ADVANCE CARE PLANNING IN ONCOLOGY:
A SCOPING REVIEW AND SOME RECOMMENDATIONS

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Key points

- Although oncology guidelines recommend advance care planning (ACP) to support patient autonomy and ensure that care is aligned with patients' goals, wishes, and values; ACP remains under-implemented in routine cancer care.
- It remains difficult to determine who should initiate ACP discussion, with which patients and at what time-points.
- Future observational studies may consider factors reported to influence ACP uptake and communication in healthcare and integrate socioemotional processes.
- ACP is a cognitively complex, relationally sensitive, emotionally intense ongoing communication process which could benefit from multidisciplinary interventions.

Abstract

Purpose of review: Cancer patients' communication with their relatives and healthcare professionals (HCPs) is essential for advance care planning (ACP). The purpose of this scoping review was to synthesize recent research findings about factors enabling cancer patients', their relatives', and physicians' communication about ACP, and to propose recommendations for future ACP implementation in cancer care.

Recent findings: This review confirmed the importance of aspects of the cancer care context (i.e., culture) as ACP uptake predisposing and -enabling factors. It highlighted the difficulty of determining who should initiate ACP discussion, with which patients and at what time-points. It also highlighted a lack of consideration for socioemotional processes in the study of ACP uptake despite evidence that cancer patients', relatives' and physicians' discomforts that arise from communication about end-of-life and the wish to safeguard each other are main obstacles to ACP implementation.

Summary: Based on these recent findings, we propose an ACP communication model, developed with the consideration of factors reported to influence ACP uptake and communication in healthcare, and integrating socioemotional processes. The testing of the model may yield suggestions for innovative interventions that can support communication about ACP and promote a better uptake in clinical practice.

Keywords: advance care planning, cancer, communication, physicians, relatives

Introduction

People with cancer face the need for complex, difficult decisions related to their treatment and end-of-life care to be made toward the ends of their lives, when their individual integrities are threatened and they are at greater risk of decision-making capacity impairment [1]. To support patient autonomy and ensure that care is aligned with patients' goals, wishes, and values, oncology guidelines recommend advance care planning (ACP) [2–5], which involves voluntary ongoing discussion among patients, their relatives, and healthcare professionals (HCPs) about prognoses to understand, review, and plan for future end-of-life care decisions [6*]. Despite the positive effects of ACP uptake, demonstrated by recent reviews [6*,7,8**,9], ACP remains under-implemented in routine cancer care [10,11**].

Communication-related factors may explain this under-implementation. ACP relies on the assumption that the actors involved are willing to engage in difficult discussions and planning, confronting patients' physical decline and death in an engaged, rational manner [3]. Thoughts of impending death and limited time, however, activate intense emotions and powerful individual and group psychological defenses that entail distraction or cognitive distortion to push the threat of death into a more distant future [12]. ACP is thus a cognitively complex, relationally sensitive, emotionally intense communication process. This scoping review was conducted to synthesize current knowledge about factors enabling communication about ACP among patients with cancer, their relatives, and physicians; and to provide recommendations for future ACP communication–centered interventions in cancer care.

Literature search and sample

The PubMed database was searched using the terms "advance(d) care planning," "cancer," “oncology,” “neoplasm,” “tumor,” and “communication.” The titles and abstracts of retrieved articles were reviewed. Articles published in English between January 2021 and January 2023 that described observational studies conducted with adult populations were selected.

Thirty-eight studies [15-52] and three reviews were identified [6*,8**,13**]. Studies were heterogeneous in terms of cancer care contexts, population size and characteristics, research designs, and assessment methods (Table 1).

Overview of factors influencing advance care planning communication in oncology

Factors associated with ACP communication were allocated to five categories (based on an ACP uptake [13**] and a communication in healthcare [14] model) : ACP uptake–predisposing factors and barriers [15–23], ACP uptake–enabling factors and barriers [15,18,24,25,26*,27–29], perceived need for ACP communication and barriers [15], ACP communication–enabling factors and barriers [17,18,23,25,26*,30–38], and willingness to communicate about ACP [23,30–32]. Fourteen articles that were not included in these categories are reported in Table 1. They address two topics: ACP uptake rates [39–44]; and ACP outcomes [45–52].

Advance care planning uptake–predisposing factors and barriers

Several predisposing, not easily modifiable, factors and barriers related to ACP uptake in the cancer care context were identified. Recent studies highlighted the roles of cultural, and religious factors and the need to consider minority groups' preferences when assessing the appropriateness of ACP [16,18–22]. These findings are in line with those of a recent review of ACP uptake among older adults with cancer [13**].

Regarding patients' demographic characteristics, older age increased the likelihood of ACP uptake in Israel [15], whereas younger age was associated with increased uptake in Australia [23]. The authors of a recent review noted that older patient age may be a facilitator or barrier to ACP uptake, and that older patients were less likely to engage in ACP when they believed that their relatives or physicians would make relevant decisions for them [13**]. ACP uptake was more frequent among male patients in Israel [15], whereas female patients and relatives in Australia were more likely to have legally appointed surrogates [23]. These findings reflect the differences in the impact of patient gender on ACP uptake revealed by the review [13**]. This review also shows that higher educational levels increased the likelihood of ACP uptake in China [13**].

