

Original Article



Multi Components in the Implementation of Advanced Care Planning for Patients with Cancer: A Scoping Review

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Article Info

Article History:

Received: August 12, 2024

Revised: November 3, 2024

Accepted: September 6, 2025

ePublished: September 10, 2025

Keywords:

Advance care planning, Advance directive, Cancer, Oncology, Scoping review

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Abstract

Introduction: Advance care planning (ACP) facilitates patients' preferences for future treatment. It has been associated with improved quality of end-of-life care. While several factors contribute to ACP implementation, little is known about the specific components involved. This scoping review aimed to identify and explore components of ACP, including knowledge, attitudes, values and beliefs, cultural and ethnic factors in patients with cancer and their families.

Methods: The scoping review followed the updated Preferred Reporting Items for Systematic Reviews and Meta-Analysis Scoping Review (PRISMA-ScR) 2020 checklist. A search was conducted in the PubMed, Scopus, and Science Direct databases until December 2023, and the selected articles were assessed using the Joanna Briggs Critical Appraisal Tool (MMAT).

Results: This scoping review included 42 studies. The included studies were grouped by design: quantitative (n=12), qualitative (n=15), and mixed methods (n=15). Key ACP components identified included knowledge and perceptions (n=28), attitudes and behaviours (n=33), values and beliefs (n=26), and cultural and ethnic aspects (n=13).

Conclusion: This review provides a summary of the crucial components including knowledge and perception, attitudes and behaviors, values and beliefs, and cultural and ethnic perspectives to consider when implementing ACP for patients with cancer.

Introduction

Advance care planning (ACP) is defined as a formal decision-making process aimed at helping patients make informed decisions about their future care.¹ ACP incorporates sharing values and preferences for medical care between the patient and health care professionals (HCPs), also often supplemented with input from and involvement of family or informal carers.² In recent decades, patient autonomy has become increasingly essential in ACP. Many patients desire to engage in making decisions and extend their autonomy to future care decisions that take effect when they lose capacity or become incapacitated.³ Over time, a more patient-centred approach evolved in medicine, leading to an enhanced involvement of patients in clinical decision-making.⁴

ACP plays a significant role in addressing palliative care needs and recognizing the end-of-life stage in a timely way,⁵ particularly for meeting patients' end-of-life wishes, as an element of comprehensive care including cancer care.⁶ ACP includes items such as preferred place of care and death, resuscitation policy, treatment limitations

and euthanasia directives.⁵ Furthermore, ACP facilitates patients' preferences for future treatments, including care intensification and invasive interventions. Considering their beliefs, goals, and perceived quality of life, ACP helps HCPs balance medical decisions with patient-centered care,⁷ and help prevent family members from the difficult situation of having to guess what kind of care their loved ones would choose.⁸

In caring for patients with cancer, the ACP has been associated with reduced use of life-sustaining treatments and cancer-directed therapy; fewer hospitalizations and healthcare costs; greater use of hospice services in the last weeks of life; and can lead to more patient-centred care.⁹ Although the ACP being an important in palliative care for those with cancer, the communication around it can be challenging.¹⁰ Further, it was reported that the patient's and family's desire and readiness to hear and accept information about prognosis, meanwhile readiness to discuss such things is variable, and was suggested to be reliant upon the values and characteristics of the individual person and family.¹¹ Additionally, including information

on patients' values, beliefs and more general wishes in the advance directives (ADs) as a part of ACP process may be helpful. When the patients are not able to communicate, their families could provide detail information about the patients preferences and make decisions on behalf of the patients.¹² Thus, it could be challenging for HCPs in providing ACP in regard to various patients and families concerns such as knowledge, attitudes, value and beliefs, culture and ethnic.¹³ So that the implementation of ACP could differ in each different country all over the world, especially the country which consist multi-ethnics and cultures.¹⁴

The growing interest in ACP has resulted in a variety of ACP interventions and programmes,² and usually used in the context of progressive illness and anticipated deterioration.¹ Otherwise, a large variation also still exists in the extent to which ACP documentation takes place,⁵ and affects the ACP and ADs often are not completed, including those in minorities and with lower education and literacy skills.¹⁵ Thus, the HCPs should document care plans and all patient's wishes in a written advance directive form, and share them with patients, family and team members.^{15,16}

As such of ACP implementation, AD_s has been reported that it's associated with a reduction in aggressive treatments, fewer in-hospital deaths, increased use of hospices, and lower hospital charges. Absence of ADs may lead to unwanted aggressive treatments, which correlates to poor quality of life.⁸

Despite growing global interest, the implementation of ACP varies significantly across regions and cultural contexts.¹⁷ Therefore, this scoping review aims to identify and explore components of ACP, including knowledge, attitudes, values and beliefs, cultural and ethnic factors in patients with cancer and their families. The guiding question is "What are the components of ACP in palliative care intervention among patients with cancer or neoplasms and their families?" This review also aims to provide culturally informed guidance for implementing ACP globally.

Material and Methods

This scoping review was conducted in accordance with the updated PRISMA-ScR 2020 checklist.¹⁸

Search Strategy

A comprehensive search was performed in PubMed, Scopus and ScienceDirect databases up to December 2023. Key search terms included "advanced care planning" OR "advance statement" OR "advanced directive planning" OR "end-of-life care planning" AND "cancer" OR "neoplasm" OR "oncology" AND "patient" OR "family".

English-language articles reporting on the implementation of a multicomponent of advance care planning in palliative care intervention targeting individuals aged 18 years and older with cancer or

their family were eligible for this review. Quantitative and qualitative or mixed-method studies that have clear findings from patients or family caregivers were included. We selected studies that discussed aspects of the multicomponent in ACP. We defined a priori a multicomponent aspect that included one or more of the following domains: (1) knowledge, (2) values, (3) attitude and belief (4) culture or ethnicity. Review or protocol were excluded.

Study Selection and Data Abstraction

All abstracts from the initial search were reviewed by 2 reviewers (ER, SA) for possible inclusion in the study. Any uncertainty regarding whether an abstract should be included was brought to the entire group and resolved by discussion. All reviewers (CE, YY, ER, SA) judge the included full-text articles if they meet the study's eligibility criteria. The reference lists of all retained articles were also reviewed to identify additional potentially eligible articles. For the final set of articles reviewed, data were abstracted independently by two reviewers and then discussed by all reviewers. Disagreements were resolved through discussion. Data from articles that detailed the same intervention were incorporated into 1 unit of analysis rather than separating them.

