' and carers' perspectives on ACP discussions. The reviews we synthesized were generally of moderate to higher quality, but the primary research contained within these reviews was generally of more limited quality.

Patients and carers generally perceived ACP discussions as positive and worthwhile, experiencing benefits such as a greater sense of peace, less worry, and increased feelings of being control. However, the picture was not wholly aligned with the dominant narrative cited earlier that ACP is an "unequivocal good," nor did it always fully endorse the primacy afforded to individual autonomy within the biomedical ethics principles that underpin ACP.[2] For some patients and carers, ACP could be disruptive and distressing and could exacerbate family tensions where there were disagreements between patients and carers. It has frequently been recognized that non-Western cultures may place less emphasis on supporting individual patient autonomy,[77] but our review has shown that similar perspectives may also be found in Western populations. In the absence of ACP, people want close family members to make decisions on their behalf, believe that their family knows their wishes, and do not want to burden their families, but family members often do not know their relative's wishes and experience considerable burden.[78] Therefore, the primary benefits to patients and carers from ACP discussion may in some cases come more from reducing future stress on family members than preserving individual patient autonomy. In the context of ACP, calls for viewing autonomy as a relational construct that values interpersonal connections have been around for at least 20 years,[79] and it is evident that such essential recognition remains difficult to realize in practice.

ACP is seen as an important category of intervention to reduce inequalities in end-of-life care provision, whereby people from ethnic minority groups and people with conditions other than cancer are less likely to receive the care that meets their wishes and needs.[80] Our review has highlighted an unfortunate but perhaps unsurprising irony that ACP discussions themselves suffer from similar inequalities of implementation: ACP appears to be happening more often with patients who are older, are white, are female, are well educated, and have cancer or comorbidities, and the preferences of people from other social groups and/or with conditions other than cancer appear to be less well understood. Patients' and carers' understandings of ACP are often poor, with legal and practical uncertainties. Levels of knowledge about ACP among health care practitioners are also low to moderate, and there is a need to increase understanding of both its medical and legal implications.[81] These issues, of inequality of ACP implementation and lack of knowledge or understanding of ACP, speak to a tension between standardization and flexibility, with substantial implications for successful uptake of ACP. Some reviews in our study articulated a need for some element of standardization of practice, for example, in professional roles, or in documentation and information transfer mechanisms and processes, and these calls are reinforced by professional bodies such as the Royal College of Physicians in the U.K.[82] Standardization could lead to better-coordinated ACP interventions delivered by more confident and knowledgeable practitioners, potentially leading to greater equity in who is offered ACP and greater understanding and satisfaction among patients and carers.[83] However, as our review has shown, patients and carers have a broad range of perspectives on how they feel ACP discussions should be implemented. This means that there is a need to think very carefully about which aspects of ACP might benefit from standardization, and which should be more flexible and amenable to individualization.

Any standardization of implementation processes in the delivery of ACP would need to reflect patients' and carers' preferences for discussions to be initiated by a professional with whom they have a good and knowledgeable relationship, rather than any particular role of professional defined in advance. Another complicating factor for standardization is the issue of perceived clinical relevance that underpinned the equivocal perspectives of patients and carers on the optimum time to begin ACP discussions. Among people with dementia and their carers, there was a broad preference to begin ACP earlier, prompted by the

understanding that the patient's cognition will decline. These preferences are becoming more widely recognized in policy (e.g., in the U.K.—Department of Health,[84] Department of Health & Social Care[85]). For those with most other health conditions, the picture in our review was more varied, with some people preferring early discussions and some people preferring later discussions, contingent upon numerous clinical and psychosocial factors. Patients and carers may need time to understand the meaning of certain diagnoses, particularly for conditions that are not readily recognized as being terminal. In cancer care, initiation of ACP discussions may be deferred by the dominant societal narrative that patients and health care professionals are bravely battling the disease.[86] The military metaphor can provide powerful messages of strength and positivity but it may obscure recognition of the relevance of ACP as professionals, patients, and carers feel the need to resist overt acknowledgment that the battle might not be won.[86,87] The emotional nature of the patient-professional interaction around ACP discussions has been found to be a barrier to its implementation.[8] The findings regarding patients' and carers' diverse preferences for initiation and timing of ACP discussions emphasize that health care professionals' training requires a focus on psychological and emotional skills in ascertaining individual patient and family preferences to tailor ACP implementation to their specific context and ensure that ACP is implemented in line with person-centered approaches to care.