Regarding socio-relational characteristics, family structure was found to affect ACP initiation preferences in China; patients with only one child were more likely to prefer to make ACP decisions on their own compared to patients with more than one child [17].

Advance care planning uptake–enabling factors and barriers

Several enabling, more easily modifiable, factors and barriers related to ACP uptake in oncology were identified. Physicians identified the lack of resource access, time in clinical practice, and support for palliative care referral as significant barriers to discussions about ACP [24,25,26*]. A recent review underlined the paucity of ACP uptake–enabling resources (i.e., training, implementation tools) in cancer care contexts [13**].

Patient- and relative-related ACP uptake–enabling factors varied across studies. In China, patients' trust in their physicians was an essential element in their willingness to engage in ACP [18]. In a recent study, patients reported that engagement in ACP discussions depended on their relatives' willingness to discuss the sensitive topics of death and dying [25]. Patients in Israel reported that open communication with relatives and medical staff was an important enabling factor for ACP form completion [15]. The importance of patients' relatives' open communication and involvement in ACP was also emphasized as important enabling factors in a recent review [8**]. Patients who reported high levels of worry were more likely to describe themselves as terminally ill and less likely to have engaged in ACP [28]. Physicians also cited patients' emotional discomfort and the difficulty of talking about death while maintaining hope as important ACP uptake barriers [26*]. According to physicians, patients' and relatives' difficulties in understanding diagnoses, accepting prognoses, understanding and agreeing with care goals, and understanding the complications of life-sustaining treatments were the most important barriers to ACP uptake [24]. Recent review findings suggest that patients' positive and negative previous care experiences can promote or hinder ACP uptake [13**].

Physician-related ACP uptake–enabling factors varied across studies. In Brazil, physicians identified the lack of communication skills training as the most important barrier to ACP uptake [24]. In Japan [29] and Brazil [24], the opportunity for such training was the main factor associated with ACP discussion initiation, even though most participants in the latter study did not consider their training levels to be high [24]. In the United States, a study highlighted that HCPs perception of the value of ACP communication greatly influenced their initiation of such conversations [27].

Perceived need for advance care planning communication and barriers

Patients' and relatives' perceptions of the need to initiate ACP and barriers are influenced by contextual factors. Recent reviews demonstrated that factors such as perceived short life expectancy, long disease courses, new cancer diagnoses or complications, uncertainty about prognoses, and poor symptom control hinder ACP uptake [6*,13**]. In Israel, patients' ACP form completion was promoted by their need to be assured that the best medical decisions would be made and unnecessary medical procedures would be avoided [15]. Physicians' perceptions of the need to initiate ACP and barriers have not been studied recently.

Advance care planning communication–enabling factors and barriers

Awareness and understanding of advance care planning

Five recent studies conducted in different countries revealed patients' inadequate awareness (i.e. "has the patient heard about ACP") and understanding of ACP (i.e. "does the patient understand what ACP is and how ACP works") [17,23,25,31,32], and recent reviews demonstrate that these factors hinder ACP uptake [6*,13**]. The authors of one study emphasized that awareness does not always equate to understanding [17]. In Australia, 48.5% of patients with cancer and relatives [23] and 61% of older patients with cancer [31] had some level of ACP awareness. In China, patients showed inadequate ACP awareness and understanding despite having positive attitudes about the ACP process [17,32]. Similar results were found for patients with cancer at the US–Mexico border [25].

Advance care planning *initiation preferences*

Four recent studies conducted in Australia [23], the US [18], the Netherlands [33], and China [17] focused on ACP uptake initiation preferences. In China, female patients were more likely to prefer that their physicians initiate ACP discussions [17]. In contrast, Australian respondents preferred to initiate ACP conversations rather than wait for physicians to do so [23], reflecting a cultural difference. Trust was found to be an essential factor among US patients [18]. In a study in the Netherlands, only a minority of patients with advanced cancer felt not involved in decision-making about future medical treatment and care (2.7%) and felt that their family and friends (5.7%) and physicians (7.7%) were not aware of these preferences either. Patients’ perceptions of ACP involvement and their emotional functioning were positively associated [33].

Although some patients and relatives prefer that ACP discussions be initiated early, the majority prefer to delay ACP until treatment options have been exhausted, giving them time to cope with the shock of their diagnoses. Thirty-eight percent of respondents in an Australian survey preferred that discussions about ACP and end-of-life care be scheduled when cancer is incurable, compared with 20% who preferred discussion initiation at the time of diagnosis [23]. A study conducted in a general practice in the Netherlands revealed a difference between the perceived optimal and actual timing of ACP initiation, viewed as specific moments (e.g., at diagnosis, when no curative treatment option is available, at the start of treatment or diagnostics) in the disease timelines of patients who died with cancer [37]. In another study, general practitioners indicated that ACP initiation should be considered at the time of cancer diagnosis, after a period of illness or exacerbation (e.g., hospital admission) for patients with organ failure, and in the presence of advanced age and symptoms indicating functional and general deterioration (e.g., decreasing mobility, increasing dependence, increasing fatigue, appetite loss) in patients with multimorbidity [36]. Although patients’ unreadiness has been mentioned as a significant barrier to initiating ACP conversations, a recent study showed that patients do not have to be ready for all elements of ACP to participate in an ACP conversation [38]. HCPs should adapt the conversation to patients’ readiness for the topic.

