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# 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 critical interpretive synthesis 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 end-of-life 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.

**Key words:** Cancer, oncology, advance care planning, advance directive, end of life

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".<sup>[1]</sup> 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{Kiely, 2011 #3521}], 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 regards 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 care, further research is needed which focuses on the experiences of patients and their families when undertaking ACP.[13]

There have been no reviews which report on the views or experiences of stakeholders with regards 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, 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)” (see Table 1<sup>1</sup>).[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, grey 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 (SJ) 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 (SJ) 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 with a second author (PB). 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 a thematic content analysis was conducted. 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 two separate, manualised 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 4-8, summary of studies by theme. For further information on quality scoring, see Kmet et al.[17]

### Data synthesis

Thematic content analysis was used to organize and summarise the empirical evidence.[19]

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<sup>1</sup> All tables are located at the end of this document.

One author (SJ) developed textual descriptions, which were tabulated in the data extraction summary form. Two authors 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 dialogue to help introduce a range of perspectives.

## Results

The search strategy produced 2483 references. After deletion of duplicates and eligibility assessment, 40 studies were included (19 quantitative, 17 qualitative, 4 mixed methods)(see Figure 1). The included studies reported data from eight countries. This included the USA (19), UK (8), Europe (5), Australia (5), Taiwan (1) and one 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 3.

### 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 Table 3 for details of studies. Four studies examined the experiences and perceptions of caregivers only, a further 6 studies included caregivers in the participant groups.

Between 36% and 47% [27] [32] [30] [22] of people with cancer wanted to involve their family in decision making regarding their current or future healthcare. Some preferred to make decisions on their own [32] and some indicated that making their EOL treatment wishes clear with an 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 initiating conversations with their family, with some reporting particular difficulties arising when their expectations or fears differed from those of other family members [4]. But family can also act as a motivator for ACP [33], with patients who had signed an advance directive 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 with their family members, they generally approach it as a shared experience with loved ones.[21, 23, 27-30] [5] [3] [25] [20]

#### 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 6 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 advance directive 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.

## Theme 2: ACP may provoke fear and distress

Much of the literature on ACPs has focused on patient, caregiver and health professional views on ACP and on its implementation (see Table 3 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, 45] However, even amongst 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 getting on with life as usual. [28, 38] A proportion of participants in most studies experienced 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, 45, 46, 49-51] addressed this question. Only one study supported the introduction of ACP early in the course of a patients 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, 46, 49-52] 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 patients illness trajectory was also considered to allow patients to focus on living in the present by ‘carrying on as normal’ whilst 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, 45] 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 suggest 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.

## 2.2 Initiation of ACP discussions

Thirteen studies addressed initiation of ACP [27, 28, 34, 35, 39, 41, 42, 44, 45, 49, 50, 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 advance directives 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, 45, 51]

Physician preference for a diffusion of responsibility regarding EOL decision-making was expressed across several themes in the results. Whilst the reasoning behind this is understandable (in sensitivity to patients' readiness to discuss EOL topics) [24, 35, 41, 45, 51] 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, 32, 34, 40-42, 46-49, 51, 52]. These reveal enormous variability in the amount of information that patients and caregivers wish to hear in relation to EOL issues.[4, 43, 46] 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, 32, 34, 38, 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]

But 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 be discussed. While 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 – 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, 46, 50, 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.[46]

### 3. 2 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 healthcare.[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 healthcare 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. Advance directives were spoken of as prescriptive instructions from patients, which should be respected and upheld, by health professionals [36, 39] and caregivers.[36, 45] Health professionals admitted to having concerns regarding ACP in regard to caregivers' wishes or decision making conflicting with written directives [45], 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, 45]. 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".[45]

### Theme 4 Institutional culture is influential in ACP

Five studies examined the institutional culture surrounding ACP [36, 39, 40, 42, 45], 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, 45] "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.[45] 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, 45]

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



Six studies [2, 3, 5, 32, 36, 46, 50, 54] reported that patients' experience of healthcare 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, 32, 46]

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 end of life 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 preeminent 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, whereby rational agents can assert their control over their own healthcare 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 for 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; and 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, i.e. that while ACP is best regarded as a process of communication which incorporates goals, values and wishes, in practice ACP remains strongly linked to an advance directive framework. That is, the key aim of ACP programs within healthcare 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 which 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 United States (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 end-of-life 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 detail 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 end-of-life may misrepresent the way that ACP actually occurs in cancer care, 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

1. Romer AL, Hammes BJ. Communication, trust, and making choices: Advance care planning four years on. *Innovations in End-of-Life Care*. 2003;5(2).
2. Robinson CA. "Our best hope is a cure." Hope in the context of advance care planning. *Palliative & Supportive Care*. 2012;10(2):75-82. PubMed PMID: 2011582492. Language: English. Entry Date: 20120803. Revision Date: 20120907. Publication Type: journal article.
3. Robinson C, Carole A. Advance care planning: re-visioning our ethical approach. *Canadian Journal of Nursing Research*. 2011;43(2):18-37.
4. Fried TR, O'Leary JR. Using the Experiences of Bereaved Caregivers to Inform Patient- and Caregiver-centered Advance Care Planning. *Journal of General Internal Medicine* 2008;23(10):1602-7.
5. Michael N, C O'Callaghan, Clayton J, Pollard A, Stepanov N, Spruyt O, et al. Understanding how cancer patients actualise, relinquish and reject advance care planning: implications for practice. *Supportive Care Cancer* 2013;2013(21):2195–205.
6. Kiely BE, Tattersall MH, Stockler MR. Certain death in uncertain time: informing hope by quantifying a best case scenario. *Journal of Clinical Oncology*. 2010;28:2802-4.
7. Peppercorn J, Smith T, Helft P, al e. American Society of Clinical Oncology statement: toward individualised care for patients with advacned cancer. *Journal of Clinical Oncology*. 2011;29:755-60.

8. Michael N, O'Callaghan C, Baird A, Hiscock N, Clayton J. Cancer Caregivers Advocate a Patient- and Family-Centered Approach to Advance Care Planning. *Journal of Pain and Symptom Management*. 2013;47(6):1064-77.
9. Scott I, Mitchell G, Reymond E, M. D. Clinical focus: Difficult but necessary conversations — the case for advance care planning. *Medical Journal of Australia*. 2013;199(662-666).
10. 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):1591-8.
11. Danis M, Southerland L, Garrett J, Smith J, Hielema F, Pickard CG, et al. A prospective study of advance directives for life-sustaining care. *New England Journal of Medicine*. 1991;324(13):882-8.
12. Walling A, Lorenz KA, Dy SM, Naeim A, Sanati H, Asch SM, et al. Evidence-Based Recommendations for Information and Care Planning in Cancer Care . *Journal of Clinical Oncology*. 2008;26(23).
13. Brinkman-Stoppelenburg A, Rietjens JA, Heide Avd. The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*. 2014;28(8):100-1025.
14. Houttekier D, Cohen J, Cools F, Deliens L. Advance care planning for end-of-life care. *Cochrane Database of Systematic Reviews* 2012;2(2).
15. Tieman J, Abernethy A, Fazekas B, Currow D. CareSearch: finding and evaluating Australia's missing palliative care literature. *BMC Palliative Care*. 2005;4(1):4. PubMed PMID: doi:10.1186/1472-684X-4-4.
16. Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, et al. Physician–patient–companion communication and decision-making: A systematic review of triadic medical consultations. *Patient Education and Counseling*. 2013 4//;91(1):3-13.
17. 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.
18. Landis J, Koch G. The measurement of observer agreement for categorical data. *Biometrics*. 1977;33(159-74).
19. Thomas J, A H. Methods for the thematic synthesis of qualitative research in systematic reviews. . *BMC Medical Research Methodology*. 2008;8(45).
20. Dow LA, Matsuyama RK, Ramakrishnan V, L K, EB L, L L, et al. Paradoxes in advance care planning: the complex relationship of oncology patients, their physicians, and advance medical directives. *Journal of Clinical Oncology*. 2010;28(2):299-304.
21. Duckworth K, Forti AM, Russell G, Naik S, Hurd D, McQuellon R. The process of Advance Care Planning in HCT candidates and proxies: self- efficacy, locus of control and anxiety levels. *American Journal of Palliative Care*. 2013;Epub ahead of print.
22. Fu S, Barber F, Naing A, Wheler J, Hong D, Falchook G, et al. Advance care planning in patients with cancer referred to a phase I clinical trials program: the MD Anderson Cancer Center experience. *Journal of Clinical Oncology*. 2012;30(23):2891-6.

