

Review

Advance care planning for cancer patients: a systematic review of perceptions and experiences of patients, families, and healthcare providers

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Abstract

Background: Patients with advanced cancer may benefit from end of life (EOL) planning, but there is evidence that their willingness and desire to engage in advance care planning (ACP) varies. The reasons for this remain poorly understood. Previous reviews on ACP most commonly report outcome measures related to medical interventions and type of care. Synthesis of the literature, which aims to illuminate the salient characteristics of ACP and investigates the psychological and social features of preparation for the EOL, is required.

Methods: We searched Medline, EMBASE, PsychINFO, CINAHL, and the Cochrane Central Register of Controlled Trials for studies on perceptions or experiences regarding ACP of adults with cancer, family, friends, or professionals caring for this group. Databases were searched from earliest records to 19 November 2014. A thematic analysis of the literature generated conceptual themes.

Results: Of the 2483 studies identified, 40 were eligible for inclusion. Studies addressed the relational nature of ACP, fear surrounding ACP, the conceptual complexity of autonomy, and the influence of institutional culture and previous healthcare experiences on ACP.

Conclusions: The complex social and emotional environments within which EOL planning is initiated and actioned are not sufficiently embedded within standardized ACP. The notion that ACP is concerned principally with the 'right' to self-determination through control over treatment choices at the EOL may misrepresent the way that ACP actually occurs in cancer care and ultimately conflict with the deeper concerns and needs of patients, who experience ACP as relational, emotional, and social.

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Introduction

Advance care planning (ACP) 'is, at its most basic, a process of thinking ahead to treatment choices, goals of care, and/or choosing another person (proxy) to speak for oneself at a point in the future' [1]. Since its inception, the field of ACP has evolved from a legal, document-driven process to a process of engaging patients, families, and substitute decision-makers in conversations about hopes, wishes, values, and goals with respect to care [2,3]. These newer conceptualizations characterize ACP as a process that goes beyond the consideration of specific treatment interventions, to become an act of communication between patients, caregivers, and healthcare professionals [4].

Studies have found that the responses to ACP of cancer patients, and the values and needs they express, differ from other patient populations [4]. There is evidence that patients with advanced cancer vary in their willingness

and desire to engage in ACP discussions and often refuse to participate in ACP research [5]. Factors identified as contributing to low documented use of ACP in cancer patients include a wide age range, unpredictable disease trajectories [6], and equivocal treatment options. Low ACP uptake in cancer patients may also relate to poor understanding of treatment intent [7] and the desire to maintain hope [4,8].

It is not completely clear why ACP has failed to become a part of routine care, and questions remain as to whether ACP is even able to meet its objectives when implemented [9–12]. In this regard, it is noteworthy that a recent systematic review concluded that while there is some evidence that ACP positively impacts the quality of end of life (EOL) care, further research is needed, which focuses on the experiences of patients and their families when undertaking ACP [13].

There have been no reviews that report on the views or experiences of stakeholders with regard to ACP. There has

also been no synthesis of the ACP literature, which focuses specifically on cancer patients. This paper aims to address this gap and to further our understanding of how stakeholders approach ACP by examining the literature exploring patient, caregiver, and healthcare professional experiences and perceptions of ACP in cancer care. This review aimed to take a broad perspective on the ACP literature by including both quantitative and qualitative literature.

Methods

Search strategy and selection criteria

A search of relevant databases (Medline, EMBASE, Psych INFO, CINAHL, and the Cochrane Register of Controlled Trials) was conducted to identify papers exploring ACP. Search terms for ACP were those developed by the Cochrane Collaboration 'Advance care planning for end of life (Protocol)' (Table 1) [14]. Databases were searched from earliest records to 19 November 2014. Reference lists of included articles were searched for relevant articles, and further database searches were conducted using the names of researchers commonly publishing in this field. Finally, the CareSearch database was searched in November 2014. CareSearch is an evidence resource for palliative care practitioners and researchers, which aims to 'identify international published literature missing from the electronic indexing system' [15]. The returned search results were screened for irrelevant articles, review

papers, gray literature, and duplicates. An eligibility checklist was developed by all four authors to guide the selection of appropriate studies and is presented in Table 2. One author (S.J.) independently reviewed citations generated by the search in order to exclude those that were clearly irrelevant based on the title of the report and abstract (where available). All four authors reviewed and discussed a sample of reports to ensure that the selection was consistent with the aims of the review and the eligibility checklist. One author (S.J.) then retrieved the full text version of potentially relevant reports for further assessment. If the reviewer had doubts, the full text was retrieved and reviewed by a second author (P.B.). Doubts regarding the inclusion of a report were resolved by consensus after discussion.

Data extraction

A data extraction form developed by Powell *et al.* [16] was used to extract data using a standard format (authors, year, country, approach, design, method, sample and setting, measures, results and summary). For both qualitative and quantitative papers, the results and summary were prepared by extracting themes or categories of data using the terms used in the paper itself and a summary of the relevant material.

Quality assessment

The quality of included studies was assessed using the standardized QualSyst tool [17]. QualSyst consists of

Table 1. Search terms

Cancer terms	ACP terms
1. Neoplasms [Mesh]	17 exp Advance Care Planning/
2. 'Medical Oncology' [Mesh]	18 (advance adj5 (care or health or medical) adj5 plan*).mp.
3. Neoplasms [tiab]	19 living will*.mp
4. Cancer [tiab]	20 right to die/
5. carcinoma/	21 right to die.mp
6. carcino*	22 power of attorney.mp
7. leukaemi* or leukemi*	23 (ulysses and (contract* or directive*).mp.
8. tumour* or tumor*	24 (advance adj (directive* or decision*).mp.
9. malignan*	25 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24
10. lymphoma*	26 16 and 25
11. adenocarcinoma*	27 limit 26 to English language
12. metastat*	
13. sarcoma*	
14. teratoma*	
15. Oncolog*	
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	

ACP, advance care planning.

Table 2. Eligibility criteria for paper inclusion

Eligibility checklist:

1. Reports on advance care planning
2. Is original research
3. Involves cancer patients (plus or minus their carers) at EOL (or sample includes >50% cancer patients with results for these reported separately)
4. Involves competent adults
5. Reports on:
 - * Physician, patient, or caregiver perceptions of ACP or
 - * Physician, patient, or caregiver experience of ACP

ACP, advance care planning; EOL, end of life.

ACP: original research that explored ACP was eligible. Advance care planning was defined as 'formalised discussion between patients and healthcare providers which may include family members or friends, with possible outcome of formal documentation of EOL care wishes'. This included studies exploring advance directives with reference to a process of discussion with health professionals. We excluded studies that focus exclusively on the documentation of wishes regarding cardiopulmonary resuscitation. *Types of studies:* quantitative or qualitative studies were eligible for inclusion. This included studies utilizing: interviews/focus groups, surveys, and consultation audits (audio-taped ACP discussions). Case studies, conference abstracts, editorials, commentary, and reviews and papers published in languages other than English were excluded.

Types of participants: people with cancer and/or their family members and/or health professionals caring for this group, in any setting, were included. Studies focusing on children (<18 years) and people with mental illness were excluded. Where samples included patients with other primary diagnosis, they were included only if greater than 50% of participants had a primary diagnosis of cancer and results for this subgroup was reported separately.

two separate, manualized scoring systems, one for qualitative studies and one for quantitative studies. Two reviewers assessed all studies separately. Cohen's kappa, used to determine inter-rater reliability, was 0.438 between the two raters; indicating moderate agreement according to Landis and Koch's standards for interpretation [18]. Any identified discrepancies were resolved through iterative discussions. Each study was allocated a final score by consensus, which, as defined by Lee *et al.* [10], was used to define the quality of the study as limited (<50%), adequate (50–70%), good (71–80%), or strong (score of >80%). The quality ratings for each included study are reported in Tables 3–7, summary of studies by theme. For further information on quality scoring, see Kmet *et al.* [17].

Data synthesis

Thematic analysis was used to synthesise the empirical evidence [19]. One author (S.J.) developed textual descriptions, which were tabulated in the data extraction summary form. Two authors (S.J. and P.B.) developed a preliminary list of descriptive themes to identify the main, recurrent, and/or most important themes and/or concepts across multiple studies. Four authors engaged in a process of iterative discussion to generate conceptual themes that helped to explain the phenomena being described in the literature, constantly comparing the themes being developed against the data. All four authors engaged in continual dialog to help introduce a range of perspectives.

Results

The search strategy produced 2483 references. After the deletion of duplicates and eligibility assessment, 40 studies were included (19 quantitative, 17 qualitative, and 4 mixed methods) (Figure 1). The included studies reported data from eight countries. This included the USA (19), UK (8), Europe (5), Australia (5), Taiwan (1), and 1 study from Canada (which was reported in two papers).

Themes

Five primary themes were identified from the literature: ACP is relational; ACP provokes fear and distress; autonomy is conceptually complex and contested; institutional culture is influential in ACP; and knowledge of ACP and previous healthcare experiences can act as motivator or barrier to ACP. A summary of the classification of included articles according to theme is provided in Table 8.

Theme 1: ACP is relational

1.1 Family is a motivator or barrier to ACP

Seventeen studies [3–5,8,20–31] reported on the role or influence of the family or caregivers in ACP. Refer

to Tables 3 and 8 for details of studies and references for included articles. Four studies examined the experiences and perceptions of caregivers only, a further six studies included caregivers in the participant groups.

Between 36% and 47% [22,27,30,32] of people with cancer wanted to involve their family in decision-making regarding their current or future health care. Some preferred to make decisions on their own [32], and some indicated that making their EOL treatment wishes clear with an advance directive (AD) would have no impact on their family [21]. For some, including family in EOL decision-making raised concerns over upsetting or placing undue stress or burden on family members [8]. Others reported difficulty in initiating conversations with their family, with some reporting particular difficulties arising when their expectations or fears differed from those of other family members [4]. Family can also act as a motivator for ACP [33], with patients who had signed an AD often being of the view that ADs might ease the burden of decision-making on relatives and facilitate the physician's decision [23].

Indeed, the literature on ACP makes it clear that the majority of patients with cancer consider the welfare of their family members when deciding whether or not to participate in ACP and that where they choose to engage in ACP they generally approach it as a shared experience with loved ones [3,5,20,21,23,25,27–30].

1.2 The therapeutic relationship

The majority of studies [21,22,24,25,29,34–44] addressed the relationship between patients and health professionals in some way with 16 studies describing the perspectives of patients or caregivers and six describing the views of health professionals.

Physicians generally described the importance of developing rapport with patients in opening up discussions about ACP [41], noting 'palliative care as an art not a science, based on relationships' [42]. Where physicians reported time and privacy as barriers to ACP, they did so because they believed these were fundamental to establishing relationships with patients and families [39,40]. Further, some health professionals expressed concerns that ACP may damage their relationships with patients and were concerned that formal ACP 'did not take account of professional–patient relationships and individual patient needs' [42].

Patients generally preferred to do ACP with the physician who knows them best [20], preferred that their physicians initiated discussion regarding ACP, and were more likely to participate in ACP or draw up an AD if they had discussed this with their oncologist [34], suggesting that the explicit or implicit endorsement of ACP by the patient's principal health professional caregiver may be influential.