Self-efficacy beliefs

Patients’, their relatives’, and HCPs’ communication about ACP theoretically depends on their beliefs about their ability to do so. In Taiwan, nurses’ self-efficacy in efficiently managing a variety of stressful conditions positively affected their ACP practice with terminally ill patients [34]. To our knowledge, no study has examined the effects of patients’ or relatives’ self-efficacy beliefs on their perceived ability to communicate about ACP.

Expectations about advance care planning discussion outcomes

Patients', their relatives', and HCPs' willingness to communicate about ACP theoretically depends on their beliefs regarding the expected outcomes of that communication (i.e., outcome expectancy beliefs). Three recent studies highlighted negative outcome expectancy beliefs regarding ACP among HCPs [35] and patients with cancer [25,30]. HCPs reported that ACP discussions may overwhelm and upset patients and relatives, inducing unnecessary stress or unleashing uncontrollable emotions, with worrisome psychological outcomes [35]. Hispanic and Latino patients in the US reported that the wish to safeguard their families from confronting death, and thereby distressing them, was a barrier to engaging in ACP discussions [26*].

Positive outcome expectancy beliefs were noted in one study [26*]. Older patients reported that communication about ACP with their clinicians would ensure that their loved ones would have more peaceful experiences if their diseases progressed and/or their conditions declined; that it offered the opportunity to share what is meaningful to them with their clinicians; and that it connected them more with their care teams, thereby improving outcomes [26*]. They felt that ACP discussions would improve their understanding of their diseases, increase their empowerment, and provide the knowledge needed to more confidently adapt to their diagnoses [26*]. A recent review showed that most nurses also recognized the benefits of advance directives [13**].

Willingness to communicate about advance care planning

In a recent study conducted in China, only 18.3% of patients were not willing to talk about ACP [32]. Another study indicates, however, that doctors' authority in mainland China and Taiwan may override patients' wishes in some circumstances, and that patients are less willing to communicate about ACP because they believe that their doctors know their wishes regarding end-of-life care [30]. In Australia, one survey reported that 72% of patients with cancer had talked to someone (children, 73%; spouses, 24%; doctors, 23%) about their care preferences [31]; another survey showed that 65% of patients with cancer and relatives had discussed their end-of-life care values or preferences with someone (relatives, 93%; HCPs, 3.7%) [23].

Conclusion

This scoping review confirmed the importance of aspects of the cancer care context (i.e., culture) as ACP uptake–predisposing and –enabling factors. It highlighted the difficulty of determining who should initiate ACP discussion, with which patients and at what time-points. Based on these findings and our clinical experience in cancer care and communication skills training, we propose an ACP communication model (Fig. 1), developed with the consideration of factors reported to influence ACP uptake [13**] and communication in healthcare [14], and integrating socioemotional processes [53**].

The model was developed with the recognition of the highly emotional and relational nature of ACP discussions [8**]. According to it, factors that may impact ACP communication include actors' tolerance of uncertainty (as end-of-life decisions imply multiple uncertainties), reactions to moral dilemmas (as end-of-life care is frequently associated with conflicting existential values), and emotional discomfort (as ACP is associated with talking about potential impending death). Moreover, communication about ACP is influenced by factors related to the relationship histories of involved actors. It is also influenced by enabling factors such as decision-making preferences [which may differ markedly between patients and their relatives [8**]], communication experience [as previous discussions about sensitive topics may promote or inhibit the willingness to address end-of-life issues [13**]], and satisfaction with care [as patients report that trust in their HCPs is an ACP uptake–enabling factor [18]]. According to our model, specific ACP communication–enabling factors (ACP knowledge and attitudes, preferences, self-efficacy, and outcome expectancy beliefs) influence the link between the perceived need for communication and the willingness to communicate about ACP. This review showed that physicians identify the lack of training in the communication skills required to address patients' advanced cancer prognoses as a barrier to their initiation of ACP with their patients [24,29].

Our review, like others before it, shows that the discomfort that arises from communication about death is a main obstacle to ACP implementation. In addition to interventions targeting the cancer care setting [54] and the involvement of patients' relatives in ACP [8**], interventions may seek to lessen this discomfort. Physicians need to be trained to initiate discussions about ACP. Table 2 proposes a conversational protocol for physicians called CERTAIN, a mnemonic communication system to help physicians in their use of complex communication skills needed to address uncertainty and support hope while initiating a discussion about ACP. This conversational protocol was proposed in a communication skills training program [55]. Results of a randomized controlled trial showed how physicians used this communication conversational protocol to discuss uncertainty and hope while discussing advanced cancer prognoses [56]. Finally, patients and their relatives need to be supported in this iterative process not only by their physicians but also by other HCPs. This multidisciplinary work will allow them to confront, alone or with each other, thoughts and fears related to death and the multiple losses that the end of life entails [8**].