23. Oorschot Bv, Schuler M, Simon A, Flentje M. Advance directives: prevalence and attitudes of cancer patients receiving radiotherapy. *Supportive Care in Cancer*. 2012;20(11):2729-36.
24. 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. *Oncology Nursing Forum*. 2010;37(6):E400-10.
25. Lamont E, Siegler M. Paradoxes in Cancer Patients' Advance Care Planning. *Journal of Palliative Medicine*. 2000;3(1):27-35.
26. Loberiza Jr FR, Swore-Fletcher BA, Block SD, Back AL, Goldman RE, Tulsy JA, et al. Coping styles, health status and advance care planning in patients with hematologic malignancies. *Leukemia and Lymphoma*. 2011;52(12):2342-8.
27. Barnes K, Barlow C, Harrington J, Ornelas K, Tookman A, King M, et al. Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. *Palliative & Supportive Care*. 2011;9(1):73-9.
28. Barnes k, Jones L, Tookman A, King M. Acceptability of advance care planning interview schedule: a focus group. *Palliative Medicine*. 2007 January 1, 2007;21(1):23-8.
29. Carrion I, Nedjat-Haiem F, Martinez-Tyson D, Castañeda H. Advance care planning among Colombian, Mexican, and Puerto Rican women with a cancer diagnosis. *Supportive Care Cancer*. 2013;21(5):1233-9.
30. 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. *International Journal of Nursing Studies*. 2012;49:718-26.
31. Elliott J, Olver I. Perceptions of "Good Palliative Care" Orders: A Discursive Study of Cancer Patients' Comments. *Journal of Palliative Medicine*. 2003 Feb;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. *Palliative & Supportive Care*. 2003;1(3):221-30. PubMed PMID: 16594422.
33. McKinley E, Garrett J, Evans A. Differences in end-of-life decision making among black and white ambulatory cancer patients. . *Journal of General Internal Medicine*. 1996;11:651-6.
34. Barakat A, Barnes S, Casanova M, Stone M, Shuey K, Miller A. Advance care planning knowledge and documentation in hospitalised cancer population. *Baylor University Medical Center Proceedings*. 2013;26(4):368-72.
35. Sahm 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. . *Supportive Care Cancer*. 2005;13(4):206-14.
36. Jezewski MA, Brown J, Wu YW, Meeker MA, Feng JY, Bu X. Oncology nurses' knowledge, attitudes, and experiences regarding advance directives. *Oncology Nursing Forum*. 2005;32(2):319-27. PubMed PMID: 15759069.
37. Stearns L, Butler S, Hollander J. Patients' and families' receptivity to discussions about future healthcare: Decisions and advance directives. *Community Oncology*. 2005;2(5):446-51.

38. Horne G, Seymour J, Shepherd K. Advance care planning for patients with inoperable lung cancer. *International Journal of Palliative Nursing*. 2006 April;12(4):172-8.
39. Jezewski MA, Meeker MA, Schrader M. Voices of Oncology Nurses: What Is Needed to Assist Patients With Advance Directives. *Cancer Nursing*. 2003;26(2):105-12.
40. Vleminck AD, Pardon K, Beernaert K, Deschepper R, Houttekier D, Audenhove CV, 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).
41. Almack K, Cox K, Seymour J, Moghaddam N, Porock D. Communication strategies to initiate conversations planning for end of life care (EOLC). *Palliative Medicine*. 2010;24(4):S102.
42. Boyd K, Stephen Barclay, Chinn D, Thomas K, Sheikh A. Advance care planning for cancer patients in primary care: a feasibility study. *The British journal of general practice : the journal of the Royal College of General Practitioners*. 2010;60(581):e449-58.
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? *Journal of Palliative Medicine*. 2005;8(6):1176-85.
44. Samara J, Larkin D, Chan C, Lopez V. Advance care planning in the oncology settings. *International Journal of Evidence-Based Healthcare*. 2013;11(2):110-4.
45. 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 Palliative Care* 2011;10(18).
46. Walczak A, Henselmans I, Tattersall MHN, Clayton JM, Davidson PM, Young J, 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*. 2014.
47. Vogel RI, Petzel SV, Cragg J, McClellan M, Chan D, Dickson E, et al. Development and pilot of an advance care planning website for women with ovarian cancer: A randomized controlled trial. *Gynecologic Oncology*. 2013;131(2):430-6.
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. *European Journal of Cancer Care*. 2012;21(5):623-33. PubMed PMID: 2011638471. Language: English. Entry Date: 20120831. Revision Date: 20130913. Publication Type: journal article.
49. El-Sahwi KS, Illuzzi J, Varughese J, Carusillo N, Ratner ES, Silasi D-A, et al. A survey of gynecologic oncologists regarding the End-of-Life discussion: A pilot study. *Gynecologic Oncology*. 2012;124:471-3.
50. Keating NL, Landrum MB, Rogers S, Baum SK, Virnig BA, Huskamp HA, 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. *Supportive Care in Cancer*. 2014.
52. Díaz-Montes TP, Johnson MK, Giuntoli RL, Brown AJ. Importance and Timing of End-of-Life Care Discussions Among Gynecologic Oncology Patients. *American Journal of*

Hospice & Palliative Medicine. 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, Tookman A, Drake R, Barnes K, et al. Advance care planning in advanced cancer: can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. *Palliative & Supportive 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. *Social Science & Medicine*. 2010 Jun;70(11):1701-4. PubMed PMID: 2010-09012-009.
55. Johnstone M-J, Kanitsaki O. Ethics and Advance Care Planning in a Culturally Diverse Society. *Journal of Transcultural Nursing*. 2009;20:406.
56. Seal M. Patient advocacy and advance care planning in the acute hospital setting. *Australian Journal of Advanced Nursing*. 2007;24:29.
57. Mackenzie C. Relational Autonomy, Normative Authority and Perfectionism. *Journal of Social Philosophy*. 2008;39:512-33.
58. Sherwin S. A relational approach to autonomy in health care. In: Sherwin S, ed. *The Politics of Women's Health: Exploring Agency and Autonomy*. Philadelphia: Temple University Press; 1998.
59. MacDonald C. Relational Professional Autonomy. *Cambridge Quarterly of Healthcare Ethics*. 2002;11:282-9.
60. Auriemma C, Nguyen C, Bronheim R, et al. Stability of End-of-Life Preferences: A Systematic Review of the Evidence. *Journal of the American Medical Association*. 2014;174(7):1085-92.

Table 1. Search Terms

<b>Cancer terms</b>	<b>ACP terms</b>
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	



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:* 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 utilising: 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, was included. Studies focusing on children (<18 years) and people with mental illness other than dementia were excluded.

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

**Table 4. ACP is relational (Studies ordered by Quality Rating)**

Authors				
Year	Quality Rating	Methodology and data collection method	Sample & Setting	Results Summary
Country				
Quantitative Studies				
Duckworth, K et al. <sup>1</sup> 2013 USA	95%	Cross-sectional study <b>Method:</b> Questionnaire	<b>Sample:</b> 49 HCT (Hematopoietic Cell Transplant) candidates and 44 proxies <b>Response rate:</b> Not reported <b>Setting:</b> 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 AD's.
Loberiza F et al. <sup>2</sup> 2007 USA	95%	Prospective observational study <b>Method:</b> Self-administered survey and an interview prior to consultations with a physician. Repeat interview at 1 week and 3 months.	<b>Sample:</b> 364 people with hematological malignancy <b>Response rate:</b> 47% (364 of 770) <b>Setting:</b> 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, B. et al. <sup>3</sup> 2012 Germany	95%	Cross-sectional study <b>Method:</b> Written, standardized questionnaire	<b>Sample:</b> 589 completely evaluated questionnaires <b>Response rate:</b> 48.7% (589 of 1,208) <b>Setting:</b> Tumor patients older undergoing radiation therapy	Half of the participants wanted their close family members to participate in the decision-making process.
Zhou, G et al. <sup>4</sup> 2010 USA	95%	Descriptive cross-sectional pilot survey study <b>Methods:</b> Survey distributed to 300 Advance practice Nurses (APNs) via e-mail and sent again to the 89 APNs who responded to the initial survey.	<b>Sample:</b> 89 oncology APNs responded to the initial survey, and 53 of the 89 respondents returned the retest survey <b>Response rate:</b> 30% (90 of 300). <b>Setting:</b> 300 oncology APNs from one authors professional networks	Family and physician attitude ranked highly as perceived barriers to ACP.
Barakat, A et al. <sup>5</sup> 2013 USA	90%	Cross-sectional survey <b>Method:</b> A printed questionnaire returned in sealed envelope.	<b>Sample:</b> 68 completed surveys <b>Response rate:</b> 68% (68 of 100) <b>Setting:</b> 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 et al. <sup>6</sup> 2010 USA	86%	Cross-sectional survey <b>Method:</b> Semi structured interviews and questionnaires	<b>Sample:</b> 75 completed interviews <b>Response rate:</b> 88% (75 of 85) <b>Setting:</b> 117 Patients with cancer consecutively admitted to the hematology-oncology in-patient service at an urban academic medical center.	Most patients had discussed their AD with their family.
Díaz-Montes et al. <sup>7</sup> 2013 USA	0.85%	Cross-sectional survey <b>Method:</b> Written questionnaires	<b>Sample:</b> 122 completed questionnaires <b>Response rate:</b> Not reported <b>Setting:</b> 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  Amongst the 9 important factors in decision-making determined by the authors, family preference was ranked 6 <sup>th</sup> .