Table 3. ACP is relational (studies ordered by quality rating)

Authors	Year	Country	Quality rating	Methodology and data collection method	Sample and setting	Results summary
Quantitative studies						
Duckworth, K <i>et al.</i> [21]	2013	USA	95%	Cross-sectional study Method: questionnaire	Sample: 49 HCT candidates and 44 proxies Response rate: not reported Setting: HCT candidates or the designated proxy of the candidate, attending the routine, pre-transplant psychosocial assessment	HCT candidates reported that powerful others, such as doctors involved in their care, have the strongest influence over their health status. Many participants reported that the written expression of healthcare wishes will not impact their family members significantly, and that they are not unwell enough to complete ADs.
Loberiza F <i>et al.</i> [26]	2007	USA	95%	Prospective observational study Method: self-administered survey and an interview prior to consultations with a physician. Repeat interview at 1 week and 3 months.	Sample: 364 people with hematological malignancy Response rate: 47% (364 of 770) Setting: three hospital-based cancer centers	Most (79%) participants discussed life support with family. Participants with written plans were more likely to have discussed their wishes with family and doctors.
Oorschot Bv <i>et al.</i> [23]	2012	Germany	95%	Cross-sectional study Method: written, standardized questionnaire	Sample: 589 completely evaluated questionnaires Response rate: 48.7% (589 of 1208) Setting: older patients with tumor undergoing radiation therapy	Half of the participants wanted their close family members to participate in the decision-making process.
Zhou, G <i>et al.</i> [24]	2010	USA	95%	Descriptive cross-sectional pilot survey study Methods: survey distributed to 300 APNs via e-mail and sent again to the 89 APNs who responded to the initial survey	Sample: 89 oncology APNs responded to the initial survey, and 53 of the 89 respondents returned the retest survey Response rate: 30% (90 of 300) Setting: 300 oncology APNs from one author's professional networks	Family and physician attitude ranked highly as perceived barriers to ACP
Barakat, A <i>et al.</i> [34]	2013	USA	90%	Cross-sectional survey Method: a printed questionnaire returned in sealed envelope.	Sample: 68 completed surveys Response rate: 68% (68 of 100) Setting: inpatients in the oncology and blood and marrow transplantation units.	Patients who had discussed EOL care with their oncologist were more likely to have an AD.
Dow LA <i>et al.</i> [20]	2010	USA	86%	Cross-sectional survey Method: semi-structured interviews and questionnaires	Sample: 75 completed interviews Response rate: 88% (75 of 85) Setting: 117 patients with cancer consecutively admitted to the hematology-oncology inpatient service at an urban academic medical center.	Most patients had discussed their AD with their family.
Díaz-Montes <i>et al.</i> [52]	2013	USA	85%	Cross-sectional survey Method: written questionnaires	Sample: 122 completed questionnaires Response rate: not reported Setting: all women with a diagnosis of gynecologic cancer attending the gynecologic oncology clinic	Most patients reported making arrangements for someone to make decisions on their behalf if the need arises. Among the nine important factors in decision-making determined by the authors, family preference was ranked sixth.
Lamont, E.; Siegler, M. [25]	2000	USA	82%	Cross-sectional survey Method: face to face structured interviews using a verbally administered questionnaire.	Sample: 111 completed questionnaires Response rate: 87% (111 of 128) Setting: cancer patients admitted to the University of Chicago Hematology-Oncology inpatient service	Few cancer patients discussed or wished to discuss their advance care preferences with their oncologist. A higher proportion did wish to discuss their ACP preferences with family.
Fu, S <i>et al.</i> [22]	2012	USA	77%	Cross-sectional survey Method: written survey	Sample: 215 completed or partially completed questionnaires Response rate: 49% (215 of 435) Setting: patients with advanced cancer being considered for enrollment onto an early-phase clinical trial.	Many patients wish to involve their physicians (59%) and family (36%) in ACP.

(Continues)

Table 3. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection method	Sample and setting	Results summary
Hwang, S et al. [32]	2003	USA	77%	Gross-sectional survey Method: written questionnaire	Sample: 254 veterans with symptomatic cancer Response rate: 86% (254 of 296 surveys) Setting: veterans seen at the inpatient/outpatient clinic in a hematology tertiary referral center. Sample: 794 usable surveys Response rate: 23% (883 of 3840) Setting: a stratified random sample of 4000 Oncology Nursing Society members	Almost half of veterans with symptomatic cancer wanted to include their family members in EOL decision-making, although many (34.3%) preferred to make decisions on their own. 77% of nurses agreed that nurses should be actively involved in helping patients complete ADs.
Jezewski M. et al. [36]	2005	USA	77%	Descriptive, correlation survey Method: mailed survey	Sample: 100 cancer patients, 100 healthy controls, 100 nursing staff, and 100 physicians Response rate: estimated 40% Setting: cancer patients treated at the Oncological Clinic and Breast Cancer Centre. Healthy people who had visited the clinic for a medical checkup and nursing staff and physicians of the German Clinic for Diagnosis and participants at a conference.	Every fourth doctor expressed emotional discomfort about writing a directive.
Sahm, S., Will R, Hommel, G [35]	2005	Germany	73%	Gross-sectional survey Method: interview with verbally administered questionnaire		
Stearns L, Butler S, Hollander J [37]	2005	USA	59%	Longitudinal study Method: anonymous survey mailed to 100 patients who had previously been provided with an information booklet, AD forms and assistance in preparing an AD.	Sample: 123 consecutive patients Response rate: 33% (33 of 123) Setting: patients attending routine clinic visits	Survey respondents indicated that it was beneficial to have the information presented in a relaxed, informative, and professional manner by health professionals involved in the study.
Qualitative studies Barnes, Barlow & Harrington [27]	2011	UK	90%	Exploratory patient preference randomized controlled trial Method: semi-structured interview as part of an ACP intervention	Sample: 40 patients with recurrent, progressive cancer and 52 interviews. Response rate: not reported Setting: patients attending oncology and palliative care outpatient clinics in two London teaching hospitals.	Most expressed a desire or intention to talk more openly with family members about the future. Although some expressed concern that talking about the future may burden or upset family and family members may find it difficult to cope.
Fried T & O'Leary, JR [4]	2008	USA	90%	Qualitative thematic analysis Method: semi-structured interview	Sample: caregivers of community-dwelling patients who were age 60 years or older who died with advanced cancer (52%), chronic obstructive pulmonary disease (27%), or HF (21%). Response rate: not reported Setting: community	Open communication was seen as having many benefits, and participants described the adverse consequences of failing to communicate. However, they also, in many cases, described barriers to communication including differing hopes and fears within the family.
Michael et al. [5]	2013	Australia	90%	Qualitative grounded theory study Method: caregivers first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique	Sample: 18 patients with cancer Response rate: 62% (26 of 29) Setting: patients at the lung and gastrointestinal tumor streams with more than 4 weeks to live.	A number described how they were happy to discuss different components of ACP with different people, and many favored ACP discussions with someone specifically trained. Most considered families' and/or friends' welfare when considering ACP. Some believed planning for their funeral would support bereaved relatives, while others did not want to 'dictate from the grave'.

(Continues)

Table 3. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection method	Sample and setting	Results summary
Michael <i>et al.</i>	2013	[8] Australia	90%	Qualitative descriptive design with grounded theory overtones Method: focus groups, semi-structured interviews, which incorporated the vignette technique	Sample: 18 caregivers of patients with lung and gastrointestinal cancer Response rate: 43% (18 of 42) Setting: participants were recruited as part of a pilot ACP implementation and research program in a large tertiary cancer center.	Decision-making styles varied in the caregiver, patient, and family groups.
Almack K <i>et al.</i>	[41]	2010 UK	85%	Exploratory qualitative case study Method: interviews and group interviews	Sample: 18 interviews and 6 follow-up interviews with patients with cancer, HF and dementia as well as family/friends. Five group interviews with 15 HCPs. Response rate: not reported Setting: GP practice and various hospital and community-based care services	HCPs reported that developing rapport with patients and family over time meant they felt able to open up discussions about ACP.
Carrion I <i>et al.</i>	[29]	2013 USA	85%	Qualitative grounded theory study Method: in-depth open semi-structured interview	Sample: 45 Latin (15 Columbian, 15 Mexican, and 15 Puerto Rican) women diagnosed with cancer Response rate: not reported Setting: Spanish-speaking women recruited from community health clinics, churches, cultural centers, and cancer support groups.	Latin women express a preference for a shared approach (with family and HCPs) to decision making.
Elliot J & Olver I	[31]	2003 Australia	85%	Qualitative discourse analysis Method: semi-structured interview	Sample: 23 consecutive patients with cancer who were unlikely to die in the near future Response rate: not reported Setting: oncology clinic outpatient department	Some mentioned the need or opportunity for discussions involving family, patient, and carers regarding EOL issues.
Horne G, Seymour J & Shepherd K	[38]	2006 UK	85%	Qualitative grounded theory study Method: Patients participated in an ACP discussion with a trained lung cancer nurse and then completed structured interviews	Sample: 15 patients with inoperable lung cancer and their family members (nine patients, six family members) Response rate: not reported Setting: one urban health community	Most patients reported that the relationship with the nurse conducting the ACP enabled them to discuss options. Many were not open to discussing prognosis and reported barriers to discussing future care with family and HCPs.
Horne G, Seymour J & Payne S	[30]	2012 UK	85%	Qualitative grounded theory study Method: semi-structured interviews and focus groups	Sample: 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews), and two family focus groups were conducted. Setting: a specialist local cancer center	Planning for the social and familial aspects of dying and death was of most importance. Concern for the family appeared to be the main factor that was reported to influence engagement in planning for the future.
Boyd K <i>et al.</i>	[42]	2010 UK	80%	Mixed method study—cross-sectional analysis of a pilot educational intervention Method: semi-structured interviews after a practice-based workshop, followed by telephone interviews with nine others	Sample: 20 GPs and eight community nurses Response rate: not reported Setting: staff at four general practices	HCPs prized palliative care as an art not a science, based on relationships. Formal ACP was perceived as 'planning for dying' too soon and in a way that did not take account of professional-patient relationships and individual patient needs. 'I think that what really makes for really good successful palliative care is the relationship you develop between yourself, the patient, and the carers'.
Barnes k, Jones L, Tookman A, King M	[28]	2007 UK	75%	Qualitative focus group Method: interview	Sample: 22 palliative care (18%) and oncology patients (82%). Response rate: 59% (22 of 37) Setting: patients attending a palliative care day unit or oncology outpatient clinic	Some participants voiced concerns that EOL discussion with their doctor may alter the doctor-patient relationship.

(Continues)

Table 3. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection method	Sample and setting	Results summary
Robinson CA & Carole A	[3]	2011 Canada	55%	Prospective qualitative design Method: semi-structured interview	Sample: 18 participants composed of patients diagnosed with advanced lung cancer and their significant other or loved one Response rate: not reported Setting: not described	Family members participated actively in the ACP interview, and dyads frequently used the word 'we' when referring to the illness experience.
Jezewski M, Meeker MA & Schrader M	[39]	2003 USA	45%	Qualitative thematic analysis Method: open-ended question at the end of a quantitative survey	Sample: 900 oncology nurses Response rate: 23% (900 of 3840) Setting: oncology nurses from four states	Participants placed a great deal of importance on the development of communication skills that could be of help to patients. Nurses referred to the need for more time to spend establishing relationships (rapport) with patients and their families.
Mixed methods studies						
Cherlin E et al.	[43]	2005 USA	QN 73% QL 75%	Mixed methods study Method: quantitative survey and additional in-depth interview with 12 family 12caregivers	Sample: 12 primary family caregivers of people with cancer whose loved ones were enrolled in hospice Response rate: not reported Setting: hospice	Every caregiver saw communication regarding life expectancy and treatment alternatives as an important aspect of their experience caring for the patient.
McKinley E, Garrett J & Evans A	[33]	1996 USA	QN 68% QL 30%	Mixed methods study—quantitative survey and open-ended questions for qualitative analysis. Method: in-person interviews	Sample: 206 (92 Black patients and 114 White patients) completed patient interviews Response rate: 76% (206 of 270) Setting: ambulatory cancer patients from medical oncology clinics	When asked why they had a living will, one emergent theme was 'to relieve family or financial burden'. Few had discussed their preferences for EOL care with their physicians. Over 50% felt confident or very confident their physicians knew their wishes. 94% felt doctors could be trusted.
Samara J, et al.	[44]	2013 Australia	QN 45% QL 55%	Mixed methods study—cross-sectional qualitative plus pre-implementation and post-implementation audit Method: focus group plus delivery of an education program on ACP either in face-to-face sessions or via an e-learning package plus pre-session and post-session written questionnaires.	Sample: 25 nurses Response rate: not reported Setting: oncology department of a public hospital	The barriers reported by the participants included: lack of time to implement and lack of space and privacy to talk about ACP in the clinical settings.

