

Advance care planning for patients with cancer in palliative care: A scoping review from a professional perspective

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**Advance care planning for patients with cancer in palliative care: A scoping review from a professional perspective**

**Abstract**

**Aims and objectives:** To describe advance care planning (ACP) for patients with cancer in palliative care from professionals' perspective.

**Background:** The number of patients with cancer is increasing. Palliative care should be based on timely ACP so that patients receive the care they prefer.

**Design:** A scoping review

**Methods:** A systematic literature search was conducted in January 2019. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used. The methodological quality of the studies was evaluated using the Joanna Briggs Institute (JBI) Critical Appraisal tools. Data were analysed with content analysis.

**Results:** Of 739 studies identified, 12 were eligible for inclusion. The settings were inpatient and outpatient facilities in special and primary care including oncology, palliative and hospice care. ACP consisted of patient-oriented issues, current and future treatment, and end-of-life matters.

The participants were nursing, medical or social professionals. ACP conversations rarely occurred; if they did, they took place at the onset, throughout, and late in the cancer.

**Conclusions:**

Professionals could not separate day-to-day care planning and ACP. ACP documentation was scattered and difficult to find and use. Professionals were unfamiliar with ACP and established practices were lacking. ACP conversations mostly occurred in late cancer. Further research clarifying concepts and exploring the significance of ACP for patients and relatives is recommended.

**Relevance to clinical practice:**

Our results support the use of ACP by a multidisciplinary team from the early stages of cancer as a discussion forum around patients' wishes and choices. We showed the need to raise professionals' awareness of ACP. Education and appropriate data tools for ACP are important as they may reduce reluctance and promote ACP use. This paper contributes to the wider global clinical community by pointing out the importance of standardising ACP contents and practices.

**KEYWORDS**

Advance care planning, patient with cancer, palliative care, professional perspective, electronic health record, scoping review

## What does this paper contribute to the wider global clinical community?

- Palliative care for a patient with cancer requires ACP including both Advance Care Planning (oral discussion) and an Advance Care Plan (written document). In this scoping review, we describe ACP for patients with cancer in palliative care from a professional perspective.
- ACP is an essential part of overall care planning for patients with cancer in palliative care, but the ACP content, participants involved in the preparation, and timing of ACP are not well established, suggesting the diversity of ACP in clinical practices.
- Awareness of ACP among professionals, especially nurses, needs to be increased. Professionals should be provided with education and training on the importance of ACP.

## 1 INTRODUCTION

Every year, more than 29 million people worldwide die of a disease that requires palliative care. A large proportion of adults requiring palliative care die from cancer. (Connor & Bermedo 2014.) According to a US National Cancer Institute (2019) estimate, the number of new cancer cases per year is expected to rise to 23.6 million by 2030. Early onset palliative care concurrent with curative treatment (Ferrell et al. 2017) can reduce unnecessary use of health and medical services and hospitalisation (Johnson et al. 2016). Palliative care means active holistic treatment of a patient when a fatal or life-threatening illness like cancer causes patients and their relatives suffering and undermines their quality of life. The need of palliative care increases as cancer progresses and death approaches. (World Health Organisation 2019.)

One part of palliative care should be Advance Care Planning (ACP), which is a multifaceted, family-centred and social process (Johnson et al. 2016) by which patients make decisions regarding their future medical care (Rietjens et al. 2017). The primary goal of ACP is to enable patients to consider their goals at the end of life (Agarwall & Epstein 2017, Rietjens et al. 2017, Sudore et al. 2017, Kok et al. 2018, Lamas et al. 2018) so that they will receive the care they desire (Peppercorn et al. 2011). The aim is that their preferences can be taken into account even if they are unable to make their own decisions (Rietjens et al. 2017, Walbert 2017). The starting point of ACP should be patients' right to self-determination (Johnson et al. 2016). Documentation of ACP conversations and/or completion of legal documents on ACP is

recommended (Rietjens et al. 2017). In this review, ACP refers to both oral discussion (Advance Care Planning) and written document (Advance Care Plan). This approach may be more effective than written documents alone (Brinkman-Stoppelenburg et al. 2014, Robinson et al. 2017). It is extremely important to ensure that the medical care provided aligns with the patient's preferences (Sudore et al. 2017), which may vary at different stages of the cancer (Vaartio-Rajalin & Leino-Kilpi 2011), and to help health professionals find, use and discuss ACP to provide care aligned with patients' goals (Lakin et al. 2016, Turley et al. 2016). The failure to engage in ACP may, for example, result in inappropriate resuscitation, which is not in line with the patient's preferences (Pearse et al. 2019).