**Table 4. (Continued)**

<b>Authors</b>				
<b>Year</b>	<b>Quality Rating</b>	<b>Methodology and data collection method</b>	<b>Sample &amp; Setting</b>	<b>Results Summary</b>
<b>Country</b>				
Lamont, E.; Siegler, M. <sup>8</sup> 2000 USA	82%	Cross - sectional survey <b>Method:</b> Face to face structured interviews using a verbally administered questionnaire.	<b>Sample:</b> 111 completed questionnaires <b>Response rate:</b> 87% (111 of 128) <b>Setting:</b> 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 et al. <sup>9</sup> 2012 USA	77%	Cross- sectional survey <b>Method:</b> Written survey	<b>Sample:</b> 215 completed or partially completed questionnaires <b>Response rate:</b> 49% (215 of 435) <b>Setting:</b> 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.
Hwang, S et al. <sup>10</sup> 2003 USA	0.77%	Cross sectional survey <b>Method:</b> Written Questionnaire	<b>Sample:</b> 254 veterans with symptomatic cancer <b>Response rate:</b> 86% (254 of 296 surveys) <b>Setting:</b> veterans seen at the inpatient/outpatient clinic in a hematology tertiary referral center.	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.
Jezewski M. et al. <sup>11</sup> 2005 USA	77%	Descriptive, correlation survey <b>Method:</b> Mailed survey	<b>Sample:</b> 794 usable surveys <b>Response rate:</b> 23% (883 of 3840) <b>Setting:</b> A stratified random sample of 4,000 Oncology Nursing Society members	77% of nurses agreed that nurses should be actively involved in helping patients complete ADs.
Sahm, S., Will R, Hommel, G <sup>12</sup> 2005 Germany	73%	Cross - sectional survey <b>Method:</b> Interview with verbally administered questionnaire	<b>Sample:</b> 100 cancer patients, 100 healthy controls, 100 nursing staff, and 100 physicians <b>Response rate:</b> Estimated 40% <b>Setting:</b> 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.
Stearns L, Butler S, Hollander J <sup>13</sup> 2005 USA	59%	Longitudinal study <b>Method:</b> 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.	<b>Sample:</b> 123 consecutive patients <b>Response rate:</b> 33% (33 of 123) <b>Setting:</b> 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.
<b>Qualitative Studies</b>				
Barnes, Barlow & Harrington <sup>14</sup> 2011 UK	90%	Exploratory patient preference randomized controlled trial <b>Method:</b> Semi structured interview as part of an ACP intervention	<b>Sample:</b> 40 patients with recurrent progressive cancer. Fifty-two interviews. <b>Response rate:</b> Not reported <b>Setting:</b> 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 that family members may find it difficult to cope.

**Table 4. (Continued)**

Authors				
Year	Quality Rating	Methodology and data collection method	Sample & Setting	Results Summary
Country				
Fried T & O'Leary JR <sup>15</sup> 2008 USA	90%	Qualitative Thematic analysis <b>Method:</b> Semi structured interview	<b>Sample:</b> Caregivers of community- dwelling patients who were age 60 years or older who died with advanced cancer (52%), chronic obstructive pulmonary disease (27%), or Heart Failure (21%). <b>Response rate:</b> Not reported <b>Setting:</b> 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.
Michael et al. <sup>16</sup> 2013 Australia	90%	Qualitative grounded theory study <b>Method:</b> Caregivers first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique	<b>Sample:</b> 18 patients with cancer <b>Response rate:</b> 62% (26 of 29) <b>Setting:</b> Patients at the lung and gastro-intestinal tumour 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 favoured 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 whilst others did not want to 'dictate from the grave'.
Michael et al 2013 <sup>17</sup> Australia	90%	Qualitative descriptive design with grounded theory overtones <b>Method:</b> Focus groups, semi structured interviews, which incorporated the vignette technique	<b>Sample:</b> Eighteen caregivers of patients with lung and gastrointestinal cancer <b>Response rate:</b> 43% (18 of 42) <b>Setting:</b> Participants were recruited as part of a pilot ACP implementation and research program in a large tertiary cancer centre.	Caregivers were noted to have primary and secondary caregiving roles and decision-making styles varied in the caregiver, patient and family groups.
Almack K et al. <sup>18</sup> 2010 UK	85%	Exploratory qualitative case study <b>Method:</b> Interviews and group interviews	<b>Sample:</b> 18 interviews and 6 follow up interviews with patients with cancer, HF and dementia as well as family/friends. 5 group interviews with 15 healthcare professionals. <b>Response rate:</b> Not reported <b>Setting:</b> GP practice and various hospital and community based care services	HCP's reported that developing rapport with patients and family over time meant they felt able to open up discussions about ACP.
Carrion I et al. <sup>19</sup> 2013 USA	85%	Qualitative grounded theory study <b>Method:</b> In depth open semi-structured interview	<b>Sample:</b> 45 Latina (15 Columbian, 15 Mexican and 15 Puerto Rican) women diagnosed with cancer <b>Response rate:</b> Not reported <b>Setting:</b> Spanish-speaking women recruited from community health clinics, churches, cultural centres, and cancer support groups.	Latina women express a preference for a shared approach (with family and HCP's) to decision making.
Elliot J & Olver I <sup>20</sup> 2003 Australia	85%	Qualitative discourse analysis <b>Method:</b> Semi structured interview	<b>Sample:</b> 23 consecutive patients with cancer who were unlikely to die in the near future <b>Response rate:</b> Not reported <b>Setting:</b> 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 <sup>21</sup> 2006 UK	85%	Qualitative grounded theory study <b>Method:</b> Patients participated in an ACP discussion with a trained lung cancer nurse and then completed structured interviews	<b>Sample:</b> 15 patients with inoperable lung cancer and their family members (9 patients, 6 family members) <b>Response rate:</b> Not reported <b>Setting:</b> 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 HCP's.

**Table 4. (Continued)**

Authors				
Year	Quality Rating	Methodology and data collection method	Sample & Setting	Results Summary
<b>Country</b>				
Horne G, Seymour J & Payne S <sup>22</sup> 2012 UK	85%	Qualitative grounded theory study <b>Method:</b> Semi-structured interviews and focus groups	<b>Sample:</b> 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews) and two family focus groups were conducted. <b>Setting:</b> A specialist local cancer centre	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 et al <sup>23</sup> 2010 UK	80%	Mixed method study - Cross sectional analysis of a pilot educational intervention <b>Method:</b> Semi- structured interviews after a practice-based workshop; followed by telephone interviews with 9 others	<b>Sample:</b> 20 GPs and 8 community nurses <b>Response rate:</b> Not reported <b>Setting:</b> Staff at 4 General Practices	Healthcare professionals 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 <sup>24</sup> 2007 UK	75%	Qualitative focus group <b>Method:</b> Interview	<b>Sample:</b> 22 palliative care (18%) and oncology patients (82%). <b>Response rate:</b> 59% (22 of 37) <b>Setting:</b> 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.
Robinson CA & Carole A <sup>26</sup> 2011 Canada	55%	Prospective qualitative design <b>Method:</b> Semi structured interview	<b>Sample:</b> 18 participants comprised of patients diagnosed with advanced lung cancer and their significant other or loved one <b>Response rate:</b> Not reported <b>Setting:</b> 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 <sup>25</sup> 2003 USA	45%	Qualitative thematic analysis <b>Method:</b> Open ended question at the end of a quantitative survey	<b>Sample:</b> 900 oncology nurses <b>Response rate:</b> 23% (900 of 3840) <b>Setting:</b> Oncology nurses from four states	Participants placed a great deal of importance on the development of communication skills so that could be of help to patients. It was clear from their responses that they believed more time was needed to increase their ability to assist patients with ADs. Nurses who provided an explanation referred to the need for more time to spend establishing relationships (rapport) with patients and their families.
<b>Mixed Methods Studies</b>				
Cherlin E et al <sup>27</sup> 2005 USA	QN 73% QL 75%	Mixed methods study <b>Method:</b> Quantitative survey and additional in-depth interview with 12 family caregivers	<b>Sample:</b> 12 primary family caregivers of people with cancer whose loved ones were enrolled in hospice <b>Response rate:</b> Not reported <b>Setting:</b> 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 <sup>28</sup> 1996 USA	QN 68% QL 30%	Mixed methods study - Quantitative survey and open-ended questions for qualitative analysis. <b>Method:</b> In-person interviews	<b>Sample:</b> 206 (92 black patients and 114 white patients) completed patient interviews <b>Response rate:</b> 76% (206 of 270) <b>Setting:</b> 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.