This review highlights the vast body of research conducted to better understand the benefits of ACP and predisposing and enabling factors for its uptake in cancer care. Despite this large body of research, however, ACP remains under-implemented in cancer care. We believe that this situation is due largely to difficulties associated with ACP communication experienced by the actors involved and the wish to safeguard each other. The testing of the model proposed here will yield suggestions for innovative interventions that can support communication about ACP and promote its uptake in clinical practice. The increased use of ACP would provide strong assurance that end-of-life care is consistent with the goals, wishes, and values of patients with advanced cancer and their relatives while supporting HCPs' job satisfaction.

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Conflicts of interest

None

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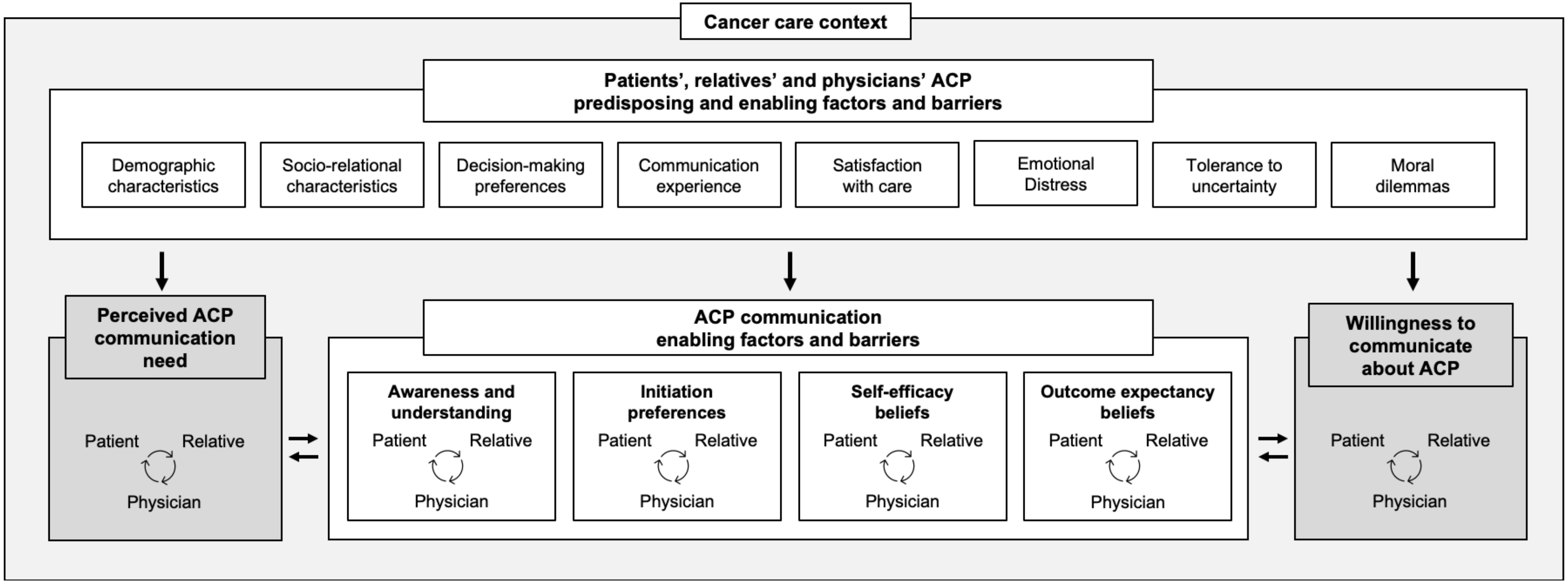

Figure 1. A comprehensive ACP communication model, developed with the consideration of factors reported to influence ACP uptake and communication in healthcare, and integrating socioemotional processes.

Table 1. Studies addressing factors enabling communication about ACP among patients with cancer, their relatives, and physicians published between January 2021 and January 2023

Authors, year	Aims	Design	Assessment	Subject	Place and culture	Main results	
						Quantitative	Qualitative
Anaka et al., 2022 [39]	Analyse changes in documented GoC designations	Retrospective	EMR and Alberta Cancer Registry analyses	Pts. with advanced pancreatic cancer (n=471)	Canada	GoC increased from 7.8% in 2010 to 50.0% in 2015. The proportion documented by medical oncologists increased from 0% in 2010 to 52.1% in 2015.	
Bar-Sela et al., 2021 [15]	Evaluate barriers and motives regarding ACP	Cross-sectional	Questionnaires	Pts. with mixed solid organ malignancy (n=109)	Israel	Most pts. who completed the ACP forms were older, had lung cancer and did not hear about the issue from sources outside the oncology division	Main enabling factors: information and open communication with family and staff members. Main motive: to ensure that the best medical decisions would be made and to avoid unnecessary medical procedures. Main reasons for not completing the forms: no close relative who would agree to take the responsibility and timing
Bar-Sela et al., 2022 [45]	Determine which element of ACP improves the likelihood of pts.' attaining their preferences	Retrospective	Structured interviews	Relatives of deceased cancer pts. (n=491)	Israel	Treatment consistent with pts.' preferences is associated with a discussion between pt. and family and the ability to speak until last week of life. Place of death consistent with pts.' preferences is associated with having an AD and a discussion between pt. and family	
Berkowitz et al., 2021 [40]	Compare ACP in pts. with cancer vs. noncancer pts. referred to PC	Retrospective	Analyses of initial outpatient PC visits	Pts. with cancer (n=1604); noncancer pts. referred to PC (n=1094)	USA; White 87%, non-Hispanic 98%	Pts. with cancer were less likely to be DNR/DNI (37% vs. 53%) and less likely to have an advance directive (53% vs. 73%). Rates of healthcare proxy identification were similar (92.8% vs. 94.5%)	
Chen et al., 2022 [30]	Describe the decisional balance, attitudes, and practice behaviors of ACP and predictors of ACP-related experiences	Cross-sectional	Questionnaire and semi-structured interviews	Pts. with stage III and IV mixed solid cancer (n=166)	Taiwan	Participants exhibited favorable ACP-decisional balance and positive ACP-attitudes and practice behaviors. ACP-practice behaviors were predicted by ACP-decisional balance, but not by ACP-attitudes	Six themes identified in responses to current medical decision making (e.g., compliance with physician instructions, family engagement in treatment decision-making), and eight themes identified pertaining to future ACP-related concerns were identified (e.g., family conflict, effectiveness of time-limited trials)
Cohen et al., 2021 [46]	Investigate the association between ACP and hope	Cross-sectional	Questionnaires	Pts. with advanced mixed solid organ cancer, prognostic <1 year (n=672)	USA; White 94%	No difference in hope between pts. who had and had not had an EoL discussion, chosen a surrogate or completed an AD	