ACP, advance care planning; HCT, hematopoietic cell transplant; APNs, advance practice nurses; EOL, end of life; HF, heart failure; AD, advance directive; HCPs, healthcare professionals; QN, quantitative; QL, qualitative. Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al. [17]) (number from QN and QL studies quality rating).

Table 4. ACP provokes fear and distress (studies ordered by quality rating)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results Summary
Quantitative studies						
Duckworth, K <i>et al.</i> [21]	2013	USA	95%	Cross-sectional study Method: questionnaire	Sample: 49 HCT candidates and 44 proxies Response rate: not reported Setting: HCT candidates or the designated proxy of the candidate, attending the routine, pre-transplant psychosocial assessment	Participants reported that they are not unwell enough to complete ACPs. Patients who completed an AD were more likely to have a positive attitude towards ACPs
Keating <i>et al.</i> [50]	2009	USA	95%	Cross-sectional study Method: survey	Sample: 4074 physician survey responses Response rate: 61% (4188 of 6871 physicians whose contact information was verified) Setting: physicians identified by patients participating in the CanCORS baseline interview as filling one or more key roles in their care	Most doctors would wait for a change in symptoms or until there were no further palliative treatments before discussing EOL topics. A minority would discuss these with patients who had 4–6 months to live and were feeling well.
Oorschot, B <i>et al.</i> [23]	2012	Germany	95%	Cross-sectional study Method: written, standardized questionnaire	Sample: 589 completely evaluated questionnaires Response rate: 48.7% (589 of 1208) Setting: older patients with tumor undergoing radiation therapy	One-third of respondents agreed that ACPs could be of little significance.
Zhou, G <i>et al.</i> [24]	2010	USA	95%	Descriptive cross-sectional pilot survey study Methods: survey distributed to 300 APNs via e-mail and sent again to the 89 APNs who responded to the initial survey	Sample: 89 oncology APNs responded to the initial survey, and 53 of the 89 respondents returned the retest survey Response rate: 30% (90 of 300) Setting: 300 oncology APNs from one author's professional networks	Although nurses scored positively in their attitude towards ACP, staff discomfort level and patient and physician attitude ranked highly as perceived barriers to ACP.
Miccinesi, G <i>et al.</i> [48]	2012	Italy	95%	Cross-sectional study Method: semi-structured interview questionnaire administered by physicians with a good clinical relationship with the patient	Sample: 88 completed patient interviews Response rate: 56% (88 of 156) Setting: advanced cancer patients in different palliative care settings (ambulatory, home care, and hospice)	Respondents expressed a clear desire to be informed and to take part in the decision-making process. 58% wanted to be constantly informed, 91% wanted to decide about treatment options with the medical staff (with or without their family), and 84% wanted detailed information on the drugs they are administered.
Barakat, A <i>et al.</i> [34]	2013	USA	90%	Cross-sectional study Method: a printed questionnaire returned in sealed envelope.	Sample: 68 completed surveys Response rate: 68% (68 of 100) Setting: inpatients in the oncology and blood and marrow transplantation units.	Only a minority of patients (29%) had an EOL discussion with their oncologist and for those that did, the majority initiated that conversation, not their doctor.
Vogel R <i>et al.</i> [47]	2013	USA	88%	Randomized control trial. Method: control arm had access to a website containing usual care information documents. Intervention arm had access to a website containing ovarian cancer care information, decision support, and an AD.	Sample: 35 women with ovarian cancer and their informal carers Response rate: not reported Setting: a gynecological oncology clinic	Women participating in a pilot of an ACP website reported satisfaction with the intervention, which included ovarian cancer care information, decision support, and access to an AD.
Dow LA <i>et al.</i> [20]	2010	USA	86%	Cross-sectional study Method: semi-structured interviews and questionnaires	Sample: 75 completed interviews Response rate: 88% (75 of 85) Setting: 117 patients with cancer consecutively admitted to the hematology–oncology inpatient service at an urban academic medical center.	Nearly all participants (87%) think it is important to have discussions about ACPs and support a policy in which they are offered as part of the hospital admission process. Only 23% would like to discuss ACPs with their medical oncologist, but paradoxically when asked directly who they would prefer to discuss ACPs with, 48% chose their oncologist.

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Table 4. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results Summary
Díaz-Montes, T et al. [52]	2013	USA	85%	Cross-sectional study Method: written questionnaires	Sample: 122 completed questionnaires Response rate: not reported Setting: all women with a diagnosis of gynecologic cancer attending the gynecologic oncology clinic	A trend was seen toward patients preferring for the physician to initiate the EOL discussion (patient: initiate 39% doctor initiate 48%, missing data 13.1%, $p = 0.33$). Patients also expressed that it was important to have EOL care addressed. Most patients responded that the most appropriate time to address EOL care was when treatment is no longer an option (41.8%). 51% of patients thought ACP were desirable, a minority wished to avoid ACP, and some showed no preference.
Jones L et al. [53]	2011	USA	85%	Exploratory randomized patient preference trial Method: written questionnaire	Sample: 77 participants with advanced cancer. Response rate: 88% (68 of 77) Setting: patients who had completed a primary course of treatment for cancer but still had clinically detectable, active, and progressive disease.	Although few cancer patients discussed or wished to discuss their advance care preferences with their oncologist, more than half supported a proposed policy in which admitting house staff offered a discussion regarding advance care preferences.
Lamont, E; Siegler, M. [25]	2000	USA	82%	Cross-sectional study Method: face to face structured interviews using a verbally administered questionnaire.	Sample: 111 completed questionnaires Response rate: 87% (111 of 128) Setting: cancer patients admitted to the University of Chicago Hematology–Oncology inpatient service	73% of patients reported that ACP had been addressed, and 69% believed they could beat their cancer. Patients supported ACP in all settings but favored initiation of ACP discussions in locations outside of critical/emergency care settings.
Fu, S et al. [22]	2012	USA	77%	Cross-sectional study Method: written survey	Sample: 215 completed or partially completed questionnaires Response rate: 49% (215 of 435) Setting: patients with advanced cancer being considered for enrollment onto an early-phase clinical trial.	86.2% of patients wanted physicians to be frank when delivering bad news.
Hwang, S et al. [32]	2003	USA	77%	Cross-sectional study Method: written questionnaire	Sample: 254 veterans with symptomatic cancer Response rate: 86% (254 of 296 surveys) Setting: veterans seen at the inpatient/outpatient clinic in a hematology tertiary referral center.	The option that physicians should broach the subject of ADs for medical care when and if they consider it appropriate was the most popular in all groups. The majority in all groups rejected the expectation that physicians should initiate a discussion about ADs as a matter of routine, most rigorously by physicians themselves. They were prepared to do this only if they considered it to be appropriate as a result of the individual situation.
Sahm, S., Will R, Hommel, G [35]	2005	Germany	73%	Cross-sectional study Method: interview with verbally administered questionnaire	Sample: 100 cancer patients, 100 healthy controls, 100 nursing staff, and 100 physicians Response rate: estimated 40% Setting: cancer patients treated at the Oncological Clinic and Breast Cancer Centre. Healthy people who had visited the clinic for a medical checkup and nursing staff and physicians of the German Clinic for Diagnosis and participants at a conference.	Physicians perceived that patients reach understanding regarding EOL discussion over several conversations. Physicians initiated EOL discussion most commonly in response to a significant change in disease progression or a major change in functional or medical health status, or at advance disease stage.
El-Sahwi K. S et al. [49]	2011	USA	60%	Cross-sectional study Method: pilot survey sent via the website Survey Monkey	Sample: 142 physician responses Response rate: 12.8% (142 out of 1105) Setting: surveys were e-mailed to members of the Society of Gynaecologic Oncology	

(Continues)

Table 4. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results Summary
Stearns L, Butler S, Hollander J	[37]	2005 USA	59%	Longitudinal study Method: an anonymous survey was mailed to 100 patients who had previously been provided with an information booklet, AD forms plus assistance in preparing an AD.	Sample: 123 consecutive patients Response rate: 33% (33 of 123) Setting: patients attending routine clinic visits	52% of patients found that an AD form was easy to complete, 41% moderately easy, and 7% found it difficult. Survey respondents indicated that it was beneficial to have the information presented in a relaxed, informative, and professional manner.
Barnes K, Jones L, Tookman A, King, M	[27]	2011 UK	90%	Exploratory patient preference randomized controlled trial Method: semi-structured interview as part of an ACP intervention	Sample: 40 patients with recurrent progressive cancer: 52 interviews. Response rate: not reported Setting: patients attending oncology and palliative care outpatient clinics in two London teaching hospitals.	Some wanted to think about the issues raised and make plans. Others were not ready to address the issues but said they would do so at a more appropriate time. Over a third of patients said it was too soon for them for such conversation but would like to talk more to their doctors if they deteriorated. Just over a quarter wanted information while they had time to plan. For most patients, maintaining a positive attitude was important, and some saw ACP as helping with this, others preferred to 'get on with life as usual' and not think too far ahead.
Fried T & O'Leary JR	[41]	2008 USA	90%	Qualitative thematic analysis Method: semi-structured interview	Sample: caregivers of community-dwelling patients who were aged 60 years or older who died with advanced cancer (52%), chronic obstructive pulmonary disease (27%), or heart failure (21%). Response rate: not reported Setting: community	Patient and caregiver willingness to accept prognostic information and to communicate with the loved ones varied greatly. Cancer patients were more willing than other groups to participate in discussions regarding the EOL.
Michael et al.	[5]	2013 Australia	90%	Qualitative grounded theory study Method: caregivers first described their initial understanding of ACP; received ACP information, and finally completed a semi-structured interview assisted by the vignette technique	Sample: 18 patients with cancer Response rate: 62% (26 of 29) Setting: patients at the lung and gastrointestinal tumor streams with more than 4 weeks to live.	Participants preferred to accept different components of ACP at different times. Illness uncertainty and staying positive were sometimes reasons to delay ACP. Illness uncertainty could also trigger ACP.
Michael et al.	[8]	2013 Australia	90%	Qualitative descriptive design with grounded theory overtones Method: focus groups, semi-structured interviews, which incorporated the vignette technique	Sample: 18 caregivers of patients with lung and gastrointestinal cancer Response rate: 43% (18 of 42) Setting: participants were recruited as part of a pilot ACP implementation and research program in a large tertiary cancer center.	Participants felt that it is important to understand patients' decisions. Participants, however, diverged on which components were needed, optimal times for related discussions, and whether decisions needed discussion or documentation.
Walczak, A et al.	[45]	2014 Australia	90%	Qualitative thematic content analysis of audio-taped communication support program intervention as part of a randomized control trial. Method: participants took part in a communication support program Exploratory qualitative design Method: focus group	Sample: 31 patients with advanced cancer and expected life expectancy of 2–12 months and 11 of their informal caregivers. Setting: Six treatment centers in Sydney, Australia	Information needs and preferences for timing of EOL discussions varied. Participants explicitly acknowledged physician discomfort as a barrier to discussing EOL.
Vleminck A D et al.	[40]	2013 Belgium	90%	Exploratory qualitative design Method: focus group	Sample: 36 GPs Setting: members of local peer review groups and palliative care networks	Lack of GP knowledge about cancer treatment options was identified as a particular problem for GPs caring for cancer patients. A patient's lack of awareness of diagnosis and prognosis in HF and dementia was expressed as a barrier to the initiation of ACP discussions more so than for cancer patients.