Study quality was assessed independently by all reviewers using the Joanna Briggs Critical Appraisal Tool for cross-sectional and cohort studies and Mixed Methods Appraisal Tool (MMAT) for mixed-method studies. Any discrepancies were resolved by discussion. The tool assesses the overall study quality in 5 areas: Reporting, external validity, internal validity—control of bias, internal validity— confounding, and power. Studies were extracted based on the following categories: Author and year of publication, study location and setting, study design, population demographic data, and ACP components being discussed.

Results

Data Synthesis and Analysis

The current systematic review included qualitative, quantitative and mixed-method studies, therefore a narrative synthesis was conducted. We conducted thematic analysis to categorise knowledge, attitudes, values and beliefs, cultural and ethnic of the patients with cancer and their families into domains from included studies.

Study Selection

Figure 1 shows the PRISMA flowchart diagram. We identified 12,591 studies for title and abstract screening. After removing 699 duplicates, 11,888 records remained. A total of 11,842 records were excluded because they did not meet the inclusion criteria. Forty-six articles were screened by reading the full-text articles.

Four articles were excluded due to irrelevant populations (e.g., studies including children or a mixed cancer and

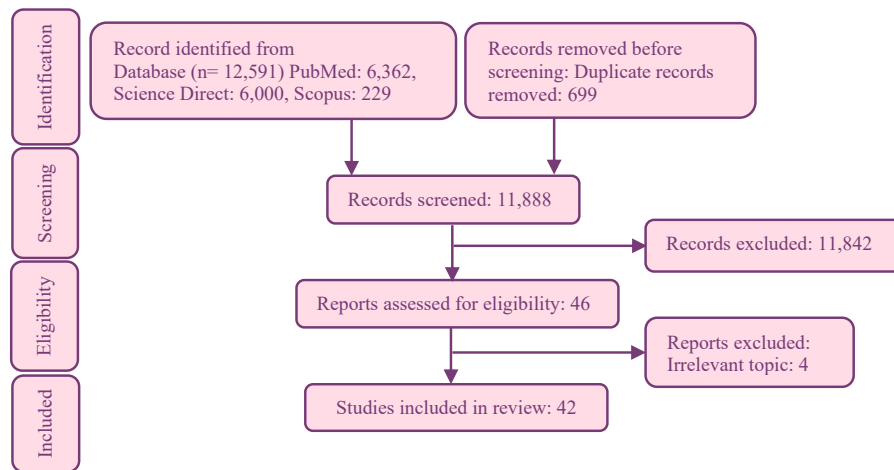


Figure 1. PRISMA flow chart for study selection

non-cancer population). In the end, 42 studies were included in the review.

Characteristics of Included Study

Table 1 shows the characteristics of included studies. The studies included were quantitative (n=12), qualitative (n=15) and mixed methods (n=15). The quality of included studies was high (n=41) and medium (n=1). All studies were conducted in high-income countries including the United States of America (n=14), Canada (n=2), the United Kingdom (n=1), Europe (n=6), China (n=6), Taiwan (n=3), South Korea (n=1), Australia (n=3), multiple countries (n=3), Indonesia (n=1) and Singapore (n=1). Most studies were conducted in hospital settings and involving patients with cancer. A total of 19,573 patients with life-limiting illness and 4,670 family caregivers were involved in the included studies. All included 42 studies reported perspectives from patients and family caregivers, of which 28 studies reported on knowledge and perceptions; 33 studies on attitudes and behaviours, 26 studies on values and beliefs, and 13 studies on culture and ethnics.

Table 2 Shows synthesis of multiple components of ACP from included study. We group the components into: (1) knowledge and perception; (2) attitude and behaviour; (3) values and belief and (4) cultural aspects and ethnic.

Patients and Family Caregivers' Knowledge and Perception on ACP

Twenty-eight studies reported patients' and family caregivers' knowledge and perceptions on ACP. We synthesised findings into three subcomponents: (1) lack of knowledge and information on ACP; (2) varied perceptions of ACP; and (3) education on ACP and its impacts. The majority of included studies found the knowledge and information of ACP was still considered low both among patients and family members, and which caused reluctance in initiating ACP discussion.^{37,30} In addition, the lack of knowledge is considered the strongest barrier in initiating ACP discussion,²² although there is an openness and willingness to engage in such discussions.

Findings of a cross-sectional study in the US show that there is an effort to improve knowledge on ACP by providing education via videos, pamphlets.⁵⁰ In addition, a study from South Korea utilised public promotion and education to facilitate ACP.¹⁹ Such efforts have positive impacts, e.g. the change of treatment preference particularly in life-prolonging treatment measures.²⁰ In addition, the provision of ACP resources patients' discussions on ACP with the physician. Two studies revealed that patients and caregivers prefer to have ACP discussions after being diagnosed.³⁵ However, another study identified that caregivers prefer to have ACP discussions when there is no more treatment or disease recurrence. Participants in the included studies reported that following ACP discussion they prefer comfort care and sought to avoid aggressive treatments.

Patients and Family Caregivers' Attitudes and Behaviour on ACP

Thirty-three studies discussed patients and family caregivers attitude and behaviour. There are three subcomponents: (1) Openness and acceptance to ACP; (2) factors influencing the decision to engage in ACP discussions; and (3) delayed decisions.⁵⁵ Abu al Hamayel et al's study discovered that generally, patients contemplate the importance of considering their end-of-life wishes.³⁹ Moreover, several studies found that the majority of patients can make their own decision regarding end-of-life, although in other studies some patients are influenced by family caregivers in the decision-making. For example, family caregivers from China tend to dominant role in the process of decision-making.