Cullen et al., 2022 [16]	Examine ACP and GoC decisions	Retrospective	EMR analyses	Veterans with mixed solid and hematological cancer (n=88)	USA; White 50%, African American 47%	Veterans with prostate cancer were more likely to elect full code status. White veterans were more likely to choose a DNR order	
Detering et al., 2021 [31]	Describe the prevalence of ADs in medical records and the self-reported awareness of and engagement in ACP; to examine the concordance between self-reported completion of and presence of documentation in medical records	Cross-sectional	Medical records analyses and questionnaires	Cancer pts. (n=97; 458 medical records)	Australia; Australian 95%, little or none ethnic diversity	30% had ≥ AD located in their record. 81% had a preference to limit some/all treatments, 10% wanted to defer decision making to someone else, 9% wanted all treatments, 58% reported having completed an ACP document. Concordance between documentation in records and self-report of completion was 61%	
Dias et al. 2022 [24]	Explore barriers to discuss GoC and ACP	Cross-sectional	Questionnaire	Oncologists (n=66)	Brasil; White 66%	Most oncologists perceived pt. and family's related barriers as the most important. The lack of access and of support for referral to PC was considered a significant barrier for ACP and GoC discussion	Physician lack of training and lack of time for GoC and ACP conversation were described as important barriers
Driller et al., 2022 [47]	Explore the effect of implementing ACP conversations on number of days at home at the EoL and on home deaths	Retrospective cohort study	EMR analyses	Pts. with cancer deceased in primary health care (n=250)	Norway	During the last 90 days of life, pts. who had an ACP conversation were mean 9.8 more days at home, 4.5 less days in nursing home and 5.3 less days in hospital. Pts. with an ACP conversation where four times more likely to die at home.	
Falzarano et al., 2021 [48]	Examine changes in grief over time and whether changes in pt. grief are associated with changes in caregiver grief; to determine how grief changed following the completion of AD	Prospective longitudinal	Structured interviews	Dyads of pts. with incurable gastrointestinal, lung, gynecological cancer and their caregivers (n=98)	USA; White pts. 61.9%, caregivers 66.0%	Changes in pt. grief were associated with changes in caregiver grief. Pts. who completed a LW experienced increases in grief, caregivers of Pts. who completed a DNR order experienced reductions in grief	
Forner et al., 2021 [41]	Describe ACP documentation before surgery for oral cancer	Retrospective	EMR and preoperative clinic notes analyses	Preoperative clinic notes and medical records of pts. with head and neck cancer (n=301)	Canada	ACP was documented for 10.3%. Pts. with locally advanced disease (T3+) were twice as likely to have ACP documentation vs. those with early disease	