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Table 4. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results Summary	
Almack K et al.	[41]	2010	UK	85%	Exploratory qualitative case study Method: interviews and group interviews	Sample: 18 interviews and six follow-up interviews with patients with cancer, HF and dementia as well as family/friends. 5 group interviews with 15 HCPs. Response rate: Not reported Setting: GP practice and various hospital and community based care services	HCPs tended to rely on patients to explicitly raise issues for discussion rather than to initiate themselves. At the same time, they were alert to cues from the patient or guided by intuition as to when to introduce issues around EOL care, what depth to go into and so on. HCPs were often hesitant to take a lead over concerns about causing distress, taking away hope or touching on topics that the patient was not ready to engage with.
Carrion I et al.	[29]	2013	USA	85%	Qualitative grounded theory study Method: in-depth open semi-structured interview	Sample: 45 Latin (15 Columbian, 15 Mexican, and 15 Puerto Rican) women diagnosed with cancer Response rate: not reported Setting: Spanish-speaking women recruited from community health clinics, churches, cultural centers, and cancer support groups.	The women in the study despite having limited knowledge of ACP articulated the importance of making decisions and considered the significance of this for their family. A minority reported being 'scared' of ACP.
Elliot J & Olver I	[31]	2003	Australia	85%	Discourse analysis Method: semi-structured interview	Sample: 23 consecutive patients with cancer who were unlikely to die in the near future Response rate: not reported Setting: oncology clinic outpatient department	For some, Good Palliative Care orders were viewed as contributing to suffering for both patient and family (by prolonging the dying process), and some patients also noted that a patient's views regarding EOL care might alter in response to different circumstances.
Horne G, Seymour J & Shepherd K	[38]	2006	UK	85%	Qualitative grounded theory study Method: patients participated in an ACP discussion with a trained lung cancer nurse and then completed structured interviews	Sample: 15 patients with inoperable lung cancer and their family members (nine patients and six family members) Response rate: not reported Setting: one urban health community	Most appreciated the information they had been given and being provided with answers to their questions. Carers' reaction to the ACP intervention varied: some were grateful for the opportunity to discuss the future; others preferred not to think ahead and to live 'one day at a time'. People preferred to focus on living in the present by 'carrying on as normal' while they still felt reasonably well. Planning ahead for dying or death was reported as being 'morbid'. Patients talked about the prognosis being an educated guess or a 'hurdle game'. Some people reported not wanting to live with a death sentence, and others talked about not wanting to know their prognosis, feeling that knowing would damage their ability to focus on the positive.
Horne G, Seymour J & Payne S	[30]	2012	UK	85%	Qualitative grounded theory study Method: semi-structured interviews and focus groups	Sample: 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews) and two family focus groups were conducted. Setting: a specialist local cancer center	Healthcare professionals differed considerably in their understanding of when to initiate discussions about forgoing cancer-specific therapy at the EOL. However, their views could be consolidated into three approaches: (1) preparing patients gradually throughout the course of disease, (2) waiting until the patient himself or herself starts the discussion about forgoing cancer-specific treatment, and (3) waiting until all tumor-specific therapeutic options are exhausted. Discussions tended to be initiated when all cancer-specific treatments had been exhausted or when therapy failed or brought about severe complication.
Laryionava K et al.	[51]	2014	Germany	85%	Qualitative grounded theory study Method: semi-structured in-depth interviews	Sample: theoretical sampling of 29 physicians and nurses Response rate: not reported Setting: Department of Hematology and Oncology at a German university hospital	

(Continues)

Table 4. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results Summary
Boyd K et al. [42]	2011	UK	80%	Mixed method study—cross-sectional analysis of a pilot educational intervention Method: semi-structured interviews after a practice-based workshop, followed by telephone interviews with nine others Qualitative study Method: focus group	Sample: 20 GPs and eight community nurses Response rate: not reported Setting: staff at four general practices	Formal ACP was perceived as 'planning for dying' too soon and in a way that did not take into account the patients' needs. Discussing ACP conflicted with 'letting patients enjoy as much of their remaining lives as possible'.
Barnes, Jones, Tookman & King [28]	2007	UK	75%	Prospective qualitative design Method: semi-structured interview	Sample: 22 palliative care (18%) and oncology patients (82%). Response rate: 59% (22 of 37) Setting: patients attending a palliative care day unit or oncology outpatient clinic	The majority of patients felt the most appropriate time to discuss ACP would be after a recurrence of disease, or when treatment has failed and the prognosis is poor. Discussion held around the time of diagnosis or active treatment may be inappropriate and do more harm than good. Patients reported that HCPs should invite patients to have EOL discussions if appropriate.
Robinson CA & Carole A [3]	2011	Canada	55%	Prospective qualitative design Method: semi-structured interview	Sample: 18 participants comprised patients newly diagnosed with advanced lung cancer and their chosen significant other. 15 interviews were conducted (nine PC-ACP 2 interviews: six follow-up interviews) Setting: Patients diagnosed with advanced lung cancer and their significant other or loved ones, recruited from within 1.5 h of the study site.	Hope was about possibilities, not expectations. All dyads spontaneously identified hope for cure in relation to their current plan of care. The dyads found the ACP interview helpful, important, and although very emotional, most found it easier than they anticipated. These individuals were able to sustain multiple hopes, including hope for cure, at the same time as choosing 'do not resuscitate' option should their heart or breathing stop.
Jeżewski M, Meeker MA & Schrader, M [39]	2003	USA	45%	Qualitative Method: open-ended question at the end of a quantitative survey	Sample: 900 oncology nurses Response rate: 2.3% (900 of 3840) Setting: oncology nurses from four states	Many participants expressed concerns about role-related issues—Nurses wanted physicians to communicate clearly and realistically prognosis, therapy choices, chance of response, potential side effects and non treatment options.
Mixed methods studies Cox K et al. [46]	2011	UK	QN 91% QL 75%	Mixed methods study—cross-sectional Method: audit of case notes on a sample of deaths and complementary group interviews with HCPs.	Sample: 13 HCPs (GP, two district nurses, practice manager, two community matrons, two Macmillan nurses, specialist palliative care team manager, nursing home manager, care co-ordinator, and two registered nurses). Setting: Four study sites were selected from across a regional cancer network (hospitals and GP practices) Sample: 12 primary family caregivers of people with cancer whose loved ones were enrolled in hospice Response rate: not reported Setting: hospice	HCPs preferred an individual approach to the initiation of ACP discussions based on patient readiness, disease stage, and waiting for patient to give them cues.
Cherlin E et al. [43]	2005	USA	QN 73% QL 75%	Mixed methods study—cross-sectional Method: quantitative survey and additional in-depth interview with 12 family caregivers	Sample: 206 (92 Black patients and 114 White patients) completed patient interviews Response rate: 76% (206 of 270) Setting: ambulatory cancer patients from medical oncology clinics	Some carers wanted more information, and some were thankful that the physician had not discussed difficult topics with them believing this would have caused distress. Some were ambivalent.
McKinley E, Garrett J & Evans A [33]	1996	USA	QN 68% QL 30%	Mixed methods study—cross-sectional quantitative survey and open-ended questions for qualitative analysis. Method: in-person interviews		A small number of mostly Black patients did feel that a living will increase their feeling of hopelessness and would decrease the quality of medical care that they would receive at the end of their lives (18% and 14%, respectively, of Black patients).

(Continues)

Table 4. (Continued)

Authors Year Country	Quality rating	Methodology and data collection methods	Sample and setting	Results Summary
Samara J et al. [44] 2013 Australia	QN 45% QL 55%	Mixed methods study—qualitative plus pre-implementation and post-implementation audit Method: focus group plus delivery of an education program on ACP either in face-to-face sessions or via an e-learning package plus pre-session and post-session written questionnaires	Sample: 25 Nurses Response rate: not reported Setting: oncology department of a public hospital	The participants reported that ACP should be the responsibility of hospital medical officers; the patient's GP; social workers; and care coordinators. Some advocated for a designated ACP team. The participants also suggested that as some patients preferred to arrange the advance care privately themselves rather than openly talking about it with the hospital staff, this should be encouraged and supported.

ACP, advance care planning; HCT, hematopoietic cell transplant; APNs, advance practice nurses; EOL, end of life; HF, heart failure; AD, advance directive; HCPs, healthcare professionals; QN, quantitative; QL, qualitative. Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al. [17]) (number from QN and QL studies quality rating).

Theme 2: ACP may provoke fear and distress

Much of the literature on ACP has focused on patient, caregiver, and health professional views on ACP and on its implementation (see Table 8 for relevant references). While results vary across studies and between stakeholders, in general terms, ACP is viewed as desirable [2,5,24,25,29,31,34,37,38,42,45–47], although some have concerns over the capacity of ACP to meet its objectives [23,42,46]. However, even among those who supported ACP, there was concern regarding at least some components of ACP. Most notably, concerns surrounding when ACP should be initiated and by whom, as well as concerns over providing or receiving information regarding the EOL. Often this concern was based on fears that ACP would be distressing, either for the patients themselves or for their loved ones. Patients and families identified tensions between wanting to discuss ACP and carrying on with life as usual [28,38]. Notably, a proportion of participants in most studies reported fear or distress surrounding ACP [5,29,31,48].

2.1 Timing of ACP discussions

Of the practical challenges raised by ACP, one of the most contested surrounds the optimal timing for initiation of discussions regarding EOL care. Sixteen studies explicitly [4,5,21,25,27,28,30,35,38,39,42,49,50,45,51,46] addressed this question. Only one study supported the introduction of ACP early in the course of a patient's illness trajectory [39]. In almost all studies, patients and health professionals preferred to delay the introduction of ACP to later in the illness trajectory, when patients are unwell, have a major change in functional status, or when treatment options have been exhausted [4,25,28,30,42,49,50,45,51,52]. This reflected a belief that if ACP were initiated at an earlier time-point, patients would simply not be 'unwell enough' for ACP [21,25,27]. Introducing ACP later in a patient's illness trajectory was also considered to allow patients to focus on living in the present by 'carrying on as normal' while they still felt reasonably well [5,30,38] and 'allow patients to enjoy what is left of their remaining lives' [42].

In one study, patients reported that 'discussion held around the time of diagnosis or active treatment may be inappropriate, and do more harm than good' [28]. Some studies endorsed an individualized approach to the timing of ACP and/or discussion of different components at different times [5,27,35,46]. For example, in one study, the option that physicians should broach the subject when and if they consider it appropriate was the most popular response [35].

Overall, the literature suggests that all stakeholders are reluctant to initiate ACP early and prefer to delay ACP until the issues raised, particularly those surrounding preferences for EOL care, are more clinically relevant and appear more 'real', or more salient.

Table 5. Autonomy is contested and complex (studies ordered by quality rating)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results summary
Quantitative studies						
Duckworth, K <i>et al.</i> [21]	2013	USA	95%	Cross-sectional study Method: questionnaire	Sample: 49 HCT candidates and 44 proxies Response rate: not reported Setting: HCT candidates or the designated proxy of the candidate, attending the routine, pre-transplant psychosocial assessment	Participants reported that powerful others, such as doctors involved in their care, have the strongest influence over their health status, and those who completed ADs were less likely to believe their health outcomes were the result of chance. Proxies had relatively high decision-making confidence in their ability to make EOL decisions for their loved ones
Keating, N. L <i>et al.</i> [50]	2009	USA	95%	Cross-sectional study Method: written survey	Sample: 4074 physician survey responses. Response rate: 61% (4188 of 6871 physicians whose contact information was verified) Setting: physicians identified by patients participating in the CanCORS baseline interview as filling one or more key roles in their care.	15% would have the discussion regarding prognosis only if the patient/family brings it up. Physicians were more likely to wait for the patient/family to bring up preferred place of death than to have the conversation 'now' (24% vs. 21%), 49% reported that they would wait to discuss hospice until there were no more non-palliative treatments, and similarly, 29% for DNR discussion. Surgeons and medical oncologists were more likely than non-cancer specialists to report discussing prognosis 'now', but non-cancer specialists were more likely than cancer-specialists to discuss DNR status, hospice, and preferred site of death 'now'. 91.3% of respondents with an AD and 87.5% of respondents without an AD agreed with the statement: that the will expressed in an AD always applies, unless there are concrete indications that imply a change of will (difference not significant). Every second respondent agreed with the statement that ADs are to support the interaction between patient, relatives, and physician, rather than representing a directive for a concrete situation (55.1% vs. 57.3% agreement) 36.4% of all respondents agreed with the statement that ADs are of little help in practice because people usually sign them before they become ill and often change their minds when they contract a disease. Most APNs believed that ADs alone (without conversation) were effective to communicate patient's wishes for EOL care. Most commonly perceived barriers to ACP were that patients/family were reluctant, physician is reluctant, and staff discomfort.
Oorschot Bv <i>et al.</i> [23]	2012	Germany	95%	Cross-sectional study Method: written, standardized questionnaire	Sample: 589 completely evaluated questionnaires Response rate: 48.7% (589 of 1208) Setting: older patients with tumor undergoing radiation therapy	Participants reported that powerful others, such as doctors involved in their care, have the strongest influence over their health status, and those who completed ADs were less likely to believe their health outcomes were the result of chance. Proxies had relatively high decision-making confidence in their ability to make EOL decisions for their loved ones
Zhou, G <i>et al.</i> [24]	2010	USA	95%	Descriptive cross-sectional pilot survey study Methods: survey distributed to 300 APNs via e-mail and sent again to the 89 APNs who responded to the initial survey	Sample: 89 oncology APNs responded to the initial survey, and 53 of the 89 respondents returned the retest survey Response rate: 30% (90 of 300). Setting: 300 oncology APNs from one author's professional networks	Participants reported that powerful others, such as doctors involved in their care, have the strongest influence over their health status, and those who completed ADs were less likely to believe their health outcomes were the result of chance. Proxies had relatively high decision-making confidence in their ability to make EOL decisions for their loved ones
Barakat, A <i>et al.</i> [34]	2013	USA	90%	Cross-sectional study Method: a printed questionnaire returned in sealed envelope.	Sample: 68 completed surveys Response rate: 68% (68 of 100) Setting: inpatients in the oncology and blood and marrow transplantation units.	71% of those who had a discussion with their oncologist also reported that they had a living will or other AD versus 48% among those who did not have a discussion with oncologist
Jones L <i>et al.</i> [53]	2011	UK	85%	Exploratory randomized patient preference trial Method: questionnaire	Sample: 77 participants with advanced cancer. Response rate: 88% (68 of 77) Setting: patients who had completed a primary course of treatment for cancer but still had clinically detectable, active, progressive disease.	The main barrier to recruitment was the reluctance of clinical staff to introduce the research to patients, because of an understandable wish not to approach patients with a challenging study unless they were sure that patients were not likely to react adversely to the concept of ACP and its implications for future prognosis and care.