Several factors influence patients and family caregivers in having ACP including the timing of these sensitive discussions, their feelings, and emotions. One study found that more than two-thirds patients think the optimal time to have ACP discussions is after being diagnosed with life-limiting illness.⁵⁶ Earlier ACP discussion leads to lower rates of aggressive care.³¹ Three studies discussed the delayed decisions made by patients and family

Table 1. Characteristics of included studies

Author, Year/ Country	Setting	Method	Population	Results
Park et al ¹⁹ (2019)/Seoul, Korea	General hospitals and National cancer centre	Cross-sectional study	1001 Cancer patients and 1006 family caregivers	Public promotion efforts and education regarding ACP were the most important means for facilitating ACP. One-third of cancer patients and family caregivers were aware AD.
Berkowitz et al ⁶ (2021)/USA	Community-based and academic PC practices	Retrospective cross-sectional study	1,604 Patients with cancer and 1,094 patients without cancer	Patients with cancer still had not identified a healthcare proxy. to assist with conversations and documentation, using decision aids and education tools with patients (eg, videos or pamphlets), and implementing electronic reminders to address ACP
Ermers et al ⁵ (2019)/Nijmegen, The Netherlands	General practices	Retrospective cohort study	163 Deceased patients with colorectal or lung cancer	Lack of documentation disadvantages continuity of care and could be improved by using predictable, homogeneous and exchangeable formats to document ACP. ACP is mainly discussed in the last 3 months of life, showing that the conversation on ACP is initiated late.
Garrido et al ²⁰ (2014)/USA	Out-patient clinic	Quantitative study	606 Patients (437 non-Latino White, 93 Black, 76 Latino) with advanced cancer	The development of interventions that educate patients about the benefits and risks of specific life-prolonging treatments so that patients with advanced cancer are equipped to clarify when they would and would not want a given treatment. Treatment preferences often change after education on the risks and benefits involved in life-prolonging treatment measures
Hu et al ²¹ (2021)/Wuhan, China	Hospital	Cross-sectional study	258 Lung cancer patients	There were 77.5% of patients who regarded hospice care important. One hundred and sixty (60%) patients wanted to make EOL decisions on their own. However, only 10.1% of patients were familiar with AD.
McDonald et al ²² (2017)/Ontario, Canada	The Cancer Centre's Chemotherapy Day Unit	Quantitative survey	193 Cancer patients	Lack of knowledge as the strongest barrier to completing an AD (identified as a strong barrier by 50 % of those surveyed). Procrastination was also identified by many as a strong barrier (46 % of those surveyed). many patients hold misperceptions about medical interventions and care at the end of life
Xing et al ²³ (2017)/China	The Oncology Department	Quantitative study	412 Adult cancer patients	Nearly all the patients deciding on their own AD knew their entire situation, including diagnosis and prognosis. Patients with less knowledge of the modern world (i.e., those not living in cities or with lower educational level) tended to end anti-cancer therapy against the recommendation of the oncologist.
Falzarano et al ²⁴ (2021)/USA	Medical and cancer center	Longitudinal cohort study	98 Dyads patient and caregivers	Advance directive completion may help facilitate terminal illness acknowledgment, making patients more cognizant of planning and coming to terms with their own death. In fact, cognitive acceptance has been associated with DNR order completion and plays a fundamental role in end-of-life decision-making and care.
McMahan et al ²⁵ (2013)/California, US	General hospital and Veteran Affairs Medical center	Qualitative study	38 Patients and 31 surrogates	The inadequacies of ADs saying that the "hypothetical situations" often used in ADs did not prepare them to face the uncertainty of "real" complex medical decision making. Most participants also stated that focusing on specific treatment preferences, such as "the DNR" (Do Not Resuscitate), was not enough to help make the "many decisions" with which they were faced, stating,
van Eechoud et al ²⁶ (2014)/Flanders, Belgium	The acute geriatric ward, the medical oncology ward, and the palliative care unit	Qualitative methodology, with constructivist grounded theory	21 Family members	Several family members, mainly spouses, lacked accurate knowledge about ACP. They either had never heard of or thought about it, or those who said they had considered ACP interpreted advance directives sometimes differently from the meaning they have in Belgian law
Carrion et al ²⁷ (2013a)/Florida, USA	Community health clinics, churches, cultural centers, and support groups	Qualitative study	15 Cancer patients	Only two of the Latino men had completed a living will and two men were knowledgeable about a living will and a health surrogate. Some of the men in the study reported not feeling ready to discuss any ACP, yet others had informally discussed ACP plans with their wives and family members. Those who had limited knowledge and understanding of a cancer diagnosis were particularly worried.
Carrion et al ²⁸ (2013)/ Florida, USA	Community health clinics, churches, cultural centres, and cancer support groups	Qualitative study	45 Cancer patients	The participants' responses highlight the misunderstanding of ACP, as they related it to insurance and financial factors. Of the 13 participants who had heard of ACP but had not completed them, none were able to satisfactorily articulate the definition of ACP.
Voltz et al ²⁹ (1998)/ USA, Germany, Japan	PC and hospice care units	Quantitative study	159 Patients	The answers were classified as positive feelings (for example, relief, happiness) or negative feelings (for example, sadness, loneliness, fear, loss of control, frustration, concern, anger). In the United States and Germany, more than 80% of the patients mentioned negative feelings. In Japan, 17% of patients said they felt no emotions facing their future decision (different from the United States). Only 45% of Japanese patients had negative emotions toward their future decision, this percentage being lower than in the United States or Germany.

Table 1. Continued.