The results of research on ACP are contradictory. First, according to a systematic review, the following benefits of ACP have been described from the patient's point of view: increased satisfaction, increased number of living wills and treatment limits, reduced family stress, hospital or intensive care periods at the end of life, and increased likelihood of dying in a care unit than in hospital (Brinkman-Stoppelenburg et al. 2014). On the other hand, ACP terminology has been difficult for patients to understand (Robinson et al. 2017) and it has been perceived to be ethically complex both for patients receiving and health professionals providing information regarding the end-of-life (Johnson et al. 2016). Professionals have recognised patient vulnerability and have been concerned about ACP increasing fear and anxiety (Johnson et al. 2016, Robinson et al. 2017) as well as disrupting patients' hope (Robinson et al. 2017). By introducing ACP, professionals are addressing issues of mortality, which is often a taboo subject (Dong et al. 2016). That is why they have not initiated end-of-life conversation with patients who are alone, look anxious and are having difficulties understanding information (Robinson et al. 2017). As for health professionals, ACP has helped them to obtain patients' end-of-life care wishes and prepare for their future medical and palliative needs (Agarwall & Epstein 2017). However, in the opinion of the nurses, it has mainly been used in the form of documentation of treatment choices, e.g. advance directives (Johnson et al. 2016, Turley et al. 2016) and do-not-resuscitate (DNR) orders (Osinski et al. 2017) rather than a communicative or supportive tool for the professional-patient relationship (Johnson et al. 2016). Physicians have reported unfamiliarity with ACP, inadequate content and lack of confidence in finding and using ACP documentation in the electronic health record (EHR), especially in cases of emergency (Lakin et al. 2016). All in

all, the use of a Care Directives Activity Tab in the EHR has been associated with increases in ACP documentation rates (Turley et al. 2016).

## **2 AIM**

The aim of this review is to describe ACP for patients with cancer in palliative care from a professional perspective. The research questions are as follows: (a) What is the content of ACP for patients with cancer in palliative care? (b) Who are the participants involved in preparation of ACP for patients with cancer in palliative care? (c) What is the timing of ACP for patients with cancer in palliative care? The ultimate goal is to promote high-quality palliative care for patients with cancer by producing information that can be of help in developing ACP.

## **3 METHODS**

### **3.1 Design**

A scoping review is a method to systematically explore the size and scope of a body of literature on a topic (Arksey & O'Malley 2005, Peters et al. 2015, Tricco et al. 2016). We used the five-step methodological approach method: 1) identifying the research questions, 2) identifying the relevant studies, 3) study selection including quality appraisal, 4) charting the data, and 5) collating, summarising and reporting the data (Arksey & O'Malley 2005). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews and meta-analyses (Liberati et al. 2009) were followed and a PRISMA checklist was completed "See Supplementary File 1".

### **3.2 Literature search**

To identify articles for this scoping review, a literature search was conducted in five databases (PubMed, CINAHL COMPLETE, Cochrane, Scopus, Web of Science Core Collection) in January 2019. No limits were applied to the language and timeframe for the search because of the limited availability of prior research on this topic. The search strategy included the following terms: (acp-document\* OR "advance care plan" OR "advance care plans" OR "advance care planning") AND (cancer OR carcinom\* OR metastat\* OR oncolog\*) AND ("content\*" OR "information\*" OR "component\*" OR "element\*") according to the requirements of each database.

### **3.3 Inclusion and exclusion criteria**

The inclusion criteria for the studies were 1) original peer-review study, 2) focused on ACP, 3) implemented in the social and health care context and 4) participants were professionals (e.g. physicians, nurses, social workers, hospital theologians) involved in palliative care of competent adult patients with cancer. Studies were excluded if they were 1) reviews, dissertations, discussions, expert opinions, deliberations, speeches or editorial papers, 2) if they concerned only advance directive or living will or code status, 3) if they did not focus on cancer or 4) if the participants were not professionals.

### **3.4 Retrieval of the studies for the review**

The database search produced a total of 739 citations (PubMed, n = 202; CINAHL COMPLETE, n = 133; Cochrane, n = 58; Scopus, n = 186; Web of Science Core Collection, n = 160) and the manual searches yielded five citations. The retrieval process was conducted in two phases. First, duplicate citations were removed in the Cinahl Complete Database using the “exclude Medline records” tool and they were removed manually when found later in the process. After that, two researchers (AK & JS or EH) examined 684 titles and 159 abstracts against the inclusion and exclusion criteria. To achieve agreement, the researchers discussed their selections and decided together which abstracts would be examined at the full-text level. In this phase, a total of 613 titles or abstracts were excluded. Second, the full texts of the 71 studies were assessed by two authors (AK & JS) for their eligibility against the inclusion and exclusion criteria. At this phase, 64 articles were excluded for the following reasons: duplicate (n = 37), did not include professional point of view (n = 19), not cancer-related (n = 6) and not original study (n = 2). Only original studies were selected because the quality of the unpublished literature (grey literature) would have been difficult to evaluate (Levac et al. 2010). Reference lists of all the identified full texts (71 articles) were manually screened for additional studies and 5 articles were eligible. A web search in Google Scholar was conducted to identify possibly overlooked published articles. A total of 113 references were screened, but none were included. The final inclusion and exclusion was approved within the research team. Based on this, 12 articles were included in the review. This process is shown in Figure 1.

### **3.5 Article quality appraisal**



The methodological quality of the 12 selected studies was evaluated by using Joanna Briggs Institute (JBI) Critical Appraisal data tools for qualitative, cross-sectional, cohort or quasi-experimental studies (JBI 2019). Quality was first assessed independently and then together by two reviewers (AK & JS) by assigning scores of either 0 or 1 point per criterion. One point was given if the item was mentioned in the study, and zero if the item was not mentioned or was unclear. The quality of the studies was fairly good (Table 1) and all were included for review.