Patients' and carers' preferences on how ACP should be implemented thus emphasize the need for flexibility in terms of which professionals they discuss ACP with, and when these discussions happen. Despite a decades-old parallel discourse on the importance of person-centered care,[88] the dominant discourse in health care practice is of standardization as the road to improved quality and safety, which means that flexibility can be difficult to sustain.[83] The limitations of this view in the context of end-of-life care were illustrated most starkly by the Liverpool Care Pathway, which failed in part because it came to be seen as a mechanistic checklist rather than a nuanced approach to care to be implemented with sensitivity.[89] There are continual warnings that ACP discussions should not be reduced to a tick-box exercise measured by blunt key performance indicators.[2] However, the extent to which nuanced, person-centered implementation of ACP that meets the diverse preferences of patients and carers will be achievable without health system change is unclear,[23] particularly when ACP implementation is largely evaluated by document completion.[10]

We suggest that this tension between standardization and flexibility has significant implications for future ACP research. The evidence we have reviewed shows ACP discussions are facilitated by a broad range of decision aids and tools, by a diverse health care workforce, and that all these formats and mechanisms of delivery are generally acceptable to patients and carers. Regarding future research into ACP intervention development and evaluation, rather than develop new ACP interventions, there may instead be a need for more diverse and creative implementation strategies of existing interventions, and research into the impacts of these strategies. Many of the reviews included in the present study lamented the quality of primary research, and several called for a whole systems approach rather than RCTs of individual components of ACP interventions; a message that was reinforced in the overview of reviews by Jimenez and colleagues.[6] For outcome measurement, trials that incorporate elements of pragmatism rather than traditional RCTs may be more appropriate to allow flexibility of ACP implementation that respects patients' and carers' preferences.[90] Use of patient-reported experience measures, or PREMs,[91] may be a more suitable metric than document completion to evaluate the quality of ACP. There is a need for a greater understanding of causal assumptions underpinning ACP—elucidating the mechanisms of ACP interventions and implementation strategies which are expected to lead to specific outcomes—which points to research grounded in realism, such as mixed-methods process evaluations.[92] This would necessitate a clear description of the ACP intervention, consideration of how it is expected to work, and incorporation of rigorous qualitative research to understand implementation contexts, patient and carer experiences, unanticipated consequences, and complex causal pathways.[92] It would also allow testing of aspects of ACP that might be amenable to standardization and aspects that are better implemented with flexibility.

There are some limitations that should be noted. The variations in ACP terminology and our application of search terms to titles of papers only mean that we may have missed some reviews. Nonetheless, our database searches retrieved over 200 unique peer-reviewed literature reviews, complemented by scanning the recent synthesis of the full spectrum of ACP research reviews by Jimenez and colleagues,[6] which followed Cochrane methodology. We began our searches from 2007, but 45 of the 55 reviews included in our study were published in 2014 or later, showing that the burgeoning interest in ACP research is relatively recent. We are also aware of more literature reviews that have been published after the end of our search period. For example, a review of the perspectives of people with dementia and their carers on ACP published in November 2018 concluded that

there is a need for ACP to respect people's uncertainty in decision making and not appear to represent rigid pathways of care.[93] This again speaks to the debate about standardization and flexibility that we have elucidated previously. We are therefore confident that we have captured the vast majority of the literature relating to patients' and carers' perspectives on ACP discussions and that any reviews we may have missed would be highly unlikely to alter our overall conclusions.

We chose the AMSTAR tool for quality appraisal because it is the most widely used tool to assess the quality of systematic reviews,[94] but we found its applicability to be limited for reviews of methodologically heterogeneous primary research. Some AMSTAR items address properties associated with systematic reviews that have employed meta-analysis (e.g., Item 9 – methods used to combine findings; Item 10 - publication bias), which were far less relevant to the majority of our included reviews, and thus a negative mark against these items may misrepresent the overall quality of a review.[20] In addition, the AMSTAR items do not necessarily carry equal weighting, both in terms of their relevance to our included reviews and also because the tool itself was not designed to yield numerical scores.[95] We share others' criticisms that the AMSTAR lends itself more toward recording the presence or absence of an item than inviting interpretation of its implications for methodological quality.[95] Therefore, our quality appraisal needs to be viewed as indicative only.

In the present study, we have synthesized over a decade's worth of literature reviews on patient and carer perceptions of ACP. Although ACP is intended to reduce inequalities in end-of-life care, the implementation of ACP is itself inequitable. We conclude patients and carers perceive many benefits from ACP discussions, but these may differ from the dominant narratives about ACP in health policy and may move away from the narratives of RCTs and standardization in research and practice. Our review suggests that researchers and clinicians need to adjust their approaches as current practices are not aligned enough with patients' and carers' preferences. Future research may need to test implementation strategies of ACP interventions to resolve the tension between standardization and flexibility and elucidate how benefits from both might be realized.

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