**Table 4. (Continued)**

<b>Authors</b>				
<b>Year</b>	<b>Quality Rating</b>	<b>Methodology and data collection method</b>	<b>Sample &amp; Setting</b>	<b>Results Summary</b>
<b>Country</b>				
Samara J, et al. <sup>29</sup>	QN 45% QL 55%	Mixed methods study - Cross sectional qualitative plus Pre- and post-implementation audit	<b>Sample:</b> 25 nurses <b>Response rate:</b> Not reported <b>Setting:</b> 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.
2013				
Australia		<b>Method:</b> Focus group plus delivery of a an education programme on ACP either in face to face sessions or via an e-learning package plus pre and post session written questionnaires.		

*Note:* Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Number from quantitative [QN] and qualitative [QL] studies quality rating)

**Table 5. ACP provokes fear and distress (Studies ordered by Quality Rating)**

Authors				
Year	Quality Rating	Methodology and data collection methods	Sample & Setting	Summary
Country				
<b>Quantitative Studies</b>				
Duckworth, K et al. <sup>1</sup> 2013 USA	95%	Cross-sectional study <b>Method:</b> Questionnaire	<b>Sample:</b> 49 HCT (Hematopoietic Cell Transplant) candidates and 44 proxies <b>Response rate:</b> Not reported <b>Setting:</b> 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 AD's.  Patients who completed an AD were more likely to have a positive attitude towards AD's
Keating et al. <sup>30</sup> 2009 USA	95%	Cross-sectional study <b>Method:</b> Survey	<b>Sample:</b> 4074 physician survey responses. <b>Response rate:</b> 61% (4188 of 6871 physicians whose contact information was verified) <b>Setting:</b> Physicians identified by patients participating in the CanCORS baseline interview as filling 1 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 months to 6 months to live and were feeling well.
Oorschot, B et al. <sup>3</sup> 2012 Germany	95%	Cross-sectional study <b>Method:</b> Written, standardized questionnaire	<b>Sample:</b> 589 completely evaluated questionnaires <b>Response rate:</b> 48.7% (589 of 1,208) <b>Setting:</b> Tumor patients older undergoing radiation therapy	One third of respondents agreed that AD s could be of little significance.
Zhou, G et al. <sup>4</sup> 2010 USA	95%	Descriptive cross sectional pilot survey study <b>Methods:</b> Survey distributed to 300 Advance practice Nurses (APNs) via e-mail and sent again to the 89 APNs who responded to the initial survey.	<b>Sample:</b> 89 oncology APNs responded to the initial survey, and 53 of the 89 respondents returned the retest survey <b>Response rate:</b> 30% (90 of 300). <b>Setting:</b> 300 oncology APNs from one authors 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 et al. <sup>31</sup> 2012 Italy	95%	Cross-sectional study <b>Method:</b> Semi structured interview questionnaire administered by physicians with a good clinical relationship with the patient	<b>Sample:</b> 88 completed patient interviews <b>Response rate:</b> 56% (88 of 156) <b>Setting:</b> 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 et al. <sup>5</sup> 2013 USA	90%	Cross sectional study <b>Method:</b> A printed questionnaire returned in sealed envelope.	<b>Sample:</b> 68 completed surveys <b>Response rate:</b> 68% (68 of 100) <b>Setting:</b> 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 et al. <sup>32</sup> 2013 USA	88%	Randomised control trial. <b>Method:</b> 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 advance directive.	<b>Sample:</b> 35 women with ovarian cancer and their informal carers <b>Response rate:</b> not reported <b>Setting:</b> A gynaecological 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 advance directive.



**Table 5. (Continued)**

Year	Quality Rating	Methodology and data collection methods	Sample & Setting	Summary
2010	86%	Cross-sectional study <b>Method:</b> Semi structured interviews and questionnaires	<b>Sample:</b> 75 completed interviews <b>Response rate:</b> 88% (75 of 85) <b>Setting:</b> 117 Patients with cancer consecutively admitted to the hematology-oncology in-patient service at an urban academic medical center.	Nearly all participants (87%) think it is important to have discussions about AD's and support a policy in which they are offered as part of the hospital admission process.  Only 23% would like to discuss ADs with their medical oncologist, but paradoxically when asked directly who they would prefer to discuss ADs with, 48% chose their oncologist.
2013	0.85%	Cross-sectional study <b>Method:</b> Written questionnaires	<b>Sample:</b> 122 completed questionnaires <b>Response rate:</b> Not reported <b>Setting:</b> 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 EOLC addressed.  Most patients responded that the most appropriate time to address EOLC was when treatment is no longer an option (41.8%).
2011	85%	Exploratory randomized patient preference trial <b>Method:</b> Written questionnaire	<b>Sample:</b> 77 participants with advanced cancer. <b>Response rate:</b> 88% (68 of 77) <b>Setting:</b> Patients who had completed a primary course of treatment for cancer, but still had clinically detectable, active, progressive disease.	51% of patients thought ACP were desirable, a minority wished to avoid ACP and some showed no preference.
2000	82%	Cross-sectional study <b>Method:</b> Face to face structured interviews using a verbally administered questionnaire.	<b>Sample:</b> 111 completed questionnaires <b>Response rate:</b> 87% (111 of 128) <b>Setting:</b> Cancer patients admitted to the University of Chicago Hematology-Oncology inpatient service	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.
2012	77%	Cross-sectional study <b>Method:</b> Written survey	<b>Sample:</b> 215 completed or partially completed questionnaires <b>Response rate:</b> 49% (215 of 435) <b>Setting:</b> Patients with advanced cancer being considered for enrollment onto an early-phase clinical trial.	73% of patients reported that ACP had been addressed and 69% believed they could beat their cancer.  Patients supported ACP in all settings but favoured initiation of ACP discussions in locations outside of critical/emergency care settings.
2003	77%	Cross-sectional study <b>Method:</b> Written Questionnaire	<b>Sample:</b> 254 veterans with symptomatic cancer <b>Response rate:</b> 86% (254 of 296 surveys) <b>Setting:</b> veterans seen at the inpatient/outpatient clinic in a hematology tertiary referral center.	86.2% of patients wanted physicians to be frank when delivering bad news.
2005	73%	Cross-sectional study <b>Method:</b> Interview with verbally administered questionnaire	<b>Sample:</b> 100 cancer patients, 100 healthy controls, 100 nursing staff, and 100 physicians <b>Response rate:</b> Estimated 40% <b>Setting:</b> 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.	The option that physicians should broach the subject of advance directives 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 advance directives 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. They would much rather delegate this initiative to other people, usually to the patient's relatives.
	60%	Cross-sectional study <b>Method:</b> Pilot survey sent via the website Survey	<b>Sample:</b> 142 physician responses. <b>Response rate:</b> 12.8% (142 out of 1105)	Physicians perceived that patients reach understanding regarding EOL discussion over several conversations.