### **3.6 Data analysis**

The data were analysed by inductive content analysis by study questions (Elo & Kyngäs 2008) in accordance with the protocol for the scoping review method (Arksey & O'Malley 2005). First, the following common characteristics of the studies (n = 12) were collected and tabulated: authors, year of publication, country, purpose, design, participants, setting, sample and main results (Table 2). Second, in order to get the best overall view, the Results sections of the articles were read many times (Bettany-Saltikov 2012) asking “What is the content of advance care plans for patients with cancer in palliative care?”, “Who are the participants in the preparation of ACP for patients with cancer in palliative care?” and “What is the timing of ACP for patients with cancer in palliative care?”. After that, the descriptions of the three research questions were written in three different lists and marked with colour codes. Next, the descriptions (original phrases) were simplified. The data resulted in 79 simplifications describing the content of the ACPs, 42 simplifications describing the participants involved in the preparation ACP, and 32 simplifications describing the timing of ACP. According to their data content, the simplified expressions were classified into subcategories. The subcategories consisted essentially of similar simplifications that had accumulated. Substantially similar subcategories were compiled into categories. (Elo & Kyngäs 2008.)

## **4 RESULTS**

### **4.1 Description of the studies**

The twelve original studies were included in this review (Table 2). The studies were conducted in the USA (n = 5), Europe (n = 4), Asia (n = 2) and Australia (n = 1) and they were published in the years 2008–2019 in interdisciplinary (n = 9), medical (n = 2) or nursing (n = 1)

journals. The study designs were cross-sectional ( $n = 5$ ), quasi-experimental ( $n = 2$ ), cohort studies ( $n = 2$ ), observational ( $n = 1$ ), action research ( $n = 1$ ) and mixed methods ( $n = 1$ ). The most commonly used data collection methods were audit of textual data ( $n = 4$ ), which consisted of electronic health and medical records and informed consent forms, interviews ( $n = 3$ ) and surveys ( $n = 3$ ). The data were collected from physicians, nurses, nurse practitioners and social workers. The study settings were inpatient and outpatient facilities in special and primary care including oncology, palliative and hospice care. The data were analysed by qualitative and quantitative methods.

## **4.2 Content of ACP for patients with cancer in palliative care**

The inductive content analysis resulted in three categories: patient-oriented issues, current and future treatment, and end-of-life care, which are the three ACP content areas (Table 3).

### **4.2.1 Patient-oriented issues**

Patient-oriented issues in ACP include six subcategories (Table 3).

*Individuality of the patient* in ACP means that the patient's autonomy is respected and the information provided is individualised (Boyd et al. 2010).

*Patient's abilities to deal with death* was considered a starting point of patient-oriented ACP. It included patient's readiness to discuss ACP as well as their understanding of illness and prognosis (Bickel et al. 2016).

*Patient's wishes and goals* encompassed patient's end-of-life preferences (Samara et al. 2013, Ermers et al. 2018), palliative care and psychosocial needs (Bires et al. 2018) as well as views about future care and treatment (Seymour et al. 2010). Living will (Hu et al. 2010) is one part of ACP where patients can present their personal, emotional, spiritual and medical wishes (Zhou et al. 2010).

*Patient's worries and threats* included any concerns (Bickel et al. 2016) the patient had, such as concerns for the future (Seymour et al. 2010) and the efforts by professionals to avoid them (Bires et al. 2018).

*Substitute decision maker* is a trusted individual named by the patient (Zhou et al. 2010). Different names were used, like power of attorney for health care (Hu et al. 2010, Zhou et al. 2010, Obel et al. 2014), healthcare proxy (Zhou et al. 2010, Thomas et al. 2019) or health care surrogate (Bickel et al. 2016).

*Involvement of patient's relatives* was viewed as important (Samara et al. 2013, Bickel et al. 2016). Their contribution to ACP was visible in their understanding of the patient's illness, prognosis, goals of care and treatment (Bickel et al. 2016), telling them about the disease prediction (Tokito et al. 2015) as well as having received education regarding changes that may occur in the end-of-life phase (Samara et al. 2013). Relatives' ability to plan patient's future care has been assessed (Bickel et al. 2016). Their involvement in discussion about palliative care options has been reported (Zhou et al. 2010) and when confirming DNR order (Tokito et al. 2015).

#### **4.2.2 Current and future treatment**

Current and future treatment in ACP includes three subcategories (Table 3).

*Cancer-related issues and appropriate treatment possibilities* involved all relevant issues as the person's state of health alters (Samara et al. 2013), such as information on disease trajectory (Bires et al. 2018), "incurable disease" (Tokito et al. 2015), prognosis (Boyd et al. 2010) as well as expected effects of disease on symptoms and quality of life (Bickel et al. 2016). Information about future care (Boyd et al. 2010) included areas such as treatment possibilities concerning reasonable treatment options (Bires et al. 2018), expectations for disease control (Bickel et al. 2016) and policies regarding referral, hospitalisation and intensive care (Ermers et al. 2018).

*Anticancer therapy-related issues* concerned information on the goal of therapy (Hirvonen et al. 2018), expected length and frequency of treatment (Bickel et al. 2016), chemotherapy risks, benefits, expenses and supportive care as well as information on participation in clinical trials (Tokito et al. 2015).

*Orders regarding life-sustaining treatment* – in other words, restrictions placed on the care provided (Hirvonen et al. 2018) – included orders regarding medical treatment (Ermers et al.