(Continues)

Table 5. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results summary
Fu, S et al. [22]	2012	USA	77%	Cross-sectional study Method: written survey	Sample: 215 completed or partially completed questionnaires Response rate: 49% (215 of 435) Setting: patients with advanced cancer being considered for enrollment onto an early-phase clinical trial. Sample: 794 usable surveys Response rate: 23% (883 of 3840) Setting: a stratified random sample of 4000 Oncology Nursing Society members	The majority (59%) expressed wishes to discuss ACP matters with their physician. However, the majority had not actually done so. High level of agreement with 'Nurses should uphold the patient's wishes even if they conflict with the nurse's own view'; 'Nurses should help inform patients about their condition and treatment alternatives'; and 'Patients with decision-making capacity who are not terminally ill should have a right to refuse life support even if that decision may lead to death'. 17% answered that they had provided treatment to patients whose AD indicated otherwise, and 42% had observed others providing treatment to patients whose AD indicated otherwise. The majority (73.9%) defined EOL discussion as the discussion about code status, ADs, and withholding treatment when recommended by physician and transitioning hospice.
El-Sahwi K. S et al. [49]	2011	USA	60%	Cross-sectional study Method: pilot survey sent via the website Survey Monkey	Sample: 142 physician responses. Response rate: 12.8% (142 out of 1105) Setting: surveys were e-mailed to members of the Society of Gynecologic Oncology	Many patients trust HCPs to make future healthcare decisions in their best interests.
Qualitative studies Barnes K, Jones L, Tookman A, King, M [27]	2011	UK	90%	Exploratory patient preference randomized controlled trial Method: semi-structured interview as part of an ACP intervention	Sample: 40 patients with recurrent progressive cancer and 52 interviews. Response rate: not reported Setting: patients attending oncology and palliative care outpatient clinics in two London teaching hospitals Sample: caregivers of community-dwelling patients who were aged 60 years or older who died with advanced cancer (52%), chronic obstructive pulmonary disease (27%), or heart failure (21%). Response rate: not reported Setting: community	Cancer patients were more willing than other groups to participate in discussions regarding the EOL, and there were several stories of patients choosing to forgo aggressive therapy even when they had previously indicated a willingness to undergo invasive therapy.
Fried T & O'Leary JR [4]	2008	USA	90%	Qualitative thematic analysis Method: semi-structured interview	Sample: 18 caregivers of patients with lung and gastrointestinal cancer Response rate: 43% (18 of 42) Setting: participants were recruited as part of a pilot ACP implementation and research program in a large tertiary cancer center	Participants felt that it is important to understand patients' decisions to help fulfill patients' wishes, and allow patients some control. Participants, however, diverged on whether decisions needed discussion or documentation. Whereas caregivers mostly expected to honor their interpretations of patients' 'implied' wishes, others said that they would override patients' plans if they felt that it was in the patients' and families' best interest.
Michael et al. [8]	2013	Australia	90%	Qualitative descriptive design with grounded theory overtones Method: focus groups, semi-structured interviews, which incorporated the vignette technique	Sample: 18 patients with cancer Response rate: 62% (26 of 29) Setting: patients at the lung and gastrointestinal tumor streams with more than 4 weeks to live.	Over two-thirds suggested that they would want to be able to change ACP decisions. Many described ACP as an iterative process as they considered their priorities, values, and futures. While most believed that their informal and professional carers would enact their wishes, occasional doubts were raised. Some wanted family to make life-prolonging treatment decision in consultation with HCPs.
Michael et al. [5]	2013	Australia	90%	Qualitative grounded theory study Method: caregivers first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique		

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Table 5. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results summary
Walczak, A, et al.	[45]	2014 Australia	90%	Qualitative thematic content analysis of audio-taped communication support program intervention as part of a randomized control trial. Method: participants took part in a communication support program	Sample: 31 patients with advanced cancer and expected life expectancy of 2–12 months and 11 of their informal caregivers. Setting: Six treatment centers in Sydney, Australia	Participants explicitly acknowledged oncologists' discomfort in discussing life expectancy as a barrier to discussions regarding EOL
Canton I et al.	[29]	2013 USA	85%	Qualitative grounded theory study Method: in-depth open semi-structured interview	Sample: 45 Latin (15 Columbian, 15 Mexican, and 15 Puerto Rican) women diagnosed with cancer Response rate: not reported Setting: Spanish-speaking women recruited from community health clinics, churches, cultural centers, and cancer support groups	For the 10 women who completed ACP, they trusted that their desires would be fulfilled. They also expressed expectations that their family assume a leadership role and to heed their final decisions.
Elliot J & Oliver I	[31]	2003 Australia	85%	Discourse analysis Method: semi-structured interview	Sample: 23 consecutive patients with cancer who were unlikely to die in the near future Response rate: not reported Setting: oncology clinic outpatient department	Some mentioned the importance of feeling in control, even if the reality is different. Others disliked the idea of GPC orders because they see it as 'literally signing their life away'.
Horne G, Seymour J & Payne S	[30]	2012 UK	85%	Qualitative grounded theory study Method: semi-structured interviews and focus groups	Sample: 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews) and two family focus groups were conducted. Setting: a specialist local cancer center	8 talked about their doctor knowing what is best for them with implicit acceptance of treatment advice. 11 reported that their doctors offered different treatment options for future care. 13 reported that HCPs did not have deep discussions or initiate conversation about EOL.
Horne G, Seymour J & Shepherd K	[38]	2006 UK	85%	Qualitative grounded theory study Method: patients participated in an ACP discussion with a trained lung cancer nurse and then completed structured interviews Qualitative analysis of a pilot educational intervention Method: semi-structured interviews after a practice-based workshop, followed by telephone interviews with nine others	Sample: 15 patients with inoperable lung cancer and their family members (nine patients, six family members) Response rate: not reported Setting: one urban health community	Some patients who recorded their future wishes in an ACP record had high expectations that their wishes would be carried out; others held the view that they may not necessarily obtain what they wanted even if it is recorded.
Boyd K et al.	[42]	2010 UK	80%	Qualitative analysis of a pilot educational intervention Method: semi-structured interviews after a practice-based workshop, followed by telephone interviews with nine others	Sample: 20 GPs and eight community nurses Response rate: not reported Setting: Staff at four general practices	Expertise in EOL care was mostly considered to be something that could not be taught, based on intuition and experience.
Barnes K, Jones L, Tookman A, King, M	[28]	2007 UK	75%	Qualitative study Method: focus group	Sample: 22 palliative care (18%) and oncology patients (82%). Response rate: 59% (22 of 37) Setting: patients attending a palliative care day unit or oncology outpatient clinic	Some expressed concern about a person changing their mind regarding what is written in an AD. Some clinicians were wary of introducing the research to patients, citing reasons such as their stage of disease, a judgment that they would not be interested in taking part, or that the patient would not be able to emotionally cope with a study of this kind.
Robinson CA & Carole A	[3]	2011 Canada	55%	Prospective qualitative design Method: semi-structured interview	Sample: 18 participants comprised patients diagnosed with advanced lung cancer and their significant other or loved one Setting: not described	Most patients wanted their family members to use his or her judgment rather than strictly follow their stated preferences. It was clear that they viewed ACP as a family affair and felt safe knowing that their wishes were clearly understood by a trusted loved one who could speak on their behalf.
Jezewski M, Meeker MA & Schrader, M	[39]	2003 USA	45%	Qualitative Method: open-ended question at the end of a quantitative survey	Sample: 900 oncology nurses Response rate: 23% (900 of 3840) Setting: oncology nurses from four states	Many nurses said that they needed the support of their physicians. The nurses stated that they needed collaborative working relationships with physicians and that they needed to be included in the discussions with patients when prognoses and ADs were discussed.

(Continues)

Table 5. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results summary
Mixed methods studies Cherlin E et al.	2005	USA	QN 73% QL 75%	Mixed methods study Method: quantitative survey and additional in-depth interview with 12 family caregivers	Sample: 12 primary family caregivers of people with cancer whose loved ones were enrolled in hospice Response rate: not reported Setting: hospice	Some carers desired more information from physicians, believing that they may have made different decisions had they known more. All carers believed physician communication was central to their experience. 'I don't think the decisions were in our control at all. We were not the empowered ones in this because we did not know.'
McKinley E, Garrett J & Evans A	1996	USA	QN 68% QL 30%	Mixed methods study—quantitative survey and open-ended questions for qualitative analysis Method: in-person interviews	Sample: 206 (92 black patients and 114 white patients) completed patient interviews Response rate: 76% (206 of 270) Setting: ambulatory cancer patients from medical oncology clinics	84% of black participants and 92% of white participants agreed that living wills help maintain control over future care. The themes that emerged from the 37 participants who had living wills included 'to make sure things are taken care of, and to have final control over decisions about terminal care.'

ACP, advance care planning; HCT, hematopoietic cell transplant; APNs, advance practice nurses; EOL, end of life; AD, advance directive; DNR, do not resuscitate; HCPs, healthcare professionals; QN, quantitative; QL, qualitative.

2.2 Initiation of ACP discussions

Thirteen studies addressed the initiation of ACP [27,28,34,35,39,41,42,44,49,50,46,52]. In almost all studies, participants expected an individual or group other than themselves to initiate ACP, with most believing that physicians were responsible for initiating discussions regarding ACP.

Studies involving nurses reported that they believed that a wide range of 'other' persons should initiate ACP discussions, including physicians, patients, social workers, care coordinators, or other pastoral care providers [39,44]. Patients almost universally preferred that their physician initiated ACP discussions [27,28,41,52]. Studies reporting physicians' attitudes to initiation of ACP were contradictory. In two studies, physicians directly rejected the responsibility for initiating discussion of ADs or ACP, preferring to delegate this to either the patient or their family members [35,41]. In other studies, physicians acknowledged that they did have a responsibility for initiating ACP discussions but suggested that these discussions should be prompted by implicit cues from the patient indicating that they wished to discuss ACP [41,42,51,46].

Physician preference for a diffusion of responsibility regarding EOL decision-making was expressed across several themes in the results. While the reasoning behind this is understandable (in sensitivity to patients' readiness to discuss EOL topics) [24,35,41,51,46], it is incongruent with the clear expectations of other ACP stakeholders that physicians should and will initiate ACP discussions.