Gotanda et al., 2022 [42]	Compare ACP completion and receipt of high-intensity care at the EoL between cancer vs. dementia decedents	Retrospective longitudinal cohort study	Questionnaires	Surrogate reports of deceased pts. with cancer (n=1137) vs. deceased pts. with dementia (n=2099)	USA; Non-Hispanic white dementia 83.0%, cancer 88.0% pts.	LW and discussion about preferences were lower in dementia vs. cancer pts. (49.9% vs. 56.9% and 53.0% vs. 68.1% respectively). In-hospital death was higher in dementia vs. cancer pts. (29.5% vs. 19.8%), although use of ICU care was lower (20.9% vs. 26.1%). Use of durable POA for healthcare and use of life support were similar in both groups	
Hjorth et al., 2021 [49]	Examine who were offered an ACP conversation, those not offered it who would have wanted it and whether the outcomes differed between those groups	Cross-sectional	Questionnaire	Relatives of deceased pts. with mixed solid organ and hematological cancer (n=276)	Norway and Argentina	56% had been invited, and they had significantly more positive perceptions about care and support than those not invited. 68% not invited would have wanted an invitation, and they had less favorable perceptions about care	
Hou et al., 2021 [32]	Describe knowledge and attitude towards ACP	Cross-sectional	Questionnaire	Pts. with stage IV mixed solid organ cancer (n=264)	China	82.2% had never heard about ACP and 83.0% had never talked about ACP, but only 18.3% were not willing to talk about ACP. 70.8% hoped to have surrogate decision makers when they became unconscious	
Hu et al., 2021 [17]	Describe knowledge of ACP, EoL care preferences and predictors of preference for ACP, and who should mention ACP	Cross-sectional	Questionnaire	Pts. with lung cancer (n=258)	China	91.1% favored ACP on EoL issues, 60% wanted to make EoL decisions on their own, 10% were familiar with AD and 31.8% with DNR/DNI. ACP was not mentioned in 92.2% of pts. Female pts. and pts. currently receiving treatment are 2.7 and 1.8 times, respectively, more willing to need ACP initiated by doctors	
Jia et al., 2022 [18]	Explore barriers and facilitators to ACP	Cross-sectional	Semi-structured interviews	Dyads of pts. with stage IV gastrointestinal, breast, lung cancer (n=20) and their caregivers (n=8)	China		Participants' trust in their clinicians and the institution are primary supports for clinicians to lead ACP. Participants' preconceptions of clinicians' professional responsibilities and belief in an uncertain future may hinder an open discussion of goals and values for future medical care. A key moderating factor in how participants view ACP may be their level of acculturation to local care, behavioral, and communication norms.

Kelly et al., 2021 [19]	Assess the influence of intrapersonal factors on overall preferences for future medical treatment, including documentation in EMR	Retrospective	EMR analyses	Pts. with mixed solid organ cancer (n3463)	USA; Caucasian/White 83.4%	Pts. who identified as religious had 61% higher odds of having a DNR and approximately 30% higher odds of having a POA or AD. Pts. with depression had more than twice the odds of having a DNR. White pts. had higher odds of having a POA and an AD	
Ko et al., 2022 [25]	Explore facilitators and barriers for ACP and elicit suggestions to promote ACP	Cross-sectional	Semi-structured interviews	Pts. with cancer (30)	US/Mexico border region; Hispanic/latino		A common theme for facilitators and barriers for ACP was safeguarding family. Additional facilitators included (1) desire for honoring EoL care wishes and (2) experience with EoL care decision making. Additional barriers include (1) family's reluctance to participate in EoL communication and (2) patient–clinicians' lack of EoL communication. Practice suggestions include (1) death education and support for family, (2) ACP education, (3) dialogue vs. documentation.
Kroon et al., 2021 [33]	Investigate the association between perceptions of ACP involvement and emotional functioning	Cross-sectional	Questionnaires	Pts. with advanced mixed solid cancer (n=1101)	Netherlands; without migrant background 97%	A positive association was found between pts.' perceptions of ACP involvement and their emotional functioning	
Lakin et al., 2021 [43]	Compare data extracted from dedicated structured Electronic EMR fields for ACP to a chart review of corresponding ACP documentation in medical charts	Cross-sectional	EMR and electronic fields for ACP analyses	Pts. with advanced sarcoma, head, neck, and gastrointestinal cancer (n=187)	USA; White 82.4%	Structured ACP data existed for 43.2% of pts. and varied by site (25.7%-48.9%), 59.2% of recorded elements in structured ACP were correct, 23.7% incorrect, and 17.1% were duplicates with heterogeneity across sites	
Leak et al., 2021 [50]	Investigate whether implementation of ACP consults leads to improved AD completion rates	Retrospective case-control study	EMR analyses	Pts. with mixed solid and hematological cancer (n=790); primary care pts. (n=420)	USA	Among pts offered consults, completed ADs were present in 28.1% of pt. EMR compared with historic rates of 3%	
Li et al., 2021 [20]	Explore indigenous pts.' ACP perceptions	Cross-sectional	Medical records analyses, semi-structured interviews, questionnaire	Pts. with stage III and IV mixed solid cancer (n=9)	Taiwanese aboriginal tribes		Lack of fundamental ACP awareness, insufficient healthcare resources, life-sustaining value in a Christian faith context, and the prevalent health disparity in the remote communities negatively affect pts.' intention to participate in ACP. Terminal pts.' ACP readiness was at a precontemplation stage.