2018). They were advance directives (Hu et al. 2010, Zhou et al. 2010, Obel et al. 2014, Bickel et al. 2016, Bires et al. 2018), Physician Orders for Life-Sustaining Treatment (POLST) (Zhou et al. 2010) and code status orders (Obel et al. 2014, Bickel et al. 2016, Thomas et al. 2019). They determine the type of emergent treatment a patient would or would not receive if their breathing or heart were to stop, such as decision on resuscitation (Seymour et al. 2010, Obel et al. 2014, Tokito et al. 2015, Bickel et al. 2016, Ermers et al. 2018, Hirvonen et al. 2018).

#### **4.2.3 End-of-life care**

End-of-life care matters in ACP include two subcategories (Table 3).

*Alleviation of suffering* contained issues related to alleviation of suffering, such as preferences for palliative care (Zhou et al. 2010), documenting encounter for palliative care with ICD-10 code Z51.5 (palliative care) (Hirvonen et al. 2018), euthanasia, palliative sedation (Ermers et al. 2018) and hospice care (Zhou et al. 2010, Ermers et al. 2018, Thomas et al. 2019).

*Preferred place of death* references were home (Boyd et al. 2010, Thomas et al. 2019) and nursing care home (Seymour et al. 2010) and were connected with impending death (Ermers et al. 2018).

#### **4.3 Participants involved in preparation of ACP for patients with cancer in palliative care**

The results of the inductive content analysis describing professionals involved in the preparation of ACP for patients with cancer are shown in Table 4.

*Nursing professionals* who cared for patients with cancer were specialists in oncology (Zhou et al. 2010) or palliative care (Seymour et al. 2010) and other nurses; in other words, nurse practitioners (e.g. Seymour et al. 2010, Samara et al. 2013) and practice nurses (Boyd et al. 2010).

*Medical professionals* involved in the treatment of patients with cancer were oncologists (e.g. Thomas et al. 2019) and other physicians in other words, doctors (e.g. Hu et al. 2010) and general practitioners (e.g. Boyd et al. 2010, Ermers et al.).

*Social professionals* were either social workers (Samara et al. 2013, Hirvonen et al. 2018) or care coordinators (Samara et al. 2013).

*Interdisciplinary palliative care interventions* means that physicians, nurses and social workers form a multidisciplinary team for ACP (e.g. Samara et al. 2013, Hirvonen et al. 2018).

#### **4.4 Timing of ACP for patients with cancer in palliative care**

The results of the inductive content analysis describing the timing of ACP for patients with cancer at starting point, throughout the cancer process, and in late cancer are shown in Table 5.

*ACP at starting point* means that the ACP process should start very early on; for example, before the patient is admitted to the hospital, or in the emergency department before being transferred to the ward (Samara et al. 2013). In practice, it was started 1) at disease progression, often at the diagnosis of advanced cancer (Seymour et al. 2010, Zhou et al. 2010, Obel et al. 2014, Bickel et al. 2016, Bires et al. 2018), 2) before first-line chemotherapy (Tokito et al. 2015), or 3) when symptoms, such as pain, were persistent and became impossible to ignore (Boyd et al. 2010). In Finland, ACPs were systematically started in palliative outpatient unit using the ICD-10 code of Z51.5 (Hirvonen et al. 2018).

*ACP throughout the cancer process* aims to ensure that regardless of the stage of cancer (Bires et al. 2018), all relevant issues can be taken into account if the patient's health state alters (Samara et al. 2013). These things were noted when preparing and updating the care plan, but not at every visit (Bickel et al. 2016). Do-not-resuscitate (DNR) orders and intensive care policies were documented especially after the patient had been hospitalised (Ermers et al. 2018). Determining the best timing to initiate ACP with different cancer stages and prognoses is challenging (Seymour et al. 2010, Tokito et al. 2015). However, ACP conversations occurred rarely (Bires et al. 2018), not routinely (Boyd et al. 2010), or not at all (Zhou et al. 2010).

*ACP in late cancer* designates that it was started very late in the disease trajectory (Seymour et al. 2010). In practice, this meant when patients were discharged from hospital care once oncology treatment had ended (Boyd et al. 2010) and had only a couple of months to live (Bires et al. 2018, Ermers et al. 2018), or only with late-stage patients, particularly those with deadly or quickly progressing cancers nearing end-of-life (Bires et al. 2018). However, Thomas et al. (2019) found a low frequency of ACP on outpatient visits after first and second cancer

progressions although according to Hirvonen et al. (2018), both DNR and living wills should be in order in the case of late palliative or end-of-life-stage cancer.

## 5 DISCUSSION

The benefits of ACP have been identified from the perspective of patients (Brinkman-Stoppelenburg et al. 2014) and professionals (Agarwall & Epstein 2017). However, ACP is still a new concept in health care (Lakin et al. 2016, Rietjens et al. 2017) and lack of relevant research on the subject is prominent. Based on the reviewed studies, the ACP contents, participants involved and timing of ACP for patients with cancer in palliative care were summarised.