Author, Year/ Country	Setting	Method	Population	Results
Tsai et al ³⁰ (2022)/Taiwan	Family medicine clinic	cross-sectional study	198 Adults who were outpatients of a family medicine clinic	Most (138/198) respondents indicated that ACP is important to very important, of which 60% (85/138) showed a high willingness to participate in AC.
Enguidanos & Ailshire ³¹ (2017)/USA	Data from the Health and Retirement Study	Survey Study	2904 Proxy of deceased cancer patients	The higher prevalence of preference for aggressive care associated with ADs completed in the last three months of life. As the result of hurried discussions around urgent treatment procedures rather than in-depth goals of care discussion. Early completion of an AD is not associated with a preference for more aggressive. Additionally, even ADs completed 10 years or more before death were associated with lower rates of preferences for aggressive care.
Feng et al ⁸ (2020)/Sichuan, China	Oncology outpatient clinic	Cross-sectional study	148 LUNG cancer patients and 149 caregivers	Lung cancer patients, there were significant differences in attitude toward having ADs among patients choosing different time to have ADs and those relying on different people's advice to make medical choices. For caregivers, there were differences in attitude toward having ADs among groups with different attitudes toward the management of patients, including whether patients should know the diagnosis and prognosis of the disease, willingness to advocate surgery and radiotherapy for patients, and caregivers own willingness to receive radiotherapy and chemotherapy if they were diagnosed with cancer.
Kish et al ³² (2000)/Texas, USA	Medical ICU	Prospective quantitative	872 Critically ill cancer patients, Solid and nonsolid cancer	African American generally had a positive attitude about AD, although many did not trust formal documents. Completion of AD will compromise their care; they agree living will help them keep control over their terminal care. African American wanted more life sustaining treatment and less likely to complete a living will
Pautex et al ³³ (2010)/Geneva, Switzerland	Hospital	Retrospective chart review	50 Patients with an advanced oncological disease	Motivations of patients to complete their ADs were: to enhance autonomy, to enhance communication with caregivers, fear of over treatment, not to be a burden, to enhance communication with their surrogates and to be sure their preferences will be respected. Wish to have everything attempted to prolong his life, to have everything done to keep or improve their cognitive function even if symptoms like pain would be experienced, wish not to die alone, and nominated proxies they wanted to stay along during the dying process.
Sahm et al ³⁴ (2005)/Hesse, Germany	The Oncology Clinic and in the Breast Cancer Centre	Survey cohort study	100 Cancer patients	Only a minority of the participants had written an advance directive and knew about the possibility of authorising a health care proxy. Deteriorating health was associated with increasing willingness to make a directive. Despite a majority belief that ADs may influence treatment at the end of life, other factors limit their employment, such as fear of abuse.
Zhang et al ³⁵ (2016)/Guangzhou, China	Seven organ-specific departments in the Sun Yat-sen University Cancer Center	Quantitative study	209 Cancer patients and 215 family caregivers	Most participants (74%) agreed with ADs. More than 80% answered that "when they were diagnosed with a life-threatening disease" was the optimal time for completing ADs.
Driller et al ³⁶ (2022)/Norway	Home care	Retrospective observational cohort study	250 Cancer patients	The patients with ACP conversations also more frequently died at home (impact of ACP)
Hou et al ³⁷ (2021)/Beijing, China	Tumour hospital	Cross-sectional study	264 Advanced cancer patients	The main reasons for refusing to talk about ACP included "trust relatives to make appropriate decisions for them", "trust doctors to make appropriate decisions for them" and "fear of making their relatives sad". Most (67.8%) chose to refuse resuscitation attempts or life-sustaining medical interventions. they considered to accept resuscitation attempts or life-sustaining medical interventions were "could comfort their relatives" and "may prolong their own life", and the main reasons why they refused were "let nature take its course", "were unwilling to drag their family down", "hope to die with dignity" and "were unwilling to have low quality of life". most (70.8%) hoped to have a surrogate decision maker, and their wife or husbands were the most important proxy decision maker.
Michael et al ³⁸ (2014)/Melbourne, Australia	A large tertiary cancer centre	A qualitative descriptive design with grounded theory	18 Caregivers and 17 patients	Caregivers can acknowledge patients' future care wishes while developing subsidiary plans. According to the caregivers, there is often a mismatch between primary and secondary caregivers' and patients' desires to discuss various ACP components. Although agreeing with ACP themselves, some believed that patients would not discuss the concept.

Table 1. Continued.

Author, Year/ Country	Setting	Method	Population	Results
Abu Al Hamayel et al ³⁹ (2019)/Maryland, US	An academic suburban primary care clinic	Qualitative study	20 Older patients	Generally, patients thought it was important to think about their end-of-life wishes and start planning sooner rather than later, when they are not able to make decisions for themselves. This thought process entailed having discussions about wishes and future illness with family members and primary care clinicians in advance of preparing these documents. Patients were aware of the relevance/ importance of ACP as a whole process that includes both discussions with family members and/or primary care clinicians, and completion of ADs or similar forms. Aging and the consequences of aging (e.g., being forgetful) motivated patients to begin exploring their wishes and preferences, and patients' career field, specifically those in medicine or law, which made them more aware of issues that could surface if preferences were not considered early.
Andreassen et al ⁴⁰ (2017)/Aarhus C, Denmark	The departments of cardiology, pulmonology and oncology.	Qualitative study	10 Patients with seriously ill from lung disease, heart disease or cancer	One patient and three relatives described different positive effects the ACP discussion had had on their lives or on the patient's EOL. Three factors in particular were emphasised as having been affected in a positive way by ACP: communication, awareness of dying and a sense of empowerment. Distrust that the preferences described in the advance directive would be met. Another reason for perceiving ACP as insignificant was the view that no one can foresee or control events in connection with EOL care and death which makes it difficult or even impossible to plan for in advance. Patient-relative conflict reveals how an ACP discussion has the potential to obstruct communication about EOL care and death, if one or more of the involved parties are offended or overwhelmed by the subject matter.
Johnson et al ⁴¹ (2017)/New South Wales, Australia	Metropolitan hospitals	Qualitative study	5 Metastatic cancer patients and 6 family members	Cancer and death was framed in terms of a threat to self, and to others, with an accompanying loss of control. Participants described trust as a central element of the experience of having cancer, as patients and family are dependent on other people's expertise and care. Trust extended not only to individuals such as spouses, but doctors and the healthcare system as a whole.
Barnes et al ⁴² (2012)/London, UK	Out-patient clinic	Qualitative study	22 Palliative care and oncology patients	The majority of participants felt the most appropriate time to discuss advance care planning would be after a recurrence of disease, or when treatment has failed and the prognosis is poor. Advance care planning discussions may enhance a sense of control by providing the opportunity to make choices regarding the end-of-life. A number of participants said that having cancer had changed the way they viewed life, so that they wanted to live more in the present and not dwell too much on the future. Some said there were things they would appreciate discussing, but they also wanted to be able to close the topic down again.
Chiang et al ⁴³ (2021)/Hualien, Taiwan	Transnational (Taiwan, Hongkong, Singapore, Australia)	Qualitative study	111 Participants were conducted in Taiwan, Singapore, Hong Kong, and Australia	They were not receptive to life-sustaining treatments that prolonged the near-death process, including intubation, defibrillation, and cardiac massage, as they felt that such treatments not only increase the pain of the patient but also cause distress for their relatives. Participants from Singapore and Australia exhibited significantly more open attitudes. They were willing to engage in end-of-life discussions on any occasion, e.g., during hospitalisation or everyday life at home.
Lipnick et al ⁴⁴ (2020)/Philadelphia and Massachusetts, US	Tertiary care centers	Mixed Method	285 Adult patients with advanced illness alone or with spokespersons (285), 198 spokespersons for interview	Spokespersons indicated that their attitudes toward ACP conversations influenced their stress. For example, those who stated that ACP conversations were stressful focused on the inherent difficulty in having the end-of-life conversations, whereas those who did not experience stress focused on the importance of ACP conversations for gathering information about their loved one's wishes. Many spokespersons focused on their self-described personality, identity, and belief system as impacting whether or not subsequent ACP conversations were stressful. Those who reported ACP conversations as being stressful often said that they were emotional people, and stress often resulted from trying to hide their emotions from their loved ones during conversations. Many spokespersons noted that their stress during ACP conversations was related to their existing interpersonal relationship with their loved one
Karches et al ⁴⁵ (2012)/Chicago, USA	The general internal medicine	Quantitative study	8308 Patients	Religious characteristics, in multivariate analysis, were not significantly associated with having a DNR order, ADs were slightly more common among patients with moderate spirituality than among those with low spirituality
Kubi et al ⁴⁶ (2020)/Maryland, USA	The surgical oncology and medical oncology units	A cross-sectional 19-question survey	200 Cancer patients	Four participants reported that their "religion has direct consequences for [their] medical decisions." This subset of patients felt that ACP was the most powerful way to prevent others from infringing upon their values.
Zheng et al ⁴⁷ (2016)/Chengdu, China	Hospital inpatient services	Quantitative study	526 Cancer patients	Patients in the approved ADs group were more willing to discuss about ADs in the place of cancer centre, were more likely to choose comfort care near the EOL compared with those in the disapproved ADs group. Most of respondents would like to pass away at home. Religious beliefs were more likely to have willingness to designate ADs.