**Table 5. (Continued)**

Authors				
Year	Quality Rating	Methodology and data collection methods	Sample & Setting	Summary
Country				
2011		Monkey	<b>Setting:</b> Surveys were e-mailed to members of the Society of Gynaecologic Oncology (SGO).	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.
USA				
Stearns L, Butler S, Hollander J. <sup>13</sup>	59%	Longitudinal study <b>Method:</b> 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.	<b>Sample:</b> 123 consecutive patients <b>Response rate:</b> 33% (33 of 123) <b>Setting:</b> Patients attending routine clinic visits	Fifty-two 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.
2005				
USA				
Qualitative Studies				
Barnes k, Jones L, Tookman A, King, M <sup>14</sup>	90%	Exploratory patient preference randomized controlled trial <b>Method:</b> Semi structured interview as part of an ACP intervention	<b>Sample:</b> 40 patients with recurrent progressive cancer. Fifty-two interviews. <b>Response rate:</b> Not reported <b>Setting:</b> 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.
2011				
UK				
Fried T & O'Leary JR <sup>15</sup>	90%	Qualitative thematic analysis <b>Method:</b> Semi structured interview	<b>Sample:</b> Caregivers of community- dwelling patients who were age 60 years or older who died with advanced cancer (52%), chronic obstructive pulmonary disease (27%), or Heart Failure (21%). <b>Response rate;</b> Not reported <b>Setting:</b> 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 end of life.
2008				
USA				
Michael et al. <sup>16</sup>	90%	Qualitative grounded theory study <b>Method:</b> Caregivers first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique	<b>Sample:</b> 18 patients with cancer <b>Response rate:</b> 62% (26 of 29) <b>Setting:</b> Patients at the lung and gastro-intestinal tumour 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.
2013				
Australia				
Michael et al <sup>17</sup>	90%	Qualitative descriptive design with grounded theory overtones <b>Method:</b> Focus groups, semi structured interviews, which incorporated the vignette technique	<b>Sample:</b> Eighteen caregivers of patients with lung and gastrointestinal cancer <b>Response rate:</b> 43% (18 of 42) <b>Setting:</b> Participants were recruited as part of a pilot ACP implementation and research program in a large tertiary cancer centre.	Participants felt that it 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.
2013				
Australia				
Walczak, A et al. <sup>35</sup>	90%	Qualitative thematic content analysis of audiotaped communication support program intervention as part of a randomised control trial. <b>Method:</b> Participants participated 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. <b>Setting:</b> Six treatment centres in Sydney, Australia	Information needs and preferences for timing of EOL discussions varied. Participants explicitly acknowledged physician discomfort as a barrier to discussing EOL.
2014				
Australia				

**Table 5. (Continued)**

Authors	Quality Rating	Methodology and data collection methods	Sample & Setting	Summary
Vleminck A D et al. <sup>36</sup> 2013 Belgium	90%	Exploratory qualitative design <b>Method:</b> focus group	<b>Sample:</b> 36 GPs <b>Setting:</b> 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 of ACP over cancer patients.
Almack K et al. <sup>18</sup> 2010 UK	85%	Exploratory qualitative case study <b>Method:</b> Interviews and group interviews	<b>Sample:</b> 18 interviews and 6 follow up interviews with patients with cancer, HF and dementia as well as family/friends. 5 group interviews with 15 healthcare professionals. <b>Response rate:</b> Not reported <b>Setting:</b> GP practice and various hospital and community based care services	HCPs tended to rely on patients to explicitly raise issues for discussion rather than initiate these them. At the same time they were alert to cues from the patient or guided by intuition as to when to introduce issues around EOLC, what depth to go into and so on. HCP's 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. <sup>19</sup> 2013 USA	85%	Qualitative grounded theory study <b>Method:</b> In depth open semi-structured interview	<b>Sample:</b> 45 Latina (15 Columbian, 15 Mexican and 15 Puerto Rican) women diagnosed with cancer <b>Response rate:</b> Not reported <b>Setting:</b> Spanish-speaking women recruited from community health clinics, churches, cultural centres, 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 <sup>20</sup> 2003 Australia	85%	Discourse analysis <b>Method:</b> Semi structured interview	<b>Sample:</b> 23 consecutive patients with cancer who were unlikely to die in the near future <b>Response rate:</b> Not reported <b>Setting:</b> Oncology clinic outpatient department	For some GPC 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 end-of-life care might alter in response to different circumstances.
Horne G, Seymour J & Shepherd K <sup>21</sup> 2006 UK	85%	Qualitative grounded theory study <b>Method:</b> Patients participated in an ACP discussion with a trained lung cancer nurse and then completed structured interviews	<b>Sample:</b> 15 patients with inoperable lung cancer and their family members (9 patients, 6 family members) <b>Response rate:</b> Not reported <b>Setting:</b> 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".
Horne G, Seymour J & Payne S <sup>22</sup> 2012 UK	85%	Qualitative grounded theory study <b>Method:</b> Semi-structured interviews and focus groups	<b>Sample:</b> 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews) and two family focus groups were conducted. <b>Setting:</b> A specialist local cancer centre	People preferred to focus on living in the present by 'carrying on as normal' whilst 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 'mind 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.
Laryionava K et al. <sup>37</sup> 2014 Germany	85%	Qualitative grounded theory study <b>Method:</b> Semi structured in depth interviews	<b>Sample:</b> Theoretical sampling of 29 physicians and nurses <b>Response rate:</b> not reported <b>Setting:</b> Department of Haematology and Oncology at a German university hospital	Health-care 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 him/herself starts the discussion about forgoing cancer specific treatment, and (3) waiting until all tumour 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..

**Table 5. (Continued)**

Boyd K et al <sup>23</sup>	80%	Mixed method study - cross sectional analysis of a pilot educational intervention <b>Method:</b> Semi- structured interviews after a practice-based workshop; followed by telephone interviews with 9 others	<b>Sample:</b> 20 GPs and 8 community nurses <b>Response rate:</b> Not reported <b>Setting:</b> Staff at 4 General Practices	Formal advance care planning 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".
2011				
UK				
Barnes, Jones, Tookman & King <sup>24</sup>	75%	Qualitative study <b>Method:</b> Focus group	<b>Sample:</b> 22 palliative care (18%) and oncology patients (82%). <b>Response rate:</b> 59% (22 of 37) <b>Setting:</b> 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.
2007				
UK				Patients reported that HCPs should invite patients to have EOL discussions if appropriate.
Robinson CA & Carole A <sup>26</sup>	55%	Prospective qualitative design <b>Method:</b> Semi structured interview	<b>Sample:</b> 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) <b>Setting:</b> Patients diagnosed with advanced lung cancer and their significant other or loved ones, recruited from within 1.5 hours 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.
2011				
Canada				
Jezewski M, Meeker MA & Schrader, M <sup>25</sup>	45%	Qualitative <b>Method:</b> Open ended question at the end of a quantitative survey	<b>Sample:</b> 900 oncology nurses <b>Response rate:</b> 23% (900 of 3840) <b>Setting:</b> 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."
2003				
USA				
<b>Mixed Methods Studies</b>				
Cox K et al. <sup>38</sup>	QN 91% QL 75%	Mixed methods study – cross sectional <b>Method:</b> Audit of case notes on a sample of deaths and complementary group interviews with healthcare professionals.	<b>Sample:</b> 13 HCP's (GP, 2 District Nurses, Practice Manager, 2 Community Matrons, 2 Macmillan Nurses, Specialist Palliative Care Team Manager, Nursing Home Manager, Care Co-coordinator and 2 Registered Nurses). <b>Setting:</b> Four study sites were selected from across a Regional Cancer Network (Hospitals and GP practices)	HCP's preferred an individual approach to the Initiation of ACP discussions of ACP, based on patient readiness, disease stage and waiting for patient to give them cues.
2011				
UK				
Cherlin E et al <sup>27</sup>	QN 73% QL 75%	Mixed methods study – cross sectional <b>Method:</b> Quantitative survey and additional in-depth interview with 12 family caregivers	<b>Sample:</b> 12 primary family caregivers of people with cancer whose loved ones were enrolled in hospice <b>Response rate:</b> Not reported <b>Setting:</b> Hospice	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.
2005				
USA				
McKinley E, Garrett J & Evans A. <sup>28</sup>	QN 68% QL 30%	Mixed methods study - cross- Sectional quantitative survey and open-ended questions for qualitative analysis. <b>Method:</b> In-person interviews	<b>Sample:</b> 206 (92 black patients and 114 white patients) completed patient interviews <b>Response rate:</b> 76% (206 of 270) <b>Setting:</b> Ambulatory cancer patients from medical oncology clinics	A small number of mostly black patients did feel that a living will would 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)
1996				
USA				
Samara J et al. <sup>29</sup>	QN 45% QL 55%	Mixed methods study - qualitative plus Pre- and post-implementation audit <b>Method:</b> Focus group plus delivery of a an education programme on ACP either in face to face sessions or via an e-learning package plus pre and post session written questionnaires.	<b>Sample:</b> 25 nurses <b>Response rate:</b> Not reported <b>Setting:</b> 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 that this should be encouraged and supported.
2013				
Australia				