This scoping review was carried out from a professional point of view but patient-oriented issues, such as patient's wishes (e.g. Ermers et al. 2018, Hirvonen et al. 2018), were included in ACP alongside current and future treatment and end-of-life matters. These findings are in line with Sudore et al. (2017) in that ACP should include the things that the patient wants. Situations where professionals need to make end-of-life decisions without knowing the patient's preferences are difficult. Based on this study, patient's living will as part of ACP should be included in high-quality palliative care (Bickel et al. 2016). They have seldom been confirmed (Tokito et al. 2015), but their number and quality has increased after the establishment of palliative outpatient clinics (Hirvonen et al. 2018). Previously, Johnson et al. (2016) argued that ACP should be a supportive tool for professional-patient relationship. In our study, legal documents like DNR (Ermers et al. 2018) were valued more than communicating patients' end-of-life wishes (Zhou et al. 2010), and professionals were confused by the differences between day-to-day care planning and ACP (Seymour et al. 2010). These findings are in line with earlier statements by Robinson et al. (2017) that oncologists viewed conversations about the goals of cancer treatment completely differently from those oriented to end-of-life treatments, which led them to question the utility of both. We found that ACP documentation was not structured in EHR (Ermers et al. 2018), which resulted in information being scattered and difficult to find and use. This confirms the earlier findings (Lakin et al. 2016). We found only one study where palliative care line was mentioned (Hirvonen et al. 2018). This is a significant finding because patients in need of palliative care should be identified in the service system. Lack of care policies as well as inadequate and poorly accessible instructions for symptom management can lead to unnecessary emergency visits.

Based on our scoping review, the professionals involved in ACP were mainly medical or nursing professionals, less frequently social professionals. This is in line with recommendations that non-physician professionals can support patients in ACP (Rietjens et al. 2017). We did not find references to other professionals' point of view on ACP unlike Johnson et al. (2016), who found pastoral providers involved in ACP. Our results are similar to a previous systematic review where professionals in other words nurses and physicians expected an individual or group other than themselves to initiate ACP. Studies involving nurses reported that they believed that physicians, patients, social workers, care coordinators or pastoral care providers should initiate ACP discussion. (Johnson et al. 2016.) In our study, nurses reported that ACP is the responsibility of physicians, social professionals or other qualified persons (Samara et al. 2013). One reason for this may be that based on this review, nurses were unfamiliar with ACP (Seymour et al. 2010) and their practices were not routine (Zhou et al. 2010). This is a significant finding, as the need for nurses to be familiar and comfortable with discussing and documenting ACP is essential across all fields of specialism and community care teams. We found that education could reduce nursing staff's reluctance towards ACP (Zhou et al. 2010). Previously Robinson et al. (2017) have suggested that ACP should be prepared by patients and other cancer care professionals than oncologists. We found many references to ACP conducted by a multidisciplinary team, which is in line with previous findings (Kok et al. 2018) where the ACP document initiated by the healthcare team was feasible and improved the content of the ACP.

In line with the previous finding of Johnson et al. (2016), we found that providers were reluctant towards early initiation of ACP (Boyd et al. 2010, Zhou et al. 2010). Median period from the first ACP documentation to death was 2 weeks (Ermer's et al. 2018) and most patients with advanced cancer had no ACP discussion (Zhou et al. 2010), contrary to clinical practice guidelines (Ferrell et al. 2017). Before now, oncologists have believed that the appropriate trigger for ACP is a diagnosis of advanced cancer, not simply a diagnosis of cancer (Robinson et al. 2017). Our findings are in line with recommendations that individuals can engage in ACP in any stage of their life (Rietjens et al. 2017, Sudore et al. 2017, Walbert 2017, Kok et al. 2018), but revisiting their wishes, especially when health worsens (Rietjens et al. 2017) or during transition (Sudore et al. 2017) is important. Earlier, Robinson et al. (2017) have called for selective and strategic targeted ACP. In our review, Bires et al. (2018) stated a need for ACP especially in patients with predictable problems, but Samara et al. (2013) are in favour of

extending ACP use from oncological patients to all hospital patients. In their review, Obel et al. (2014) stated that those professionals who were comfortable with conducting ACP and had suitable tools for it could develop ACP early. Previous studies show a lack of standards to guide ACP documentation in EHR (Johnson et al. 2016, Lamas et al. 2018) and inappropriate tools (Lakin et al. 2016). All in all, determining the best timing of ACP with different cancer stages and prognoses is challenging (Seymour et al. 2010, Tokito et al. 2015). New cancer therapies and rapid drug development have made prognosis and estimation of life expectancy difficult (US National Cancer Institute 2019).

### *Strengths and limitations*

This scoping review was conducted in an honest and open manner in accordance with good scientific practice (TENK 2012) and it meets high scientific quality standards and guidelines for scoping reviews (Peters et al. 2015, Tricco et al. 2016), including the five-step methodological approach method (Arksey & O'Malley 2005) and PRISMA guidelines and checklist (Liberati et al. 2009). We used the evaluation criteria tools for methodological quality appraisal (JBI 2019) to increase reliability, although it is not necessary in scoping reviews (Peters et al. 2015). The questions were well suited because only two statements were not applicable (Table 1). Four articles in the original material were of high quality while one was of lower quality. High quality means that the articles received full score and low quality that the article received less than half of the maximum score in the quality evaluation. Calculating the number of simplified descriptions represents the coverage of the material. Ethical approval was not needed. In this scoping review, we synthesised and appraised previously published studies. We did not recruit participants.