LoCastro et al., 2022 [26*]	Better understand ACP from multiples perspectives	Cross-sectional	Semi-structured interviews	Dyads of pts. with AML, MDS (n=15) and their caregivers (n=5); oncology clinicians (n=11); PC clinicians (n=9)	USA; White pts. 93.3%, caregivers 100%, oncology clinicians 87.5%, PC clinicians 88.9%		Four themes merged: (1) the language of ACP and medical order for life-sustaining treatment does not resonate with pts., (2) there is no uniform consensus on when ACP is currently happening, (3) oncology clinician-perceived barriers to ACP, (4) pts. felt that they are balancing fear and hope when navigating their AML or MDS diagnosis
Martina et al., 2022 [21]	Explore the perspectives and experiences of HCP on ACP for cancer pts.	Cross-sectional	Focus-group	Physicians (n=16) and nurses (n=16) working in oncology	Indonesia		Participants considered four aspects of ACP as important: (1) the family's role in medical decision-making, (2) sensitivity to communication norms, (3) pts.' and families' religious beliefs regarding the control and sanctity of life, (4) the availability of a support system for ACP
Martina et al., 2022 [22]	Study ACP perspectives by exploring experiences with medical information-disclosure, decision-making, and ACP	Cross-sectional	Semi-structured interviews	Dyads of pts. with mixed solid cancer or leukemia (n=16) and their family caregivers (n=15)	Indonesia		Participants considered four aspects of ACP as important: (1) perceptions on the importance or harmfulness of cancer-related information, (2) communicating bad news sensitively, (3) motives for participating in medical decision-making, (4) complexities of future planning
Nortjé and Stepan, 2021 [27]	Assess how physicians can successfully plan for and initiate ACP conversations with their patients and families	Cross-sectional	Questionnaire	Physicians working in oncology identified as having the most ACP conversations (n=13)	USA		Themes related on how the physicians can successfully plan for and initiate ACP conversations touched upon self-awareness, one's outlook on the value of life, and the importance of death as part of the care continuum. A physician's own perception of the value of ACP conversations greatly influences them having those conversations
Pan et al., 2021 [34]	Expand on previous research elucidating the effects of dispositional resilience and self-efficacy on ACP practice	Cross-sectional	Questionnaires	Nurses working with terminal cancer pts. (n=266)	Taiwan	Factors influencing ACP practices: dispositional resilience, self-efficacy, medical, surgical, hematology and oncology wards, previous experience in caring for terminally ill friends or relatives, participating in the DNR signature, and the frequency of caring for terminally ill pts.	
Prater et al., 2022 [51]	Evaluate the association between billed ACP services and EoL hospital admissions in the final 30 days of life	Retrospective cohort study	EMR analyses	Pts. with advanced cancer referred to hospice (n=3705)	USA	Pts. with billed ACP were less likely to experience inpatient hospital admissions in the final 30 days of life vs. those without billed ACP	

Prigerson et al., 2023 [52]	Determine which ACP activities are associated with the greatest likelihood of receiving value-concordant care; and how results may vary based on pt.-reported EoL care priorities	Prospective cohort studies	EMR analyses and interview	Dyads of pts. with terminal metastatic cancer, refractory to chemotherapy and their caregivers (n=278)	USA; White no acp 42%; any acp 70%	The ACP combination associated with the largest proportion of pts. receiving value-concordant care was DNR, HCP, and EoL discussions (87% vs. 64% for no ACP activities), DNR orders were associated with decreased likelihood of life-extending care (89% vs. 75%) and EoL discussions were associated with increased likelihood of hospice care (77% vs. 55%) among pts. prioritizing comfort
Rodenbach et al., 2021 [28)	Explore relationships between worry about dying and illness understanding, treatment preferences, and ACP	Cross-sectional used baseline data from an intervention trial	Questionnaires	Pts. with metastatic mixed solid cancer (n=672)	USA; Caucasian/white 94%	47% reported worrying about dying not at all, whereas 9.7% worried quite a bit or very much. Pts. who reported high levels of worry were more likely to describe themselves as terminally ill, preferred life extending therapy over symptom-focused care, were less likely to have completed an AD
Rodi et al., 2021 [23)	Explore ACP awareness, experiences, and preferences	Cross-sectional	Questionnaire	Pts. with mixed solid and hematological cancer (n=440); support people (n=265)	Australia; 75,9% of pts. and 78,5% of support people born in Australia	48.5% had already heard of ACP and 65% had discussed their values or preferences with someone, 93% discussions occurred with family or friends and 3.7% occurred with a health professional. 33% had documented their preferences. 3.0% did not want to discuss ACP at all
Sagara et al., 2021 [29)	Examine the current status of ACP and EoL communication between oncologists and pts.	Cross-sectional	Questionnaire	Physicians working with metastatic / advanced pts. with breast cancer (n=118)	Japan	72% had engaged in ACP. Among these, 33% used a structured format to facilitate the conversation and 8% settled triggers or sentinel events for the initiation of ACP. The opportunity to learn communication skills was associated with physicians' engagement with ACP. Communication about pts.' life expectancy was less frequent vs. other topics
Spring et al., 2021 [35)	Evaluate physicians' perspectives surrounding ACP	Cross-sectional	Questionnaire	Intensivists and hematologic oncologists (n=111)	Canada and UK	15.5% reported that ACP happens routinely at their institution, whereas 8.3% stated that code status is routinely discussed. ACP discussions were most commonly reported at the onset of critical illness (84.3%), during disease recurrence (52.9%), or during the transition to a strictly palliative approach (54.9%)