Table 1. Continued.

Author, Year/ Country	Setting	Method	Population	Results
Menon et al ⁴⁸ (2018)/Singapore	Health care institutions	An explorative qualitative study	61 Participants (15 doctors, 13 nurses, 5 MSWs, 15 patients, and 13 caregivers).	All participants expected that ACP had limited value because the relatives were often the key decision-makers. This was especially so for elderly patients as well as patients and caregivers.
Abu Al Hamayel et al ³⁹ (2019)/Maryland, USA	An academic suburban primary care clinic	Qualitative study	20 Older patients	Personal values helped shape patients' preferences. Patients expressed not wanting extreme measures or interventions if they were not getting better, but still wanted to be kept comfortable. Patients highlighted quality of life as a central concept for their preference for refraining from extreme measures. Patients also valued being at home and surrounded with loved ones rather than being in a hospital or a nursing home.
Shen et al ⁴⁹ (2020)/New York, USA	Outpatient cancer clinics	Qualitative study	20 Patients and 9 caregivers	Participants' discussions of the intersection of care with religious faith indicated a powerful belief in the ability of a higher power to restore the patient to health. The consequence of this firm belief or all patients and caregivers who reported that they subscribed to it was that hope was never lost, provided that faith remained strong.
Carrion et al ²⁸ (2013)/Florida, USA	Community health clinics, churches, cultural centers, and support groups	Qualitative study	15 Cancer patients	The participants reported that family members were supportive yet were not always aware of the role changes that occurred as a result of their diagnosis. His religious beliefs enabled him to openly discuss with his physician his inability to accept a blood transfusion during brain surgery.
Epstein et al ⁵⁰ (2015)/New York, USA	Outpatient medical oncologist	Qualitative study	54 Patients with advanced hepato-pancreatic-biliary cancers	Participants were apprehensive about ACP but wanted to discuss it. Information about the process of cardiopulmonary resuscitation (CPR) affirmed existing personal beliefs/ knowledge/ values: 'The video reinforced what we felt inside,' 'I am guided by my [religious] laws,' and 'I don't want my family to suffer' were examples of the various ways in which the themes of affirmation emerged.
Michael et al ³⁸ (2014)/Victoria, Australia	A large tertiary cancer center	Qualitative study	18 Caregivers of the lung and gastrointestinal cancer patients	The caregivers' lack of experience, caring-related fatigue, belief that others will make ACP decisions, or concern that their views will affect patients' plans. ACP, many caregivers said, was confronting in cancer care because of cancer's association with death. Conversations may not occur because imagining the patient's deterioration is "scary" or "things are good now so you tend to forget about it." although agreeing with ACP themselves, some believed that patients would not discuss the concept. "There is no way on this earth that ACP would have suited my parents because that would be like encouraging (other group participants: 'fate?' and 'bad aura?') something."
Agarwal et al ⁹ (2020)/New York, USA	GI medical oncology clinics	Mixed method	151 Patients with advanced gastrointestinal (GI) cancers	The participants with increased distress, thematic analysis demonstrated that nearly all preferred limited or comfort care at the end of life had a negative emotional response and expressed fear of life-prolonging measures (CPR and mechanical ventilation) as depicted in the video and identified their familial relationships and religious faith as sources of support. We believe that distress may therefore be a by-product of engaging in a value-based interview while coping with disease-related emotions and processing information from the video about end-of-life care options.
Zwakman et al ¹² (2020)/six European countries Belgium, Denmark, Italy, the Netherlands, Slovenia and the United Kingdom	Hospital	Mixed method	125 Patients with advanced cancer	Religion was described by most patients. Fifteen patients specified their religion (e.g. Church of England, Catholic or Christian). The same number of patients elaborated on the role their religion played in their lives regarding their disease or described preferences based on their religion. Regarding personal beliefs, a few patients described living day-by-day, not giving up and being positive. One patient described: "I believe in faith, that the course of life and experiences are predestined".
Tsai et al ³⁰ (2022)/Taiwan	Family medicine clinic	Cross-sectional study	198 Adults who were outpatients of a family medicine clinic	Confucianism has deeply influenced the Chinese culture, and thus, consideration of the family is a significant ethical consideration in medical decision making

Table 1. Continued.