The limitations of this study were seen in the terminology, which affected the research questions and search terms. The keywords are strictly delineated into certain concepts and, therefore, some aspects of ACP in the patients with cancer context may remain excluded. The ACP concept is still in the definition phase (Rietjens et al. 2017) and the lack of well-defined terminology may hide relevant publications under terms such as end-of-life or goal of care discussion or conversation. The use of general keywords like 'cancer' instead of specific terms like 'glioma' (Walbert et al. 2017) and excluding 'palliative care' from search terms may have excluded some studies. In the analysis phase, the diversity of the studies challenged the



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synthesis. In the case of any unclear points, the original material was referred to for better understanding. The original studies describe the ACP in the context of very different health service systems with their own political, cultural and legal issues. This should be taken into account when applying the results. ACP provides professionals with a discussion forum around patients' wishes and choices but ACP practices are not yet well established.

## 6 CONCLUSIONS

In general, the results of this scoping review confirm and complement the recommendation of Rietjens et al. (2017) for patients with cancer from a professional perspective. Professionals could not separate day-to-day care planning and ACP, which included patient-oriented issues like patient's wishes alongside treatment at the moment and in the future and at end of life. ACP documentation was scattered and difficult to find and use. Physicians, nurses, and to a lesser extent, social workers, but no other professional groups, were involved. Professionals were unfamiliar with ACP and their practices were not established. ACP conversations occurred rarely and if they did, took place at starting point, throughout and late in the cancer. Further research clarifying the concepts and exploring the significance of ACP for patients with cancer and their relatives is recommended.

## 7 RELEVANCE TO CLINICAL PRACTICE

The results of this scoping review are important for clinical practice for developing evidence-based practice for patients with cancer in palliative care. Our results support the use of ACP conducted by a multidisciplinary team in early cancer to promote the continuity of patient's care. We showed that there is a need to raise professionals' awareness of ACP. Education and appropriate tools for ACP are important. They may reduce reluctance and promote ACP use. This paper contributes to the wider global clinical community by pointing out the importance of standardising ACP contents and practices.

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## **SUPPORTING INFORMATION**

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**TABLE 1** Appraisal of the methodological quality of the studies (*n* = 12)

Appraisal of qualitative studies (n = 3)												
	Is there congruity between the stated philosophical perspective and the research methodology?	Is there congruity between the research methodology and the research question or objectives?	Is there congruity between the research methodology and the methods used to collect data?	Is there congruity between the research methodology and the representation and analysis of data?	Is there congruity between the research methodology and the interpretation of results?	Is there a statement locating the researcher culturally or theoretically?	Is the influence of the researcher on the research, and vice-versa, addressed?	Are participants, and their voices, adequately represented?	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data	JBIC Total Quality scores	
Boyd et al. (2010)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10	
Seymour et al. (2010)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	10/10	
Thomas et al. (2019)	Y	Y	Y	Y	Y	Y	Y	Y	unclear	Y	9/10	
Appraisal of cohort studies (n = 2)												
	Were the two groups similar and recruited from the same population?	Were the exposures measured similarly to assign people to both exposed and unexposed groups?	Was the exposure measured in a valid and reliable way?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	Were the outcomes measured in a valid and reliable way?	Was the follow-up time reported and sufficient to be long enough for outcomes to occur?	Was follow-up complete, and if not, were the reasons to loss to follow-up described and explored?	Were strategies to address incomplete follow-up utilised?	Was appropriate statistical analysis used?	JBIC Total Quality scores
Ermers et al. (2018)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	11/11
Hirvonen et al. (2018)	N	Y	Y	Y	Y	Y	Y	Y	Y	n/a	Y	9/11

(Continues)



**TABLE 1 (Continues)**

Appraisal of analytical cross sectional studies (n = 5)										
	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of condition?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the outcomes measured in a valid and reliable way?	Was appropriate statistical analysis used?	JBIC Total Quality scores	
Bickel et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	8/8	
Bires et al. (2018)	Y	Y	n/a	N	N	N	N	Y	3/8	
Hu et al. (2019)	Y	Y	Y	Y	Y	Y	N	Y	7/8	
Tokito et al. (2015)	Y	N	Y	Y	Y	N	Y	Y	6/8	
Zhou et al. (2010)	Y	Y	Y	Y	N	N	Y	Y	6/8	
Appraisal of quasi-experimental studies (non-randomised experimental studies) (n = 2)										
	Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Were the participants included in any comparison similar?	Were the participants included in any comparisons receiving similar treatment/ care, other than the exposure or intervention of interest?	Was there a control group?	Were there multiple measurements of the outcome both pre and post the intervention/ exposure?	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Were the outcomes of participants included in any comparisons measured in the same way?	Were outcomes measured in a reliable way?	Was appropriate statistical analysis used?	JBIC Total Quality scores
Obel et al. (2014)	Y	Y	Y	Y	unclear	Y	Y	Y	Y	8/9
Samara et al. (2013)	Y	Y	N	N	Y	Y	Y	Y	Y	6/9