Tros et al., 2022 [37]	Investigate how perceived optimal timing of ACP initiation and its triggers relate to recorded actual timing	Retrospective	EMR analyses	General practitioners (n=83; n=51 EMR) of deceased pts. with cancer, organ failure or multimorbidity	Netherlands	The actual timing of ACP initiation was significantly closer to death than the perceived optimal timing in pts. with cancer (median 88 vs. 111 days before death), organ failure (227 vs. 306 days before death) and multimorbidity (113 vs. 338 days before death)	Triggers for recorded actual vs. perceived optimal timing were similar across the three groups, the most frequent being "expressions of pts.' reflections or wishes" and "appropriate setting"
Tros et al., 2022 [36]	Identify the optimal moment for, and reasons to initiate ACP	Cross-sectional	Questionnaire	General practitioners (n=83; n=90 EMR) of deceased pts. with cancer, organ failure or multimorbidity	Netherlands	The median optimal ACP timing according to the GPs was 228 days before death. This moment was closer to death for cancer pts. (87.5 days before death) than for organ failure (266 days before death) and multimorbidity (290 days before death)	The most frequently mentioned reason for cancer was “receiving a diagnosis” (21.5%), for organ failure was “after a period of illness” (14.7%), and for multimorbidity was “age” and “pts” expressed wishes or reflections’ (both 12.0%)
Van der Padt-Pruijsten et al., 2022 [44]	Examine why pts. are hospitalized in the last stage of life	Retrospective	Medical records analyses	Deceased pts. with mixed solid and hematological cancer (n=264)	Netherlands	80% had been admitted to the hospital because of symptom distress. Dyspnea (39%) and pain (33%) were the most common symptoms. A DNR code had been recorded before admission in 42% of the pts. and in an additional 52% during admission	
Zwakman et al., 2021 [38]	Determine how readiness is expressed and develops throughout an ACP conversation	Cross-sectional sub-study of a RCT	Semi-structured interviews	Pts. with stage III and IV lung or colorectal cancer (n=15)	Netherlands		Signs of being ready for ACP conversations included anticipating possible future scenarios or demonstrating an understanding of one’s disease. Signs of not being ready included limiting one’s perspective to the here and now or indicating a preference not to talk about an ACP topic. Signs of not being ready occurred more often when future-oriented topics were discussed.

Abbreviations: ACP: Advance Care Planning; AD: Advance Directives; AML: Acute Myeloid Leukemia; DNI: Do-Not-Intubate; DNR: Do-Not-Resuscitate; EMR, electronic medical records; EoL: End-of-Life; GoC: Goals of Care; ICU: Intensive Care Unit; LW: Living Will; MDS: Myelodysplastic Syndromes; PC: Palliative Care; POA: Power of Attorney; Pt(s): patient(s).

Table 2. The conversational protocol CERTAIN: a mnemonic communication system to help physicians in their use of complex communication skills needed to address uncertainty and support hope while initiating a discussion about advance care planning (ACP)

Steps	Aims	Methods[1]	Examples[2]
Create a clear, safe, and positive setting	Propose to talk about expectations	Offer an adapted setting (i.e., place, time, and confidentiality)	*In the next 20 minutes, I would like to discuss what we can expect from this new treatment.*
		Assess patient willingness	*What do you think about that?*
	Allow refusal	Postpone the discussion by negotiating a follow-up	*If I understand properly, now is not the right time for you to talk about what we can expect from this new treatment. We can address this topic at your convenience at a later date.*
Explore general expectations[3]	Explore and clarify general expectations	Ask open questions	*How do you anticipate this new treatment will be? What do you expect from this new treatment?*
	Elucidate specific expectations	Acknowledge and clarify	*So, you don't know where you're going. What do you mean, more precisely?*
Recognize specific expectations[3]	Assess specific expectations	Summarize specific expectations	*If I understand, you think this treatment may control your cancer, but not cure it.* *If I understand, you think this treatment may cure your cancer.* *If I understand, you think there's no chance this treatment will control your disease.*
	Encourage corrections or comments	Allow to react to the proposed summary	*Is that right?*
Tackle beliefs and expectations[3]	Correct unrealistically optimistic expectations	Break bad news	*I need to tell you that your medical situation is more severe.*
	Correct unrealistically pessimistic expectations	Break good news	*I have to tell you that your medical situation is more favorable.*
Acknowledge remaining expectations[3]	Share common expectations	Acknowledge common expectations	*We both think, indeed, that this treatment may control your cancer, but not cure it.*
Investigate and support hope[3]	Investigate and support wishes	Assess wishes within common expectations	*Considering this, what is most important for you?*
		Acknowledge wishes within common expectations	*So, you do not wish to become a burden for your loved ones.*
	Investigate and support resources	Assess perceived resources to achieve wishes	*What would help you to not become such a burden to your loved ones?*
		Acknowledge perceived resources to achieve wishes	*So, if your life is in danger and you can no longer live alone, you do not wish to be resuscitated.*
	Initiate a discussion about ACP	Exchange of views and starting a shared decision making	*I should inform you that we may avoid some of your concerns by implementing what we call advance care planning.*
Negotiate follow-up	Debrief the emotional state	Ask open questions	*How do you feel right now?*
	Offer to continue the discussion about ACP	Inform about availability to discuss ACP further	*We can return to this discussion whenever you want*

[1] Due to the highly emotional topics discussed, these strategies must be complemented by acknowledgement (i.e., rephrasing what the patient is saying to allow him/her to feel heard) and support (i.e., empathizing with the emotions the patient has expressed).

[2] To be used in the context of sentinel events that physicians might consider to trigger the need to redefine care goals and initiate ACP (i.e., hospital or intensive care unit admission, new diagnosis of central nervous system metastasis, new chemotherapy regimen, major surgery).

[3] If the patient's physical or psychological discomfort is too great, the physician may proceed directly to step 7 (negotiating follow-up).