**Table 5. (Continued)**

*Note:* Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Number from quantitative [QN] and qualitative [QL] studies quality rating)

**Table 6. Autonomy is contested and complex (Studies ordered by Quality Rating)**

Authors				
Year	Quality Rating	Methodology and data collection methods	Sample & Setting	Results Summary
Country				
Quantitative Studies				
Duckworth, K et al. <sup>1</sup> 2013 USA	95%	Cross-sectional study <b>Method:</b> Questionnaire	<b>Sample:</b> 49 HCT (Hematopoietic Cell Transplant) candidates and 44 proxies <b>Response rate:</b> Not reported <b>Setting:</b> 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 AD's 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 end-of-life decisions for their loved ones
Keating, N. L et al <sup>30</sup> 2009 USA	95%	Cross-sectional study <b>Method:</b> Written survey	<b>Sample:</b> 4074 physician survey responses. <b>Response rate:</b> 61% (4188 of 6871 physicians whose contact information was verified) <b>Setting:</b> Physicians identified by patients participating in the CanCORS baseline interview as filling 1 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 noncancerous 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'.
Oorschot, B et al. <sup>3</sup> 2012 Germany	95%	Cross-sectional study <b>Method:</b> Written, standardized questionnaire	<b>Sample:</b> 589 completely evaluated questionnaires <b>Response rate:</b> 48.7% (589 of 1,208) <b>Setting:</b> Tumor patients older undergoing radiation therapy	91.3% of respondents with AD and 87.5% of respondents without 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 advance directives 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 get ill and often change their minds when they contract a disease.
Zhou, G et al <sup>4</sup> . 2010 USA	95%	Descriptive cross sectional pilot survey study <b>Methods:</b> Survey distributed to 300 Advance practice Nurses (APNs) via e-mail and sent again to the 89 APNs who responded to the initial survey.	<b>Sample:</b> 89 oncology APNs responded to the initial survey, and 53 of the 89 respondents returned the retest survey <b>Response rate:</b> 30% (90 of 300). <b>Setting:</b> 300 oncology APNs from one authors professional networks	Most APN's mistakenly believed that AD's alone (without conversation) were effective to communicate patient's wishes for end of life care.  Most commonly perceived barriers to ACP were that patients/family were reluctant., physician is reluctant and staff discomfort.
Barakat, A et al. <sup>5</sup> 2013 USA	90%	Cross-sectional study <b>Method:</b> A printed questionnaire returned in sealed envelope.	<b>Sample:</b> 68 completed surveys <b>Response rate:</b> 68% (68 of 100) <b>Setting:</b> 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.

**Table 6. (Continued)**

Authors				
Year	Quality Rating	Methodology and data collection methods	Sample & Setting	Results Summary
<b>Country</b>				
Jones L et al. <sup>33</sup> 2011 UK	85%	Exploratory randomized patient preference trial <b>Method:</b> Questionnaire	<b>Sample:</b> 77 participants with advanced cancer. Response rate: 88% (68 of 77) <b>Setting:</b> 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."
Fu, S et al. <sup>9</sup> 2012 USA	77%	Cross- sectional study <b>Method:</b> Written survey	<b>Sample:</b> 215 completed or partially completed questionnaires <b>Response rate:</b> 49% (215 of 435) <b>Setting:</b> Patients with advanced cancer being considered for enrollment onto an early-phase clinical trial.	The majority (59%) expressed wishes to discuss ACP matters with their physician. However, the majority had not actually done so.
Jezewski M. A et al. <sup>11</sup> 2005 USA	77%	Descriptive correlation survey <b>Method:</b> Mailed survey	<b>Sample:</b> 794 usable surveys <b>Response rate:</b> 23% (883 of 3840) <b>Setting:</b> A stratified random sample of 4,000 Oncology Nursing Society members	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.
El-Sahwi K. S et al <sup>34</sup> 2011 USA	60%	Cross-sectional study <b>Method:</b> Pilot survey sent via the website Survey Monkey	<b>Sample:</b> 142 physician responses. <b>Response rate:</b> 12.8% (142 out of 1105) <b>Setting:</b> Surveys were e-mailed to members of the Society of Gynaecologic Oncology (SGO).	The majority (73.9%) defined end of life discussion as the discussion about code status, advance directives, and withholding treatment when recommended by physician and transitioning hospice.
<b>Qualitative Studies</b>				
Barnes k, Jones L, Tookman A, King, M <sup>14</sup> 2011 UK	90%	Exploratory patient preference randomized controlled trial <b>Method:</b> Semi structured interview as part of an ACP intervention	<b>Sample:</b> 40 patients with recurrent progressive cancer. Fifty-two interviews. <b>Response rate:</b> Not reported <b>Setting:</b> Patients attending oncology and palliative care outpatient clinics in two London teaching Hospitals.	Many patients trust healthcare professionals to make future healthcare decisions in their best interests.
Fried T & O'Leary JR <sup>15</sup> 2008 USA	90%	Qualitative thematic analysis <b>Method:</b> Semi structured interview	<b>Sample:</b> Caregivers of community- dwelling patients who were age 60 years or older who died with advanced cancer (52%), chronic obstructive pulmonary disease (27%), or Heart Failure (21%). <b>Response rate;</b> Not reported <b>Setting:</b> Community	Cancer patients were more willing than other groups to participate in discussions regarding the end of life and their were several stories of patients choosing to forgo aggressive therapy even where they had previously indicated a willingness to undergo invasive therapy
Michael et al <sup>17</sup> 2013 Australia	90%	Qualitative descriptive design with grounded theory overtones <b>Method:</b> Focus groups, semi structured interviews, which incorporated the vignette technique	<b>Sample:</b> Eighteen caregivers of patients with lung and gastrointestinal cancer <b>Response rate:</b> 43% (18 of 42) <b>Setting:</b> Participants were recruited as part of a pilot ACP implementation and research program in a large tertiary cancer centre.	Participants felt that it important to understand patients' decisions to help fulfil patients' wishes, and allow patients some control. Participants, however, diverged on whether decisions needed discussion or documentation. Whereas caregivers mostly expected to honour 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 in- interest.

**Table 6. (Continued)**

<b>Authors</b>				
<b>Year</b>	<b>Quality Rating</b>	<b>Methodology and data collection methods</b>	<b>Sample &amp; Setting</b>	<b>Results Summary</b>
<b>Country</b>				
Michael et al. <sup>16</sup> 2013 Australia	90%	Qualitative grounded theory study <b>Method:</b> Caregivers first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique	<b>Sample:</b> 18 patients with cancer <b>Response rate:</b> 62% (26 of 29) <b>Setting:</b> Patients at the lung and gastro-intestinal tumour 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.  Whilst 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.
Walczak, A, et al. <sup>35</sup> 2014 Australia	90%	Qualitative thematic content analysis of audiotaped communication support program intervention as part of a randomised control trial. <b>Method:</b> Participants participated 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 centres in Sydney, Australia	Participants explicitly acknowledged oncologists discomfort in discussing life expectancy as a barrier to discussions regarding EOL.
Carrion I et al. <sup>19</sup> 2013 USA	85%	Qualitative grounded theory study <b>Method:</b> In depth open semi-structured interview	<b>Sample:</b> 45 Latina (15 Columbian, 15 Mexican and 15 Puerto Rican) women diagnosed with cancer <b>Response rate:</b> Not reported <b>Setting:</b> Spanish-speaking women recruited from community health clinics, churches, cultural centres, 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 & Olver I <sup>20</sup> 2003 Australia	85%	Discourse analysis <b>Method:</b> Semi structured interview	<b>Sample:</b> 23 consecutive patients with cancer who were unlikely to die in the near future <b>Response rate:</b> Not reported <b>Setting:</b> 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 <sup>22</sup> 2012 UK	85%	Qualitative grounded theory study <b>Method:</b> Semi-structured interviews and focus groups	<b>Sample:</b> 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews) and two family focus groups were conducted. <b>Setting:</b> A specialist local cancer centre	8 talked about their doctor knowing what's best for them with implicit acceptance of treatment advice. 11 reported that their doctors offered different treatment options for future care, 13 reported that HCP's did not have deep discussions or initiate conversation about EOL.
Horne G, Seymour J & Shepherd K <sup>21</sup> 2006 UK	85%	Qualitative grounded theory study <b>Method:</b> Patients participated in an ACP discussion with a trained lung cancer nurse and then completed structured interviews	<b>Sample:</b> 15 patients with inoperable lung cancer and their family members (9 patients, 6 family members) <b>Response rate:</b> Not reported <b>Setting:</b> 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 get what they wanted even if it is recorded.
Boyd K et al. <sup>23</sup> 2010 UK	80%	Qualitative analysis of a pilot educational intervention <b>Method:</b> Semi- structured interviews after a practice-based workshop; followed by telephone interviews with 9 others	<b>Sample:</b> 20 GPs and 8 community nurses <b>Response rate;</b> Not reported <b>Setting:</b> Staff at 4 General Practices	Expertise in EOL care was mostly considered to be something that could not be taught, based on intuition and experience.