Source: Joanna Briggs Institute, Critical Appraisal Tools 2019

**TABLE 2** Characteristics of the studies (N = 12)

<b>Authors Year Country</b>	<b>Purpose</b>	<b>Design</b>	<b>Data collection and data analysis methods</b>	<b>Sample and setting</b>	<b>Main results from a ACP perspective</b>
Bickel et al. 2016 USA	To define what constitutes high-quality palliative care as delivered by medical oncology practices	Cross-sectional	Modified Delphi panel Quantitative analysis	Sample: 22 physicians, three patient advocates, two social workers, two nurses and two nurse practitioners Setting: medical oncology in USA	The highest proportions of palliative care items were end-of-life care (81%); communication and shared decision-making (79%) and ACP (78%). The lowest proportions were spiritual and cultural (35%) and psychosocial (39%) assessment and management.
Bires et al. 2018 USA	To understand the challenges and personal beliefs regarding ACP with patients undergoing active cancer treatment and their oncology providers	Cross-sectional	Semi-structured face-to-face interviews Quantitative and qualitative analysis	Sample: 20 oncology patients, seven oncologist and three nurse practitioners/fellows Setting: urban, multispecialty ambulatory care cancer centre in one region in USA	Most providers (70%) held ACP conversations with patients with advanced illness only. Ethical implications are inherent in ACP, because patients make medical decisions without always having the necessary information.
Boyd et al. 2010 UK	To assess the feasibility of implementing ACP	Qualitative mixed methods evaluation of a pilot education workshop intervention	Semi-structured face-to-face interviews before/after intervention Telephone interviews Qualitative analysis	Sample: 20/20 GPs and 8/8 community nurses and 9 GPs Setting: Four general practices in south-east Scotland and 9 GPs in palliative care across the UK	Participants supported the general principles of ACP (individualised information about prognosis and future care), but there were many barriers to early ACP, such as uncertain prognosis of the cancer, limited collaboration, a desire to maintain hope and confusion over terminology.

(Continues)

**TABLE 2** Characteristics of the studies (N = 12) (Continues)

Ermers et al. 2018 Netherlands	To examine the application and documentation of ACP for patients with cancer	Retrospective cohort study	Audit of textual data Quantitative analysis Qualitative analysis	Sample: 163 electronic medical records of deceased patients with colorectal or lung cancer Setting: 11 fully computerised general practices in the eastern part of the Netherlands	Documentation of ACP in GPs' EHRs was limited. ACP occurred mainly during the last three months of life and contained patients' preferences for euthanasia (58 %), palliative sedation (46 %) and preferred place of death (26 %). Communication of ACP was low between primary and secondary care.
Hirvonen et al. 2018 Finland	To explore the effect of the end-of-life care project and the palliative care clinic on the management practices of EOL patients with cancer	Retrospective registry-based cohort study before/after	Audit of textual data Quantitative analysis	Sample: 529/432 electronic medical records of patients with cancer attending the emergency department Setting: University hospital in south-western Finland	ACP quality has improved. Prior visits to palliative outpatient clinic correlated statistically well with the more comprehensive ACP information: DNR order; connection to primary care and documented ICD-10 code Z51.5.
Hu et al. 2010 Taiwan	To investigate participation in ACP by cancer care professionals following the enactment of the Natural Death Act in Taiwan in 2000	Cross-sectional	Survey using a structured questionnaire Quantitative analysis	Sample: 153 physicians and 260 nurses Response rate: 72% (431 of 600) Setting: Tertiary institutions, regional hospitals and community hospitals (oncology care wards, palliative care units) from nationwide organisations in Taiwan	Working in a hospice, attitudes and knowledge about the Natural Death Act were factors that positively influenced the participation in ACP. The enactment of the Act contributes to promoting the participation in ACP.
Obel et al. 2014 USA	To test whether incorporating ACP immediately after a stage IV cancer diagnosis is feasible	Quasi-experimental	A feasibility audit of textual data Quantitative analysis	Sample: 48 electronic health records of patients newly diagnosed with stage IV cancer of two oncologists Setting: Integrated community-based health system comprising outpatient and inpatient oncology	Outpatient ACP is feasible early in the care of patients with stage IV cancer through systematic improvement in workflow and motivated providers. Education and infrastructure were pivotal for development of ACP.

(Continues)

**TABLE 2** Characteristics of the studies (N = 12) (Continues)

Samara et al. 2013 Australia	To assess the uptake of ACP by health professionals and explore nurses' perceived barriers for implementing ACP	Quasi-experimental before/after audit	Questionnaire-based JBI audit criteria and focus group interview as part of an ACP intervention Quantitative analysis Qualitative content analysis	Sample: 23/27 nurses and 9/3 doctors 25 nurses participating in the focus group Setting: Oncology departments of a public teaching hospital in Canberra, Australia	The post-audit results were lower than the pre-audit results. Lack of time to implement ACP was the most frequently reported barrier. Development programme is promising to promote the uptake of ACP.
Seymour et al. 2010 UK	To examine how community palliative care nurses understand ACP and their roles within ACP	Qualitative action research	Six focus group discussions Three follow-up workshops Qualitative analysis	Sample: 23 community nurses Setting: Two cancer networks in England	Nurses assessed ACP to be important and to have the potential to serve good nursing care. They saw their roles in ACP as engaging with patients to elicit care preferences, facilitate family communication and enable a shift towards palliative care.
Thomas et al. 2019 USA	To describe the content of patient-clinician discussions among patients receiving palliative care and to compare differences between oncologists and PC clinicians	Qualitative observational study	Audio-recorded visits as part of larger randomised clinical trial Quantitative analysis Qualitative analysis	Sample: 34 oncologist and 34 palliative care clinician visits immediately after patients' (n = 19) first and second progressions, nineteen patients, seven oncologists and ten PC clinicians (physicians and nurses) Setting: not reported	Of the major topics (symptom management, medical understanding, treatment decision making, coping with illness, supporting caregivers, ACP) clinicians addressed ACP with the least frequency, although ACP occurred more often during palliative care visits than during oncology visits.