Author, Year/ Country	Setting	Method	Population	Results
Garrido et al ²⁰ (2014)/USA	Out-patient clinic	Quantitative study	606 Patients (437 Non-Latino White, 93 Black, 76 Latino) with advanced cancer	The relationship between preferences against life-prolonging care and increased likelihood of advance care planning is consistent across racial/ethnic groups.
Xing et al ²³ (2017)/China	The Oncology Department	Quantitative study	412 Adult cancer patients	Chinese family members always protected the patients from hearing their end-of-life message. Modern Chinese people, mainly living in cities, who have received better education from Western culture tended to participate more in the AD discussion. Moreover, patients with a superordinate family position presented an increased tendency to be involved in their AD discussion. When an AD had to be discussed, patients living in villages tended to follow the traditional Chinese culture and preferred to die in their family temples. Thus, they more actively accepted the concept of ADs and spent the last days of their lives at home.
Chu et al ⁵¹ (2018)/Taipei, Taiwan	Hospital inpatient services	Retrospective study	1411 CHRONIC life-limiting illness patients	All Taiwanese adults who have full capacity to make juridical decisions can establish AD regarding the EOL care and family members can become surrogate decision-makers if patients lose their decisional capacity. The findings of this study suggest that ACP and AD are feasible in the East Asia.
Van Eechoud et al ²⁶ (2014) /Flanders, Belgium	The acute geriatric ward, the medical oncology ward, and the palliative care unit	Qualitative methodology, with constructivist grounded theory	21 Family members	Family members took different positions in the end-of-life care planning for the older patient with a limited prognosis. Family members in this position did not want to be responsible for decision making but strongly felt the expectation of the patient for them to make decisions. This responsibility caused them to feel burdened, and consequently they experienced considerable tension. All family members in this position were non spouses, namely daughters
Carrion et al ²⁸ (2013)/Florida, USA	Community health clinics, churches, cultural centers, and cancer support groups	Qualitative study	45 Cancer patients	Female patients plan ahead with the assistance of their spouse and physician; consequently, they successfully documented their advance care plans. Despite the lack of formal information and the limited provision of knowledge from health professionals, the Mexican women acknowledged the precarious nature of their cancer diagnosis and informally discussed after death plans with family members, trusting that their desires would be fulfilled.
Chiang et al ⁴³ (2021)/Hualien, Taiwan	Transnational (Taiwan, Hongkong, Singapore, Australia)	Qualitative study	111 Participants were conducted in Taiwan, Singapore, Hong Kong, and Australia	Participants from Singapore had divided opinions, with some showing a preference for end-of-life care at home due to the visitor restrictions at hospitals and the inconvenience of travelling back and forth from the hospital for their family members. Other participants preferred to pass away in a hospital or hospice care unit in view of the lack of healthcare professionals and medical equipment at home, the complicated process of filing out a death certificate for a home death, and negative emotions such as fear and a sense of loss that may arise in young children.
Martina et al ⁵² (2022)/Indonesia	In patient ward at a national cancer centre in Jakarta and a tertiary academic general hospital in Yogyakarta	Qualitative study	16 Patients with cancer and 15 family caregivers	Four major themes emerged as important in advance care planning: (1) participants' perceptions on the importance or harmfulness of cancer-related information, (2) the importance of communicating bad news sensitively (through empathetic, implicit, and mediated communication), ⁵⁴ participants' motives for participating in medical decision-making (decision-making seen as patients' right or responsibility, or patients' state of dependency on others), and (4) the complexities of future planning (e.g., due to its irrelevance to participants' religious beliefs and/or their difficulties in seeing the relevance of future planning).
Anaka et al ⁵³ (2022)/Canada	Two tertiary, four regional, and 11 community cancer centers in Alberta province.	Retrospective study	471 Patients newly diagnosed with advanced pancreatic cancer	There is an increased participation of goal of care in the outpatient records of patients with advanced pancreatic cancer during the multifactorial ACP initiative. The goals of care include medical care resuscitation, full resuscitation and comfort care. Multifactorials include participants and translation multilanguage of written materials.
Huepenbecker et al ⁵⁴ (2022)/USA	Single institution but clearly explained	Need assessment	106 Patients	33% of patients had ACP documents, 26 % had discussed ACP with a physician, and the majority (82%) thought discussing ACP was important. The majority preferred these conversations in the outpatient setting (52%) with their gynecologic oncologist (80%) instead of nurses or trainees. ACP discussions with an oncologist during outpatient visits are important to patients and improve their knowledge regarding completing ACP documents.

Table 2. Synthesis of components of ACP

Author (year)	Knowledge and perception	Attitude and behavior	Values and beliefs	Cultural aspects and ethnic factors
Karches et al ⁴⁵ (2012)		✓	✓	✓
Park et al ¹⁹ (2019)	✓	✓		
Voltz et al ²⁹ (1998)		✓		
McMahan et al ²⁵ (2013)	✓			
Tsai et al ³⁰ (2022)	✓	✓	✓	
Enguidanos & Ailshire ³¹ (2017)	✓	✓		
Berkowitz et al ⁶ (2021)	✓			✓
Ermers et al ⁵ (2019)		✓	✓	
Feng et al ⁸ (2020)	✓	✓		
Garrido et al ²⁰ (2014)	✓	✓		✓
Hu et al ²¹ (2021)		✓	✓	✓
Kish et al ³² (2000)		✓	✓	✓
Kubi et al ⁴⁶ (2020)	✓	✓	✓	✓
McDonald et al ²² (2017)	✓	✓	✓	✓
Pautex et al ³³ (2010)		✓	✓	
Sahm et al ³⁴ (2005)	✓	✓	✓	
Xing et al ²³ (2017)	✓	✓	✓	✓
Zhang et al ³⁵ (2016)		✓		
Zheng et al ⁴⁷ (2016)		✓	✓	
Chu et al ⁵¹ (2018)	✓	✓		
Driller et al ³⁶ (2022)		✓		
Falzarano et al ²⁴ (2021)	✓	✓	✓	
Hou et al ³⁷ (2021)	✓	✓	✓	
Menon et al ⁴⁸ (2018)	✓	✓	✓	
Michael et al ³⁸ (2014)	✓	✓	✓	
van Eechoud et al ²⁶ (2014)	✓	✓		
Abu Al Hamayel et al ³⁹ (2019)	✓	✓	✓	
Shen et al ⁴⁹ (2020)			✓	✓
Andreassen et al ⁴⁰ (2017)		✓	✓	✓
Carrion et al ²⁷ (2013)	✓	✓	✓	✓
Carrion et al ²⁸ (2013)	✓	✓	✓	
Epstein et al ⁵⁰ (2015)	✓	✓	✓	
Johnson et al ⁴¹ (2017)	✓		✓	
Michael et al ³⁸ (2014)	✓	✓	✓	✓
Barnes et al ⁴² (2012)	✓	✓	✓	
Chiang et al ⁴³ (2021)	✓	✓	✓	✓
Lipnick et al ⁴⁴ (2020)	✓	✓	✓	✓
Agarwal et al ⁹ (2020)		✓	✓	
Zwakman et al ¹² (2020)			✓	
Huepenbecker et al ⁵⁴ (2022)	✓			
Anaka et al ⁵³ (2022)	✓			
Martina et al ⁵² (2022)				✓

caregivers^{5,31,43} and summarized that conflicting opinions were one of the main contributing factors.