**Table 6. (Continued)**

Authors				
Year	Quality Rating	Methodology and data collection methods	Sample & Setting	Results Summary
<b>Country</b>				
Barnes k, Jones L, Tookman A, King, M <sup>24</sup>	75%	Qualitative study <b>Method:</b> Focus group	<b>Sample:</b> 22 palliative care (18%) and oncology patients (82%). <b>Response rate:</b> 59% (22 of 37) <b>Setting:</b> 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 advance directive.
2007				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.
UK				
Robinson CA & Carole A <sup>26</sup>	55%	Prospective qualitative design <b>Method:</b> semi structured interview	Sample: 18 participants comprised of 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".
2011				
Canada				
Jezewski M, Meeker MA & Schrader, M <sup>25</sup>	45%	Qualitative <b>Method:</b> Open ended question at the end of a quantitative survey	<b>Sample:</b> 900 oncology nurses <b>Response rate:</b> 23% (900 of 3840) <b>Setting:</b> Oncology nurses from four states	Many nurses said 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.
2003				
USA				
<b>Mixed Methods Studies</b>				
Cherlin E et al	QN 73% QL 75%	Mixed methods study <b>Method:</b> Quantitative survey and additional in-depth interview with 12 family caregivers	<b>Sample:</b> 12 primary family caregivers of people with cancer whose loved ones were enrolled in hospice <b>Response rate:</b> Not reported <b>Setting:</b> Hospice	Some carers desired more information from physicians, believing 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."
2005				
USA				
McKinley E, Garrett J & Evans A <sup>28</sup> .	QN 68% QL 30%	Mixed methods study - quantitative survey and open-ended questions for qualitative analysis. <b>Method:</b> In-person interviews	<b>Sample:</b> 206 (92 black patients and 114 white patients) completed patient interviews <b>Response rate:</b> 76% (206 of 270) <b>Setting:</b> 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".
1996				
USA				

Note: Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Number from quantitative [QN] and qualitative [QL] studies quality rating)

**Table 7. Institutional culture is influential in ACP (Studies ordered by Quality Rating)**

Authors				
Year	Quality Rating	Methodology and data collection methods	Sample & Setting	Results Summary
<b>Country</b>				
Jezewski M et al. <sup>25</sup> 2005 USA	77%	Descriptive correlation survey <b>Method:</b> Mailed survey	<b>Sample:</b> 794 usable surveys <b>Response rate:</b> 23% (883 of 3840) <b>Setting:</b> A stratified random sample of 4,000 Oncology Nursing Society members	66% or more were confident about implementing institutional policies and procedures regarding ADs.
<b>Qualitative Studies</b>				
Jezewski M, Meeker MA & Schrader, M 2003 USA	45%	Qualitative <b>Method:</b> Open ended question at the end of a quantitative survey	<b>Sample:</b> 900 oncology nurses <b>Response rate:</b> 23% (900 of 3840) <b>Setting:</b> Oncology nurses from four states	Factors that affected assisting with AD s included: - A need to simplify the process of completing ADs - 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 ADs.
Vleminck A et al. <sup>36</sup> 2013 Belgium	90%	Exploratory qualitative design <b>Method:</b> Focus group	<b>Sample:</b> 36 GPs <b>Response rate:</b> <b>Setting:</b> Members of local peer review groups and palliative care networks.	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.
Boyd K et al. <sup>23</sup> 2010 UK	80%	Qualitative analysis of a pilot educational intervention <b>Method:</b> Semi- structured interviews after a practice-based workshop; followed by telephone interviews with 9 others	<b>Sample:</b> 20 GPs and 8 community nurses <b>Response rate;</b> Not reported <b>Setting:</b> Staff at 4 General Practices	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.
<b>Mixed Methods Studies</b>				
Cox K et al. <sup>38</sup> 2011 UK	QN 91% QL 75%	Mixed methods study - cross sectional audit and qualitative interviews <b>Method:</b> Audit of case notes on a sample of deaths and complementary group interviews with healthcare professionals.	<b>Sample:</b> 13 HCP's (GP, 2 District Nurses, Practice Manager, 2 Community Matrons, 2 Macmillan Nurses, Specialist Palliative Care Team Manager, Nursing Home Manager, Care Co-coordinator and 2 Registered Nurses). <b>Setting:</b> Four study sites were selected from across a Regional Cancer Network (Hospitals and GP practices)	Participants prefer a more individualised, 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 HCP's. They prefer to maintain discretion on when EOL discussions/ decision-making should occur.

Note: Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Number from quantitative [QN] and qualitative [QL] studies quality rating)

**Table 7. (Continued)**

<b>Authors</b>				
<b>Year</b>	<b>Quality Rating</b>	<b>Methodology and data collection methods</b>	<b>Sample &amp; Setting</b>	<b>Results Summary</b>
<b>Country</b>				
<b>Quantitative Studies</b>				
Keating, N et al. <sup>30</sup> 2009 USA	95%	Cross-sectional study <b>Method:</b> Written survey	<b>Sample:</b> 4074 physician survey responses. <b>Response rate:</b> 61% (4188 of 6871 physicians whose contact information was verified) <b>Setting:</b> Physicians identified by patients participating in the CanCORS baseline interview as filling 1 or more key roles in their care.	Physicians who strongly agreed they were knowledgeable to discuss end of life 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. <sup>39</sup> 2010 Taiwan	77%	Cross-sectional study <b>Method:</b> multi-centre survey using a structured questionnaire mailed to participant's respondents were assigned to "participation" group, or to "non-participation" group.	<b>Sample:</b> 413 HCP completed questionnaires <b>Response rate:</b> 71.8% (431 of 600 responded). 18 incomplete questionnaires excluded. <b>Setting:</b> Healthcare professionals 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 healthcare professionals' decision to execute or initiate discussion about ADs.
Hwang, S et al. <sup>10</sup> 2003 USA	77%	Cross sectional study <b>Method:</b> Written Questionnaire	<b>Sample:</b> 254 veterans with symptomatic cancer <b>Response rate:</b> 86% (254 of 296 surveys) <b>Setting:</b> veterans seen at the inpatient/outpatient clinic in a hematology tertiary referral center.	There are significant disparities between racial groups in advance care planning, knowledge, attitudes and decision-making.
Jezewski M et al. <sup>11</sup> 2005 USA	77%	Descriptive, correlation survey <b>Method:</b> Mailed survey	<b>Sample:</b> 794 usable surveys <b>Response rate:</b> 23% (883 of 3840) <b>Setting:</b> A stratified random sample of 4,000 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.
<b>Qualitative Studies</b>				
Michael et al. <sup>16</sup> 2013 Australia	90%	Qualitative grounded theory study <b>Method:</b> Caregivers first described their initial understanding of ACP, received ACP information, and finally completed a semi-structured interview assisted by the vignette technique	<b>Sample:</b> 18 patients with cancer <b>Response rate:</b> 62% (26 of 29) <b>Setting:</b> Patients at the lung and gastro-intestinal tumour streams with more than 4 weeks to live.	Positive memories of relatives end of life care trigger one participants plan 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.