2.3 Information about EOL care

Twenty-four studies addressed information about EOL [3–5,21,22,25,27–30,34,40–42,49,45,51,52,32,47,48]. These reveal enormous variability in the amount of information that patients and caregivers wish to hear in relation to EOL issues [4,43,45]. A large proportion of patients want information regarding the EOL; however, many described tensions between wanting to be involved in decision-making regarding their medical care and discomfort discussing EOL [28,29,34,38,32,48]. For example, in one study, some said 'there were things they would appreciate discussing but they also wanted to be able to close the topic down again' [28]. In another study, almost a quarter of participants said that ACP discussions gave them new information, which was challenging but valuable [27]. In contrast, some patient participants strongly rejected ACP, preferring not to discuss what may happen in the future or think about 'gory details' [25,30]. It was thought that such discussions could cause confusion or distress [30], increase feelings of hopelessness, or interfere with a person's optimism about their illness [5,25,33]. Health professionals and caregivers also appeared reluctant to discuss EOL for fear of causing distress, taking away hope or touching on topics that the patient is not ready to engage with [41–43,51].

Table 6. Institutional culture is influential in ACP (studies ordered by quality rating)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results summary
Jezewski M <i>et al.</i> [39]	2005	USA	77%	Descriptive correlation survey Method: mailed survey	Sample: 794 usable surveys Response rate: 23% (883 of 3840) Setting: a stratified random sample of 4000 Oncology Nursing Society members	66% or more were confident about implementing institutional policies and procedures regarding ACPs.
Qualitative studies Jezewski M, Meeker MA & Schrader, M	2003	USA	45%	Qualitative Method: open-ended question at the end of a quantitative survey	Sample: 900 oncology nurses Response rate: 23% (900 of 3840) Setting: oncology nurses from four states	Factors that affected assisting with ACPs included the following: a need to simplify the process of completing ACPs, to 'cut red tape', to provide 'easier forms to fill out'. Knowledge of policies was cited as a factor; and some suggested mandating nurses to assist with ACPs. Lack of knowledge about treatment options and a lack of collaboration between primary and secondary care physicians were identified as a particular problem for GPs caring for cancer patients.
Vierminck A <i>et al.</i> [40]	2013	Belgium	90%	Exploratory qualitative design Method: focus group	Sample: 36 GPs Response rate: Setting: members of local peer review groups and palliative care networks	Formal ACP was perceived as 'planning for dying' too soon and in a way that did not take account of professional-patient relationships and individual patient needs. There were general concerns about formal processes being overly prescriptive and difficult to achieve.
Boyd K <i>et al.</i> [42]	2010	UK	80%	Qualitative analysis of a pilot educational intervention Method: Semi-structured interviews after a practice-based workshop, followed by telephone interviews with nine others	Sample: 20 GPs and eight community nurses Response rate: not reported Setting: staff at four general practices	Participants prefer a more individualized, non-formal method of care planning with their patients. They believed that record keeping does not accurately reflect the reality of conversations, or the practicalities of how knowledge is actually shared between HCPs. They prefer to maintain discretion when EOL discussions/decision-making should occur.
Mixed methods studies Cox K <i>et al.</i> [33]	2011	UK	QN 91% QL 75%	Mixed methods study—cross-sectional audit and qualitative interviews Method: audit of case notes on a sample of deaths and complementary group interviews with HCPs	Sample: 13 HCPs (GP: two district nurses, practice manager; two community matrons, two Macmillan nurses, specialist palliative care team manager; nursing home manager, care co-ordinator and 2 registered nurses). Setting: four study sites were selected from across a regional cancer network (hospitals and GP practices)	

ACP, advance care planning; AD, advance directive; HCPs, healthcare professionals; QN, quantitative; QL, qualitative. Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet *et al.* [17]) (number from QN and QL studies quality rating).

Table 7. Knowledge of ACP and previous healthcare experiences can act as a motivator or barrier to ACP (studies ordered by quality rating)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results summary
Quantitative studies						
Keating, N et al. [50]	2009	USA	95%	Cross-sectional study Method: written survey	Sample: 4074 physician survey responses. Response rate: 61% (4188 of 6871 physicians whose contact information was verified) Setting: physicians identified by patients participating in the CanCORS baseline interview as filling one or more key roles in their care.	Physicians who strongly agreed they were knowledgeable to discuss EOL options were more likely to discuss DNR status (OR, 1.94; 95% CI, 1.58–2.37), hospice (OR 1.59; 95% CI 1.27–2.00) and hospice death (OR 1.60; 95% CI 1.27–2.05) 'now'
Hu WY et al. [54]	2010	Taiwan	77%	Cross-sectional study Method: multi-center survey using a structured questionnaire mailed to participant's respondents was assigned to 'participation' group, or to 'non-participation' group.	Sample: 413 HCP completed questionnaires Response rate: 71.8% (431 of 600 responded). 18 incomplete questionnaires excluded. Setting: HCPs including doctors and nurses working at oncology care wards or palliative care units.	'Workplace (hospice vs. non-hospice)', attitudes that the enactment of Natural Death Act would contribute to promoting the use of advance directives' and 'knowledge about Natural Death Act' are the three most important independent factors that affect HCPs' decision to execute or initiate discussion about ADs.
Hwang, S et al. [32]	2003	USA	77%	Cross-sectional study Method: written questionnaire	Sample: 254 veterans with symptomatic cancer Response rate: 86% (254 of 296 surveys) Setting: veterans seen at the inpatient/outpatient clinic in a hematology tertiary referral center.	There are significant disparities between racial groups in ACP, knowledge, attitudes, and decision-making.
Jezewski M et al. [36]	2005	USA	77%	Descriptive, correlation survey Method: mailed survey	Sample: 794 usable surveys Response rate: 23% (883 of 3840) Setting: a stratified random sample of 4000 Oncology Nursing Society members	Nurses who are more experienced and more confident are significantly more likely to perceive themselves as having an active role in ACP.
Qualitative studies						
Michael et al. [5]	2013	Australia	90%	Qualitative grounded theory study Method: caregivers first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique	Sample: 18 patients with cancer Response rate: 62% (26 of 29) Setting: patients at the lung and gastrointestinal tumor streams with more than 4 weeks to live.	Positive memories of relatives EOL care triggered one participant's to request palliative care, but uncomfortable memories of family members, friends' and acquaintances' advanced illnesses and comparable media reports also resulted in other participants not wanting to consider life extending treatment when seriously unwell.
Walczak, A et al. [45]	2014	Australia	90%	Qualitative thematic content analysis of audio-taped communication support program intervention as part of a randomized control trial. Method: audiotapes of a communication support program.	Sample: 31 patients with advanced cancer and expected life expectancy of 2–12 months and 11 of their informal caregivers. Setting: Six treatment centers in Sydney, Australia	Positive or negative experiences of the death of a loved one motivated engagement in ACP.
Horne G, Seymour J & Payne S [2]	2012	UK	85%	Qualitative grounded theory study Method: semi-structured interviews and focus groups	Sample: 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews) and two family focus groups were conducted. Setting: a specialist local cancer center	Patient's experiences of other people's cancer or death often influenced their level of engagement with decision-making.

(Continues)

Table 7. (Continued)

Authors	Year	Country	Quality rating	Methodology and data collection methods	Sample and setting	Results summary
Robinson CA [3]	2012	Canada	75%	Prospective qualitative Method: patients participated in an ACP discussion (PC-ACP interview) and then completed semi-structured interviews 3–6 months later Analysis: thematic analysis—constant comparative	Sample: 18 participants comprised patients newly diagnosed with advanced lung cancer and their chosen significant other. 15 interviews were conducted (nine PC-ACP interviews; six follow-up interviews) Setting: patients diagnosed with advanced lung cancer and their significant other or loved ones, recruited from within 1.5 h of the study site.	The participant's attitudes towards hope and treatment planning were influenced by the context in which participants were embedded, which included their previous experiences of serious illness.
Robinson CA & Carole A [2]	2011	Canada	55%	Prospective qualitative design Method: semi-structured interview	Sample: 18 participants comprised patients diagnosed with advanced lung cancer and their significant other or loved one Setting: not described	Many patients framed their preferences in light of experiences with others at the EOL.

ACP, advance care planning; EOL, end of life; DNR, do not resuscitate; OR, odds ratio; HCPs, healthcare professionals; AD, advance directive; PC, Patient/Carer. Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al. [17]) (number from quantitative and qualitative studies quality rating).

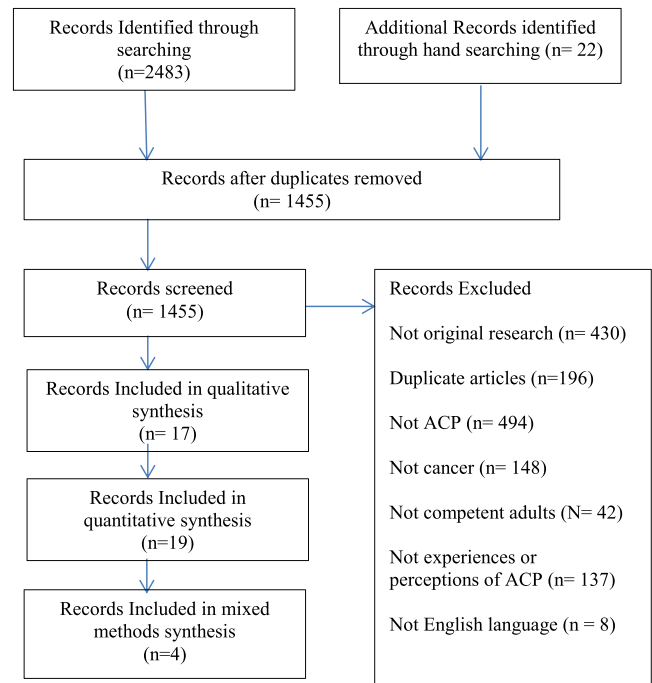


Figure 1. Review selection process. ACP, advance care planning

Although both patients and health professionals commonly expressed fears that ACP may disrupt hope, the results suggest that this is not necessarily the case [2,22,33]. In one study, despite 73% of participants having undertaken ACP, 69% believed they could beat their cancer [22].

2.4 Setting for ACP discussions

There is very limited literature dealing with stakeholders' preferences for the setting in which to conduct ACP, and those studies that have explored this issue likely reveal more about the existing institutional practices of the participants involved than any rich insight into the optimal setting for ACP.

Unsurprisingly, oncologists appear to most commonly initiate EOL discussion in outpatient clinics [49], and nurses appear to support ACP in a wide range of settings, including both pre-hospital admission, admission, and inpatient settings [22,25,44,49]. Two studies explored patient preference for where ACP should be conducted. In these two studies, 58% [25] and 87% [20] of patients supported a policy in which discussion regarding ADs was offered as part of the hospital admissions process.