Patients and Family Caregivers' Values and Belief on ACP

Twenty-six studies discussed values and beliefs related to ACP. We divided into two components: Spirituality (religious influence) and the power of belief. Three studies discussed the role of spirituality and religious influence on ACP discussion.^{12,28,45} ADs were found slightly more common among patients with moderate spirituality than among those with low spirituality.⁴⁵ The power of belief was discussed in many included studies. Three studies from the USA found that faith or belief helped patients remain strong, feel supported, and enabled them to openly discuss treatment options with their physicians, including whether to accept or reject care.^{9,28,49}

Patients and Family Caregivers' Culture and Ethnic on ACP

Thirteen studies reported that patients' and family caregivers' cultural and ethnic backgrounds influenced their perspectives on ACP. For example, a study found that modern Chinese people who live in cities and have received Western education tended to participate more in the AD discussion, while patients living in villages tended to follow the traditional Chinese culture and preferred to die in their family temples.²³ One study in Singapore showed that among elderly patients and caregivers ACP had limited value because the relatives were often the key decision-makers.⁴⁸

Table 3 shows categories of findings which consists of components and subcomponents.

Discussion

This study provides a comprehensive review of the research evidence on multiple components of ACP particularly among patients with cancer. To the best of our knowledge, it is the first review to offer a multicomponent perspective on ACP among patients with cancer and their families as caregivers. The study classified these components into key domains: knowledge, attitudes and behavior, values and beliefs, and cultural and ethnic perspectives of patients with cancer.

The evidence shows that lack of awareness and understanding of ACP is one of the main barriers among patients. This is consistent with a review by Crooks et al⁵⁷ which found that lack of knowledge is a principal barrier to ACP in minority ethnic groups. Furthermore, another study found that a lack of ACP knowledge was a key factor influencing outpatients' unwillingness to engage in ACP.³⁰ These findings are also in line with one study reporting that both lack of knowledge and procrastination were the strongest barriers to completing ADs.²² Similarly, patients who have less knowledge due to lower educational level tended to refuse treatment and against healthcare professionals' recommendations.²³ These patients often did not feel ready to discuss ACP, as their limited understanding of their disease led to increased worry and

Table 3. Category findings

No.	Component/ Sub-component	Resources
Knowledge and perception		
1	Lack of knowledge	Tsai et al (2022), ³⁰ McDonald et al (2017), ²² van Eechoud et al (2014), ²⁶ Carrion et al (2013b), ²⁸ Berkowitz et al (2021), ⁶ Carrion et al (2013) ²⁷
	Variety of perception of ACP	Park et al (2019), ¹⁹ Hu et al (2021), ²¹ Abu Al Hamayel et al (2019), ³⁹ van Eechoud et al (2014), ²⁶ Michael et al (2014), ³⁸ Agarwal et al (2020) ⁹
	Education on ACP and its impact	Berkowitz et al (2021), ⁶ Garrido et al (2014), ²⁰ Falzarano et al (2021), ²⁴ Agarwal et al (2020) ⁹
Patient's attitude and behaviours on ACP		
2	Openness and Acceptance of ACP	Xing et al (2017), ²³ van Eechoud et al (2014), ²⁶ Michael et al (2014), ³⁸ Barnes et al (2012), ⁴² Chu et al (2018), ⁵¹ Tsai et al (2022), ³⁰ Zhang et al (2016), ³⁵ Chiang et al (2021), ⁴³ Carrion et al (2013a), ²⁷ Zheng et al (2016), ⁴⁷ Epstein et al (2015), ⁵⁰ Feng et al (2020) ⁸
	Delay of decision	Ermers et al (2019), ⁵ Enguidanos & Ailshire (2017), ³¹ Chiang et al (2021), ⁴³ Feng et al (2020) ⁸
	Influencing factors to have ACP	Kish et al (2000), ³² Chiang et al (2021), ⁴³ Pautex et al (2010), ³³ Sahm et al (2005), ³⁴ Hou et al (2021), ³⁷ McMahan et al (2013) ²⁵
Value and belief		
3	Spiritually (religious influence)	Karches et al (2012), ⁴⁵ Carrion et al (2013), ²⁷ Zwakman et al (2020) ¹²
	The power of belief	Shen et al (2020), ⁴⁹ Zwakman et al (2020), ¹² Tsai et al (2022), ³⁰ Kish et al (2000), ³² Hu et al (2021), ²¹ Kubi et al (2020), ⁴⁶ McDonald et al (2016), ²² Pautex et al (2010), ³³ Sahm et al (2005), ³⁴ Xing et al (2017), ²³ Zheng et al (2016), ⁴⁷ Falzarano et al (2021), ²⁴ Hou et al (2021), ³⁷ Menon et al (2018), ⁴⁸ Michael et al (2013), ³⁸ Abu Al Hamayel et al (2019), ³⁹ Andreassen et al (2015), ⁴⁰ Carrion et al (2013), ²⁷ Carrion et al (2013), ²⁸ Epstein et al (2015), ⁵⁰ Johnson et al (2017), ⁴¹ Barnes et al (2012), ⁴² Chiang et al (2021), ⁴³ Lipnick et al (2020), ⁴⁴ Agarwal et al (2020) ⁹
Culture and ethnic		
4	Culture influence	Menon et al (2018), ⁴⁸ Karches et al (2012), ⁴⁵ Berkowitz (2021), ⁶ Hu et al (2021), ²¹ Kish et al (2000), ³² Kubi et al (2020), ⁴⁶ McDonald et al (2017), ²² Shen et al (2020), ⁴⁹ Andreassen et al (2017), ⁴⁰ Carrion et al (2013), ²⁷ Michael et al (2014), ³⁸ Chiang et al (2021) ⁴³
	Cultural conflict and boundaries	Garrido et al (2014), ²⁰ Xing et al (2017), ²³ Martina et al (2022) ⁵²