**Table 7. (Continued)**

<b>Authors</b>				
<b>Year</b>	<b>Quality Rating</b>	<b>Methodology and data collection methods</b>	<b>Sample &amp; Setting</b>	<b>Results Summary</b>
<b>Country</b>				
Walczak, A et al. <sup>35</sup> 2014 Australia	90%	Qualitative thematic content analysis of audiotaped communication support program intervention as part of a randomised control trial. <b>Method:</b> Audiotapes of a communication support program.	<b>Sample:</b> 31 patients with advanced cancer and expected life expectancy of 2-12 months and 11 of their informal caregivers. <b>Setting:</b> Six treatment centres in Sydney, Australia	Positive or negative experiences of the death of a loved one motivated engagement in ACP.
Horne G, Seymour J & Payne S <sup>22</sup> 2012 UK	85%	Qualitative grounded theory study <b>Method:</b> Semi-structured interviews and focus groups	<b>Sample:</b> 25 patients and 19 family members. A total of 27 patient interviews (two were second interviews) and two family focus groups were conducted. <b>Setting:</b> A specialist local cancer centre	Patient's experiences of other people's cancer or death often influenced their level of engagement with decision-making.
Robinson CA <sup>40</sup> 2012 Canada	75%	Prospective qualitative <b>Method:</b> Patients participated in an ACP discussion (PC-ACP interview) and then completed semi - structured interviews 3- 6 months later Analysis: Thematic analysis - constant comparative	<b>Sample:</b> 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) <b>Setting:</b> Patients diagnosed with advanced lung cancer and their significant other or loved ones, recruited from within 1.5 hours 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 <sup>26</sup> 2011 Canada	55%	Prospective qualitative design <b>Method:</b> semi structured interview	<b>Sample:</b> 18 participants comprised of patients diagnosed with advanced lung cancer and their significant other or loved one <b>Setting:</b> Not described	Many patients framed their preferences in light of experiences with others at the EOL

*Note:* Standard Quality Assessment Criteria for Evaluating Primary Research Papers (Kmet et al., 2004) (Number from quantitative [QN] and qualitative [QL] studies quality rating)

**Table 7. (Continued)**

1. Duckworth K, Forti AM, Russell G, Naik S, Hurd D, McQuellon R. The process of Advance Care Planning in HCT candidates and proxies: self- efficacy, locus of control and anxiety levels. *American Journal of Palliative Care* 2013; **Epub ahead of print**.
2. Loberiza Jr FR, Swore-Fletcher BA, Block SD, et al. Coping styles, health status and advance care planning in patients with hematologic malignancies. *Leukemia and Lymphoma* 2011; **52**(12): 2342-8.
3. Oorschot Bv, Schuler M, Simon A, Flentje M. Advance directives: prevalence and attitudes of cancer patients receiving radiotherapy. *Supportive Care in Cancer* 2012; **20**(11): 2729-36.
4. 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. *Oncology Nursing Forum* 2010; **37**(6): E400-10.
5. Barakat A, Barnes S, Casanova M, Stone M, Shuey K, Miller A. Advance care planning knowledge and documentation in hospitalised cancer population. *Baylor University Medical Center Proceedings* 2013; **26**(4): 368-72.
6. 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. *Journal of Clinical Oncology* 2010; **28**(2): 299-304.
7. Díaz-Montes TP, Johnson MK, Giuntoli RL, Brown AJ. Importance and Timing of End-of-Life Care Discussions Among Gynecologic Oncology Patients. *American Journal of Hospice & Palliative Medicine* 2013; **30**(1): 59-67.
8. Lamont E, Siegler M. Paradoxes in Cancer Patients' Advance Care Planning. *Journal of Palliative Medicine* 2000; **3**(1): 27-35.
9. 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. *Journal of Clinical Oncology* 2012; **30**(23): 2891-6.
10. Hwang SS, Chang VT, Cogswell J, Srinivas S, Kasimis B. Knowledge and attitudes toward end-of-life care in veterans with symptomatic metastatic cancer. *Palliative & Supportive Care* 2003; **1**(3): 221-30.
11. Jezewski MA, Brown J, Wu YW, Meeker MA, Feng JY, Bu X. Oncology nurses' knowledge, attitudes, and experiences regarding advance directives. *Oncology Nursing Forum* 2005; **32**(2): 319-27.
12. Sahm 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. . *Supportive Care Cancer* 2005; **13**(4): 206-14.
13. Stearns L, Butler S, Hollander J. Patients' and families' receptivity to discussions about future healthcare: Decisions and advance directives. *Community Oncology* 2005; **2**(5): 446-51.

**Table 7. (Continued)**

14. Barnes K, Barlow C, Harrington J, et al. Advance care planning discussions in advanced cancer: analysis of dialogues between patients and care planning mediators. *Palliative & Supportive Care* 2011; **9**(1): 73-9.
15. Fried TR, O'Leary JR. Using the Experiences of Bereaved Caregivers to Inform Patient- and Caregiver-centered Advance Care Planning. *Journal of General Internal Medicine* 2008; **23**(10): 1602-7.
16. Michael N, C O'Callaghan, Clayton J, et al. Understanding how cancer patients actualise, relinquish and reject advance care planning: implications for practice. *Supportive Care Cancer* 2013; **2013**(21): 2195–205.
17. Michael N, O'Callaghan C, Baird A, Hiscock N, Clayton J. Cancer Caregivers Advocate a Patient- and Family-Centered Approach to Advance Care Planning. *Journal of Pain and Symptom Management* 2013; **47**(6): 1064-77.
18. Almack K, Cox K, Seymour J, Moghaddam N, Porock D. Communication strategies to initiate conversations planning for end of life care (EOLC). *Palliative Medicine* 2010; **24**(4): S102.
19. Carrion I, Nedjat-Haiem F, Martinez-Tyson D, Castañeda H. Advance care planning among Colombian, Mexican, and Puerto Rican women with a cancer diagnosis. *Supportive Care Cancer* 2013; **21**(5): 1233-9.
20. Elliott J, Olver I. Perceptions of "Good Palliative Care" Orders: A Discursive Study of Cancer Patients' Comments. *Journal of Palliative Medicine* 2003; **6**(1): 59-68.
21. Horne G, Seymour J, Shepherd K. Advance care planning for patients with inoperable lung cancer. *International Journal of Palliative Nursing* 2006; **12**(4): 172-8.
22. 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. *International Journal of Nursing Studies* 2012; **49**: 718-26.
23. Boyd K, Stephen Barclay, Chinn D, Thomas K, Sheikh A. Advance care planning for cancer patients in primary care: a feasibility study. *The British journal of general practice : the journal of the Royal College of General Practitioners* 2010; **60**(581): e449-58.
24. Barnes k, Jones L, Tookman A, King M. Acceptability of advance care planning interview schedule: a focus group. *Palliative Medicine* 2007; **21**(1): 23-8.
25. Jezewski MA, Meeker MA, Schrader M. Voices of Oncology Nurses: What Is Needed to Assist Patients With Advance Directives. *Cancer Nursing* 2003; **26**(2): 105-12.
26. Robinson C, Carole A. Advance care planning: re-visioning our ethical approach. *Canadian Journal of Nursing Research* 2011; **43**(2): 18-37.

**Table 7. (Continued)**

27. 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? *Journal of Palliative Medicine* 2005; **8**(6): 1176-85.
28. McKinley E, Garrett J, Evans A. Differences in end-of-life decision making among black and white ambulatory cancer patients. . *Journal of General Internal Medicine* 1996; **11**: 651-6.
29. Samara J, Larkin D, Chan C, Lopez V. Advance care planning in the oncology settings. *International Journal of Evidence-Based Healthcare* 2013; **11**(2): 110-4.
30. Keating NL, Landrum MB, Rogers S, et al. Physician factors associated with discussion about end of life care. *Cancer* 2010; **116**(4): 998-1006.
31. Miccinesi G, Bianchi E, Brunelli C, Borreani C. End-of-life preferences in advanced cancer patients willing to discuss issues surrounding their terminal condition. *European Journal of Cancer Care* 2012; **21**(5): 623-33.
32. 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. *Gynecologic Oncology* 2013; **131**(2): 430-6.
33. 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. *Palliative & Supportive Care* 2011; **9**(1): 3-13.
34. El-Sahwi KS, Illuzzi J, Varughese J, et al. A survey of gynecologic oncologists regarding the End-of-Life discussion: A pilot study. *Gynecologic Oncology* 2012; **124**: 471-3.
35. Walczak A, Henselmans I, Tattersall MHN, 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* 2014.
36. Vleminck AD, 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).
37. 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. *Supportive Care in Cancer* 2014.
38. 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 Palliative Care* 2011; **10**(18).
39. 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. *Social Science & Medicine* 2010; **70**(11): 1701-4.

**Table 7. (Continued)**

40. Robinson CA. "Our best hope is a cure." Hope in the context of advance care planning. *Palliative & Supportive Care* 2012; **10**(2): 75-82.