Theme 3: Autonomy is conceptually complex and contested

3.1 ACP is controlled by physicians

It was explicitly and implicitly expressed across the literature that physicians feel they are best placed to determine when patients are ready for ACP, and what should

Table 8. Classification of included articles according to theme

Theme	Number of papers identified in quantitative literature [reference to relevant papers]	Number of papers identified in qualitative literature [reference to relevant papers]	Number of papers identified in mixed methods literature [reference to relevant papers]
1. ACP is relational			
1.1 Family is a motivator or barrier to ACP	<i>n</i> = 7 [20–26]	<i>n</i> = 9 [3–5,8,27–31]	<i>n</i> = 1 [33]
1.2 The therapeutic relationship	<i>n</i> = 8 [21,22,24,25,34–37]	<i>n</i> = 6 [29,38–42]	<i>n</i> = 2 [43,44]
2. ACP provokes fear and distress			
2.1 Timing of ACP discussions	<i>n</i> = 5 [21,25,35,49,50]	<i>n</i> = 10 [4,5,27,28,30,38,39,42,45,51]	<i>n</i> = 1 [46]
2.2 Initiation of ACP discussion	<i>n</i> = 6 [34,35,49,50,52]	<i>n</i> = 5 [27,28,39,41,42]	<i>n</i> = 2 [44,46]
2.3 Information about EOL care	<i>n</i> = 10 [4,21,22,25,34,49,52,32,47,48]	<i>n</i> = 12 [3–5,27–30,38,40–42,45,51]	<i>n</i> = 2 [33,43]
2.4 Setting for ACP discussions	<i>n</i> = 4 [20,22,25,49]	<i>n</i> = 0	<i>n</i> = 1 [44]
3. Autonomy is conceptually complex and contested			
3.1 ACP is controlled by physicians	<i>n</i> = 6 [21,24,34,36,50,53]	<i>n</i> = 5 [27,28,39,42,45]	<i>n</i> = 1 [43]
3.2.1 Patients' views regarding autonomy	<i>n</i> = 2 [23,48]	<i>n</i> = 7 [3,5,27,28,30,31,38]	<i>n</i> = 1 [33]
3.2.2 Caregivers' views regarding autonomy	<i>n</i> = 0	<i>n</i> = 1 [8]	<i>n</i> = 0
3.2.3 Health professional's views regarding autonomy	<i>n</i> = 4 [24,36,49,50]	<i>n</i> = 1 [39]	<i>n</i> = 1 [46]
4. Institutional culture is influential in ACP	<i>n</i> = 1 [36]	<i>n</i> = 3 [39,40,42]	<i>n</i> = 1 [46]
5. Knowledge of ACP and previous healthcare experiences can act as motivator or barrier to ACP	<i>n</i> = 4 [36,50,32,54]	<i>n</i> = 5 [2,3,5,30,45]	<i>n</i> = 0

ACP, advance care planning; EOL, end of life.

be discussed. Few studies explicitly addressed the fact that physicians effectively ‘control’ ACP, possessing both expert knowledge about a patient’s diagnosis, prognosis, and treatment options as well as professional power relating to the timing, structure, and content of EOL discussions and ACP. However, references to the power of the physician and the degree of control they exerted over the patient, and over other health professionals, particularly nurses, permeated the literature on ACP. Twelve studies [21,24,27,28,34,36,39,42,43,50,45,53] addressed this topic. In one study, nurses felt that they needed more autonomy to initiate ACP discussions ‘without doctors’ permission or repercussions from doctors for doing so’ [39]. In another study, ‘physician is reluctant’, ‘physician is rushed’, ‘physician delays the discussion’, and ‘physician discusses other treatment options’ were the most commonly reported barriers to ACP [24]. In one study, patients and caregivers explicitly acknowledged physician discomfort in discussing and initiating EOL conversations as a barrier to participating in discussions [45].

3.1 Patient, caregiver, and healthcare professionals views regarding autonomy

3.2.1 Patients' views

In contrast to the assumptions that are often said to justify ACP, patients rarely discussed ACP in terms of their control or influence over their treatment choices. Indeed, only two studies, both quantitative studies that offered participants restricted response options, reported

that patients felt that EOL discussion would help them to establish or maintain control over their health care [23,33]. Instead, patients tended to speak of ACP in terms of the social, psychological, and emotional issues that arise when one approaches the end of one’s life [31]. Furthermore, patients tended not to regard ACP principally as a means by which they could control decision-making regarding their health care beyond the point at which they lose capacity. A number of studies reported that patients accepted that their wishes may vary during the course of their illness, that their expressed preferences for care may not always be followed, and that family members or health professionals would use their own judgment in deciding whether their stated preferences should be followed [3,5,38] and were happy to delegate treatment decisions to trusted professionals [27,28,30,31,48].

3.2.2 Caregivers' views

Only one qualitative study specifically explored caregiver’s views regarding the role of ACP in actualizing autonomy [8]. This study described how caregivers tended to acknowledge patients’ future care wishes while also developing subsidiary plans. For the caregivers in this study, fulfilling patients’ wishes was only one of a number of the perceived functions or benefits of ACP and ‘whereas caregivers mostly expected to honor their interpretations of patients’ “implied” wishes, others said that they would override the patient’s plans if they felt that it was in the patient’s and family’s best interest’.

3.2.3 Health professional's views

In contrast to patients and caregivers, health professionals often viewed the primary function of ACP to be the documentation of treatment choices. In one study, 73.9% of physicians defined EOL discussion as the discussion about code status, advance directives, withholding treatment when recommended by the physician, and transitioning to hospice care [49]. In another study, most nurses believed that ADs alone (without conversation) were effective to communicate patients' wishes for EOL care [24]. In other words, for health professionals, ACP served principally as a form of documentation of information, rather than as a communicative tool or as a mechanism for reinforcing or deepening the health professional–patient relationship. The rationale that health professionals gave for this stance was that the documentation of advance treatment preferences was a method of empowering patients. ADs were spoken of as prescriptive instructions from patients, which should be respected and upheld by health professionals [36,39] and caregivers [36,46]. Health professionals admitted to having concerns regarding ACP in regard to caregivers' wishes or decision-making conflicting with written directives [46], with health professionals expressing the belief that in these situations they had a (moral) responsibility not only to refrain from interfering with a written course of action but to advocate for the patient where necessary by preventing others from interfering [36,46]. In a UK study, legislation was seen as supporting this position: 'we've got a lot more say in what is going to happen, the patients got a lot more say in what is going to happen, rather than the caregiver' [46].

Theme 4: Institutional culture is influential in ACP

Five studies reported on the institutional culture surrounding ACP [36,39,40,42,46]; all studies involved health professionals. Although 'institutional policies were seen as a way of encouraging and supporting the implementation of AD's' [39], they also raised concerns for health professionals [42,46]. 'Overly prescriptive' and 'tick box' approaches to ACP were generally seen as hindering rather than supporting good quality EOL care [42]. Institutionalized ACP processes and ACP documentation were felt to insufficiently reflect the reality of conversations with patients about EOL care, or the practicalities of how knowledge is actually shared between health professionals and patients [46]. As a result, many health professionals admitted to preferring more individualized, informal methods of care planning with their patients. More discursive and less structured ACP discussions with colleagues who shared responsibility for the care of particular patients was preferred to communication that they believed was based around documentation and was excessively bureaucratic [40,42,46].

Theme 5: Knowledge of ACP and previous healthcare experiences can act as a motivator or barrier to ACP

Six studies [2,3,5,36,50,45,32,54] reported that patients' experience of health care and perception of the healthcare system, as well as their previous experiences with dying people could positively or negatively influence their support for and willingness to engage in ACP [2,3,8,30,45,32].

Health professionals' knowledge of and attitudes towards ACP was also consistently found to be an important factor in their willingness to initiate or participate in ACP [39,50,54].

Discussion

Advance care planning is generally championed as a means by which competent patients can extend their involvement in and control of decisions regarding their own health care beyond the point at which they lose capacity as a result of illness or injury. This review of empirical studies of ACP in cancer care suggests that while ACP may function as a decisional 'tool', its uptake and utility is much more a function of a range of complex relational, emotional, and social factors. The literature here suggests that ACP is relational, meaning it is enacted less as an individual directive and more as a family-centered and social process. ACP also provokes fear and distress. It is seen to carry both benefits and risks—social, psychological, and emotional risks—all of which may impact upon the behavior of patients, family members, and health professionals surrounding ACP. The behavior and choices of patients, their loved ones, and the staff caring for them in relation to the EOL are strongly influenced by the institutional culture within which they are operating, as well as their previous experiences of the healthcare setting or the dying process. ACP is therefore not simply a manifestation of a patient's choice but the result of a complex and dynamic interplay between patients and their healthcare providers. The enactment of ACP is embedded within a healthcare system already inscribed by professional organizational and interpersonal power structures. ACP has emerged from existing ideas about healthcare, decision-making, and the proper role of patients, their families, and those who care for them. Within this context, facilitating patient autonomy is neither simple nor uncontested.

Autonomy has long been privileged as the pre-eminent principle in Western legal and bioethical thought and is the concept that underpins decision-making in health care and consent [55,56]. ACP, at least as it is commonly understood by health professionals, is based upon the individualistic conceptualization of autonomy. Namely, rational agents can assert their control over their own health care and enforce their right to non-interference, most usually from excessive medical treatment at the

EOL, through documentation of their care preferences and appointment of their nominated proxy.

The literature in this review suggests that this model of autonomy may not represent the reality of ACP or be appropriate to its actualization. An alternative model of autonomy—relational autonomy—emphasizes the fact that individual autonomy is socially dependent, that is, the capacity and opportunity for autonomous action is dependent on our particular social relationships and the power structures in which we are embedded [57,58]. Under this model, simply presenting patients (or the health professionals responsible for their care) with an authorized mechanism for communication and documenting a patient's preferences for EOL care may do little to optimize care or advance the patient's autonomy. Instead, what is required is a clear recognition that whether or not patients choose to engage in decision-making, the choices they make, and their capacity to implement their choices are all dependent on existing relationships with family and health professionals, as well as the healthcare context within which they are operating. 'Autonomy requires more than freedom from interference; it requires that one's relationships with particular individuals and institutions be constituted in such a way as to give one genuine opportunities for choice' [59]. Thus, where the relational, emotional, and social factors necessary for successful ACP are not in place, patients will not be able to meaningfully participate in ACP, and it will either fail or become simply a function of the need of institutions or professionals to 'get something on paper'. So, for example, if families are reluctant to participate, then patients are likely to refuse ACP. If physicians are ignorant of ACP or concerned about the negative impacts it may have on patients, then, they are unlikely to encourage patients to pursue it. If the social and healthcare environment in which patients are being treated emphasizes the unilateral authority of doctors or fails to create the time and space for ACP in different contexts, then, patients will be unable to actively and meaningfully engage in the process.

The data reported here support one of the criticisms that has been made against ACP, that is, while ACP is best regarded as a process of communication that incorporates goals, values, and wishes, in practice, ACP remains strongly linked to an AD framework. That is, the key aim of ACP programs within health care is to 'improve and support advance directives use through providing a supportive framework' [55]. Unlike health professionals, patients and their families may not see autonomy over treatment decisions as the key aspect of ACP and may not even desire a process that is concerned principally with the documentation and enforcement of previously expressed wishes for treatment. Further to this, patients may not consider non-fulfillment of their wishes by trusted professionals and loved ones to be a violation of their autonomy but rather as a manifestation of their love

and/or care. If this is the case, the social and healthcare environment may not only work against patients achieving ACP but may conflict with the needs of patients who desire it. The evidence suggests that ACP may have more to do with shared decision-making and communication than with avoidance of excessive medical treatment at the EOL and more to do with relationships and trust than with liberty and rights. This being the case, as others have noted, the 'use of standardized ACP approaches may need revisiting as they may fail to appreciate how personal, shared lives, and culturally related expectations and/or beliefs inform how patients and caregivers consider, develop, and enact on plans' [5].

Limitations of this review

While a review of empirical research into ACP in cancer care yields some important insights, there are sufficient limitations in the published data that great care must be taken in translating the results described here to specific populations.

First, the majority of ACP research has been conducted in the USA (19 of 40) or Europe (13 of 40), and almost all has been conducted within the tertiary care setting. Few studies have been conducted in outpatient or community care settings, and only limited attention has been given to cross-cultural considerations in EOL care planning [55]. In a recent systematic review of 113 studies providing empirical evidence regarding ACP, only nine studies were performed in the community [13]. For the papers included in this review, only two studies [29,33] specifically considered ethnic differences in EOL care preferences. As a consequence, little is known about the attitudes of different ethnic or cultural groups to ACP, and the findings reported here can only really be regarded as applicable to patients from Western Europe and North America.

Perhaps more importantly, however, methodological limitations raise real questions about the veracity of the findings reported here. Many of the studies failed to report details on screening, response rates, and recruitment procedures. Many of the studies were also cross-sectional studies of perceptions, and few involved patients in the terminal phases of their illness. Given what we know about the dynamic and complex nature of treatment preferences and the ways in which attitudes may change during the course of one's illness [60], such studies are unlikely to adequately reflect the perceptions that patients have about EOL care as their death approaches. And finally, it seems likely that there are systematic differences between those who choose to participate in ACP research and those who choose not to participate. For example, those who experience high levels of distress surrounding EOL discussions are unlikely to participate in ACP research. Therefore, their perspective is notably missing

from the ACP literature. This raises the possibility that the support for ACP reported in these studies over-represents support for ACP in patients with cancer and those who care for them.