(Continues)

**TABLE 2** Characteristics of the studies (N = 12) (Continues)

Tokito et al. 2015 Japan	To investigate the ACP implementation before first-line chemotherapy with reference to the American Society of Clinical Oncology Statement (ASCO)	Cross-sectional	Audit of textual data Quantitative analysis	Sample: 136 electronic medical records and informed consent forms of stage IV patients with cancer who received chemotherapy Setting: cancer centre in Japan	The ACP implementation status was as follows: patients received information on “incurable disease before first-line chemotherapy” (70%), “supportive care before first-line chemotherapy” (50%), their prognosis (32%) and DNR decision (21%).
Zhou et al. 2010 USA	To establish and test a survey focused on nurses’ knowledge, attitudes, and practice behaviours regarding ACP	Cross-sectional	Survey via e-mail Quantitative analysis	Sample: 89 of 300 oncology advanced practice nurses Response rate: not mentioned Setting: oncology, palliative or hospice care in the eastern USA	Oncology APNs are moderately knowledgeable with positive attitudes towards ACP, but their ACP practice was not routine. The most common barriers were from patients’, families and physicians’ reluctance to ACP.

**TABLE 3 Content of advance care plans for patients with cancer**

<b>Category</b>	<b>Subcategory</b>	<b>Study</b>
<b>Patient-oriented issues</b>	Individuality of the patient	Boyd et al. 2010
	Patient's ability to deal with death	Bickel et al. 2016
	Patient's wishes and goals	Hu et al. 2010, Zhou et al. 2010, Seymour et al. 2010, Samara et al. 2013, Tokito et al. 2015, Bickel et al. 2016, Bires et al. 2018, Ermers et al. 2018, Hirvonen et al. 2018
	Substitute-decision maker	Hu et al. 2010, Zhou et al. 2010, Obel et al. 2014, Bickel et al. 2016, Thomas et al. 2019
	Patient's worries and threats	Seymour et al. 2010, Obel et al. 2014, Bickel et al. 2016, Bires et al. 2018
	Patient's relatives involved in ACP	Zhou et al. 2010, Samara et al. 2013, Tokito et al. 2015, Bickel et al. 2016
<b>Treatment at the moment and in the future</b>	Cancer-related issues and appropriate treating possibilities	Boyd et al. 2010, Samara et al. 2013, Tokito et al. 2015, Bickel et al. 2016, Bires et al. 2018, Ermers et al. 2018
	Anticancer therapy-related issues	Tokito et al. 2015, Bickel et al. 2016, Hirvonen et al. 2018
	Orders regarding life-sustaining treatment	Hu et al. 2010, Seymour et al. 2010, Zhou et al. 2010, Obel et al. 2014, Tokito et al. 2015, Bickel et al. 2016, Bires et al. 2018, Ermers et al. 2018, Hirvonen et al. 2018, Thomas et al. 2019
<b>End-of life care</b>	Alleviation of suffering	Zhou et al. 2010, Ermers et al. 2018, Hirvonen et al. 2018 Thomas et al. 2019
	Preferred place of death	Boyd et al. 2010, Seymour et al. 2010, Ermers et al. 2018, Thomas et al. 2019

**TABLE 4 Participants involved in the preparation of ACP for patients with cancer**

<b>Category</b>	<b>Subcategory</b>	<b>Study</b>
<b>Nursing professionals</b>	Specialised nurses in oncology or palliative care	Seymour et al. 2010, Zhou et al. 2010
	Nurse practitioners	Boyd et al. 2010, Hu et al. 2010, Seymour et al. 2010, Samara et al. 2013, Obel et al. 2014, Bires et al. 2018, Hirvonen et al. 2018
	Practice nurses	Boyd et al. 2010
<b>Medical professionals</b>	Oncologists	Zhou et al. 2010, Samara et al. 2013, Obel et al. 2014, Bires et al. 2018, Thomas et al. 2019
	Other physicians	Boyd et al. 2010, Hu et al. 2010, Seymour et al. 2010, Zhou et al. 2010, Samara et al. 2013, Ermers et al. 2018
<b>Social professionals</b>	Social workers	Samara et al. 2013, Hirvonen et al. 2018
	Care coordinators	Samara et al. 2013

**TABLE 5 Timing of ACP for patients with cancer**

<b>Category</b>	<b>Study</b>
<b>ACP at starting point</b>	Boyd et al. 2010, Zhou et al. 2010, Obel et al. 2014, Tokito et al. 2015, Bickel et al. 2016, Bires et al. 2018, Hirvonen et al. 2018
<b>ACP throughout the cancer process</b>	Boyd et al. 2010, Seymour et al. 2010, Zhou et al. 2010, Samara et al. 2013, Tokito et al. 2015, Bickel et al. 2016, Bires et al. 2018, Ermers et al. 2018
<b>ACP in late cancer</b>	Seymour et al. 2010, Boyd et al. 2010, Bires et al. 2018, Ermers et al. 2018, Hirvonen et al. 2018, Thomas et al. 2019



## PRISMA 2009 Flow Diagram