Conclusion

While there is broad support for discussing EOL care, both among patients with cancer and those who care for them, the notion that ACP is concerned principally with the 'right' to self-determination through control over treatment choices at the EOL may misrepresent the way that ACP actually occurs in cancer care. It may undermine the principle of ACP, and ultimately conflict with the

deeper concerns and needs of patients, who experience ACP as relational, emotional, and social. Further research is needed to examine the ethical framework within which ACP is being conducted and to further understand the philosophical approach of healthcare professionals, cancer patients, and their caregivers to ACP.

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References

- Romer AL, Hammes BJ. Communication, trust, and making choices: advance care planning four years on. *J Palliat Med* 2004; **7**(2):335–340.
- Robinson CA. 'Our best hope is a cure'. Hope in the context of advance care planning. *Palliat Support Care* 2012; **10**(2):75–82.
- Robinson C, Carole A. Advance care planning: re-visioning our ethical approach. *Can J Nurs Res* 2011; **43**(2):18–37.
- Fried TR, O'Leary JR. Using the experiences of bereaved caregivers to inform patient- and caregiver-centered advance care planning. *J Gen Intern Med* 2008; **23**(10):1602–1607.
- Michael N, O'Callaghan C, Clayton J *et al*. Understanding how cancer patients actualise, relinquish and reject advance care planning: implications for practice. *Support Care Canc* 2013; **21**(21):2195–2205.
- Kiely BE, Tattersall MH, Stockler MR. Certain death in uncertain time: informing hope by quantifying a best case scenario. *J Clin Oncol* 2010; **28**:2802–2804.
- Peppercorn J, Smith T, Helft P *et al*. American Society of Clinical Oncology statement: toward individualised care for patients with advanced cancer. *J Clin Oncol* 2011; **29**:755–760.
- Michael N, O'Callaghan C, Baird A, Hiscock N, Clayton J. Cancer caregivers advocate a patient- and family-centered approach to advance care planning. *J Pain Symptom Manage* 2013; **47**(6):1064–1077.
- Scott I, Mitchell G, Reymond E, Daly M. Clinical focus: difficult but necessary conversations—the case for advance care planning. *Med J Aust* 2013; **199**(662–666):
- The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA* 1995; **274**(20):1591–1598.
- Danis M, Southerland L, Garrett J *et al*. A prospective study of advance directives for life-sustaining care. *New Engl J Med* 1991; **324**(13):882–888.
- Walling A, Lorenz KA, Dy SM *et al*. Evidence-based recommendations for information and care planning in cancer care. *J Clin Oncol* 2008; **26**(23):3896–3902.
- Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014; **28**(8):100–1025.
- Houttekier D, Cohen J, Cools F, Deliens L. Advance care planning for end-of-life care. *Cochrane Database Syst Rev* 2012; (2): Art. No.: CD009618. doi: 10.1002/14651858.CD009618
- Tieman J, Abernethy A, Fazekas B, Currow D. CareSearch: finding and evaluating Australia's missing palliative care literature. *BMC Palliat Care* 2005; **4**(1):4. PubMed PMID: doi: 10.1186/1472-684X-4-4.
- Laidsaar-Powell RC, Butow PN, Bu S *et al*. Physician–patient–companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns* 2013; **91**(1):3–13.
- Kmet L, Lee R, Cook L. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Alberta Heritage Foundation For Medical Research, 2004.
- Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977; **33**(1):159–174.
- Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008; **8**(1):45. doi: 10.1186/1471-2288-8-45
- Dow LA, Matsuyama RK, Ramakrishnan V *et al*. Paradoxes in advance care planning: the complex relationship of oncology patients, their physicians, and advance medical directives. *J Clin Oncol* 2010; **28**(2): 299–304.
- Duckworth KE, Forti AM, Russell GB, Naik S, Hurd D, McQuellon RP. The process of advance care planning in HCT candidates and proxies: self- efficacy, locus of control and anxiety levels. *Am J Hosp Palliat Med* 2014; **31**(7):710–716.
- Fu S, Barber F, Naing A *et al*. Advance care planning in patients with cancer referred to a phase I clinical trials program: the MD Anderson Cancer Center experience. *J Clin Oncol* 2012; **30**(23):2891–2896.
- Oorschot Bv, Schuler M, Simon A, Flentje M. Advance directives: prevalence and attitudes of cancer patients receiving radiotherapy. *Support Care Cancer* 2012; **20**(11):2729–2736.
- Zhou G, Stoltzfus JC, Houldin AD, Parks SM, Swan BA. Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advanced care planning for patients with cancer. *Oncol Nurs Forum* 2010; **37**(6):E400–E410.
- Lamont E, Siegler M. Paradoxes in cancer Patients' advance care planning. *J Palliat Med* 2000; **3**(1):27–35.
- Loberiza FR Jr, Swore-Fletcher BA, Block SD *et al*. Coping styles, health status and advance care planning in patients with hematologic malignancies. *Leuk Lymphoma* 2011; **52**(12):2342–2348.
- Barnes K, Barlow C, Harrington J *et al*. Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. *Palliat Support Care* 2011; **9**(1):73–79.
- Barnes K, Jones L, Tookman A, King M. Acceptability of advance care planning interview schedule: a focus group. *Palliat Med* 2007; **21**(1):23–28.
- Carrion I, Nedjat-Haiem F, Martinez-Tyson D, Castañeda H. Advance care planning among Colombian, Mexican, and Puerto Rican women with a cancer diagnosis. *Support Care Canc* 2013; **21**(5):1233–1239.
- Horne G, Seymour J, Payne S. Maintaining integrity in the face of death: a grounded theory to explain the perspectives of people affected by lung cancer about the expression of wishes for end of life care. *Int J Nurs Stud* 2012; **49**:718–726.
- Elliott J, Olver I. Perceptions of 'good palliative care' orders: a discursive study of cancer Patients' comments. *J Palliat Med* 2003; **6**(1):59–68. PubMed PMID: 2006-07156-009.

32. Hwang SS, Chang VT, Cogswell J, Srinivas S, Kasimis B. Knowledge and attitudes toward end-of-life care in veterans with symptomatic metastatic cancer. *Palliat Support Care* 2003;**1**(3):221–230. PubMed PMID: 16594422.
33. McKinley E, Garrett J, Evans A. Differences in end-of-life decision making among black and white ambulatory cancer patients. *J Gen Intern Med* 1996;**11**:651–656.
34. Barakat A, Barnes S, Casanova M, Stone M, Shuey K, Miller A. Advance care planning knowledge and documentation in hospitalised cancer population. *Baill Univ Med Cent Proc* 2013;**26**(4):368–372.
35. Sahn S, Will R, Hommel G. What are cancer patients' preferences about treatment at the end of life, and who should start talking about it? A comparison with healthy people and medical staff. *Support Care Canc* 2005; **13**(4):206–214.
36. Jezewski MA, Brown J, Wu YW, Meeker MA, Feng JY, Bu X. Oncology nurses' knowledge, attitudes, and experiences regarding advance directives. *Oncol Nurs Forum* 2005;**32**(2):319–327. PubMed PMID: 15759069.
37. Stearns L, Butler S, Hollander J. Patients' and families' receptivity to discussions about future healthcare: decisions and advance directives. *Community Oncol* 2005;**2**(5):446–451.
38. Horne G, Seymour J, Shepherd K. Advance care planning for patients with inoperable lung cancer. *Int J Palliat Nurs* 2006;**12**(4): 172–178.
39. Jezewski MA, Meeker MA, Schrader M. Voices of oncology nurses: what is needed to assist patients with advance directives. *Cancer Nurs* 2003;**26**(2):105–112.
40. De Vleminck A, Pardon K, Beernaert K et al. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. *PLoS One* 2014;**9**(1):e84905.
41. Almack K, Cox K, Seymour J, Moghaddam N, Porock D. Communication strategies to initiate conversations planning for end of life care (EOLC). *Palliat Med* 2010;**24**(4):S102.
42. Boyd K, Barclay S, Chinn D, Thomas K, Sheikh A. Advance care planning for cancer patients in primary care: a feasibility study. *Br J Gen Pract J R Coll Gen Pract* 2010; **60**(581):e449–e458.
43. Cherlin E, Fried T, Prigerson H, Schulman-Green D, Johnson-Hurzeler R, Bradley E. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? *J Palliat Med* 2005;**8**(6):1176–1185.
44. Samara J, Larkin D, Chan C, Lopez V. Advance care planning in the oncology settings. *Int J Evid Based Healthc* 2013;**11**(2):110–114.
45. Walczak A, Henselmans I, Tattersall MH, et al. A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. *Psycho-Oncology* 2015;**24**(3):287–293.
46. Cox K, Moghaddam N, Almack K, Pollock K, Seymour J. Is it recorded in the notes? Documentation of end-of-life care and preferred place to die discussions in the final weeks of life. *BMC Palliat Care* 2011;**10**(1):18. doi: 10.1186/1472-684x-10-18
47. Vogel RI, Petzel SV, Cragg J et al. Development and pilot of an advance care planning website for women with ovarian cancer: a randomized controlled trial. *Gynecol Oncol* 2013;**131**(2):430–436.
48. Miccinesi G, Bianchi E, Brunelli C, Borreani C. End-of-life preferences in advanced cancer patients willing to discuss issues surrounding their terminal condition. *Eur J Cancer Care* 2012;**21**(5):623–633. PubMed PMID: 2011638471. Language: English. Entry Date: 20120831. Revision Date: 20130913. Publication Type: journal article.
49. El-Sahwi KS, Illuzzi J, Varughese J et al. A survey of gynecologic oncologists regarding the end-of-life discussion: a pilot study. *Gynecol Oncol* 2012;**124**:471–473.
50. Keating NL, Landrum MB, Rogers S et al. Physician factors associated with discussion about end of life care. *Cancer* 2010;**116**(4): 998–1006.
51. Laryionava K, Heußner P, Hiddemann W, Winkler EC. Framework for timing of the discussion about forgoing cancer-specific treatment based on a qualitative study with oncologists. *Support Care Cancer* 2015; **23**(3):715–721.
52. Díaz-Montes TP, Johnson MK, Giuntoli RL, Brown AJ. Importance and timing of end-of-life care discussions among gynecologic oncology patients. *Am J Hosp Palliat Care Med* 2013;**30**(1):59–67. PubMed PMID: 2011805227. Language: English. Entry Date: 20130118. Revision Date: 20130118. Publication Type: journal article.
53. Jones L, Harrington J, Barlow CA et al. Advance care planning in advanced cancer: can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. *Palliat Support Care* 2011;**9**(1):3–13.
54. Hu W-Y, Huang C-H, Chiu T-Y, Hung S-H, Peng J-K, Chen C-Y. Factors that influence the participation of healthcare professionals in advance care planning for patients with terminal cancer: a nationwide survey in Taiwan. *Soc Sci Med* 2010;**70**(11):1701–1704. PubMed PMID: 2010-09012-009.
55. Johnstone M-J, Kanitsaki O. Ethics and advance care planning in a culturally diverse society. *J Transcult Nurs* 2009;**20**:406.
56. Seal M. Patient advocacy and advance care planning in the acute hospital setting. *Aust J Adv Nurs* 2007;**24**:29.
57. Mackenzie C. Relational autonomy, normative authority and perfectionism. *J Soc Philos* 2008;**39**:512–533.
58. Sherwin S. A relational approach to autonomy in health care. In *The Politics of Women's Health: Exploring Agency and Autonomy*, Sherwin S (ed.), Temple University Press: Philadelphia, 1998.
59. MacDonald C. Relational professional autonomy. *Camb Q Healthc Ethics* 2002;**11**: 282–289.
60. Auriemma C, Nguyen C, Bronheim R et al. Stability of end-of-life preferences: a systematic review of the evidence. *JAMA* 2014;**174**(7):1085–1092.