hesitation.²⁸ Even though more than half of the participants expressed a desire to make decisions about their end-of-life (EOL) care and considered hospice care important. However, only a tenth of them were familiar with ACP and AD.²¹ When information was cognitively processed and accepted by patients, it was associated with higher completion rates of Do Not Resuscitate (DNR) orders and played a fundamental role in end-of-life decision-making and care.²⁴ Undoubtedly, there are many patients and families had never heard of or considered ACP and AD prior to being admitted to hospital or palliative care unit facilities, resulting in a lack accurate knowledge about ACP.²⁶ Additionally, many patients hold misperceptions about medical interventions and care at the end of life.²²

Attitude among patients and families toward completing ACP varied widely and were affected by their concerns, knowledge, values, and beliefs. There is evidence indicating that the most respondents considered ACP to be important or very important, of which 60% showed a high willingness to participate in ACP.³⁰ Another study reported that patients' expression regarding ACP predominantly included positive feelings (for example, relief, happiness), while the rest were negative feelings (for example, sadness, loneliness, fear, loss of control, frustration, concern, anger). In the United States and Germany, more than 80% of the patients mentioned negative feelings. In Japan, 17% of patients said they felt no emotions facing their future decision (different from the United States). Only 45%

of Japanese patients had negative emotions toward their future decision, this percentage being lower than in the United States or Germany.²⁹

African Americans generally held positive attitudes toward AD, although many did not trust formal documents. Some believed that completing an AD might compromise their care; however, they agreed that having a 'living will' would help maintain control over their end-of-life care. African Americans wanted more life sustaining treatment and less likely to complete a living will.³² Additional motivations for completing ADs included: Enhancing autonomy, improving communication with caregivers and surrogates, fear of overtreatment, avoiding burdening others, and ensuring that personal preferences would be respected, a desire to pursue all available measures to prolong life, maintain cognitive function even if accompanied by pain, avoid dying alone, and designate proxies to be present during the dying process.³³

Values and beliefs were found to frequently impact the acceptability of ACP. For some participants, the end of life was pre-ordained by God, planning for the end of life was perceived to undermine God's authority, or to be unnecessary as their end of life had already been planned by a higher being. Consequently, some faith-centred ethnic groups are choosing not to engage with ACP. Although religion was not specifically measured in this study, previous research often considers ethnicity and religion to be closely intertwined.⁵⁷ Although religion and spirituality

were not significantly associated with the presence of a DNR order, ACP and AD were slightly more accepted among patients with moderate levels of spirituality.⁴⁵ A study reported that religion has direct consequences for patients' medical decisions. This subset of patients felt that ACP was the most powerful way to prevent others from infringing upon their values.⁴⁶

Further, personal values helped shape patients' preferences. Patients expressed not wanting extreme measures or interventions if they were not getting better but still wanted to be kept comfortable. Patients emphasized quality of life as a key reason for avoiding extreme life-prolonging interventions. Patients also valued being at home and surrounded by loved ones rather than being in a hospital or a nursing home.³⁹ Many participants perceived ACP as having limited value, as decisions were often made by relatives rather than the patients themselves. This was especially so for elderly patients as well as patients and caregivers.^{49,48}

The role of a patient's family was found to vary within and across ethnicities: some individuals preferred to make decisions alone and avoid burden to their family, while others placed importance on collaborative familial decision-making. The position of individuals and their families regarding familial or self-expression of end-of-life preferences may impact the perceived relevance and importance of ACP, in turn impacting engagement with ACP conversations and documentation.

Chinese family members often protected the patients from hearing their end-of-life message. Patients with a multigenerational family position presented an increased tendency to be involved in their AD discussion. When AD discussions occurred, patients in rural areas tended to adhere to traditional Chinese values and preferred to pass away in family temples. Thus, they more actively accepted the concept of ADs and spent the last days of their lives at home.²³ Confucianism has deeply influenced the Chinese culture, and thus, consideration of the family is a significant ethical consideration in medical decision making.³⁰ In contrast, in Western culture such as in Belgium, family members took different positions in the end-of-life care planning for the older patient with a limited prognosis. Family members in this position did not want to be responsible for decision-making but strongly felt the expectation of the patient for them to make decisions. This responsibility caused them to feel burdened, and consequently they experienced considerable tension. All family members in this position were non-spousal relatives, predominantly daughters.²⁶

Mexican women acknowledged the precarious nature of their cancer diagnosis and informally discussed after death plans with family members, trusting that their desires would be fulfilled.²⁷ The relationship between preferences against life-prolonging care and increased likelihood of advance care planning is consistent across racial/ethnic groups.²⁰

It is the first scoping review to investigate and map the components of ACP provision for patients with cancer, enabling it to inform ACP policy-making in various countries, particularly those with multicultural and multi-faith populations. No specific findings were identified regarding ACP within particular religious groups. Therefore, it cannot be concluded that ACP is related to religion, although it is related to values and beliefs. Thus, ACP should be viewed from a spiritual perspective.

Conclusion

Studies on ACP involving patients with cancer and their families were systematically searched and reviewed. The multiple components of the ACP were classified into four main domains: knowledge and perception, attitudes and behaviours, values and beliefs, and cultural and ethnic perspectives. Although the ACP has been widely accepted globally, several essential aspects require consideration, including values and beliefs, as well as cultural and ethnic factors.

Recommendation

This review informs us that applying ACP among patients with cancer and their families may require a slight adjustment to ensure it is delivered in a culturally respectful manner. Furthermore, this review also provides insightful findings and serves as a scientific resource for improving ACP guidelines within healthcare facilities. Various aspects are considered to support the implementation of ACP, including effective communication, addressing trust

Research Highlights

What is the current knowledge?

- Advance care planning (ACP) is a structure decision-making process that aims to help patients establish their decisions, incorporating the sharing of values and preferences for medical care between the patients and healthcare professionals.
- In a palliative care setting, ACP plays a crucial role in addressing patients' end-of-life wishes, as a part of comprehensive care particularly for those with cancer.

What is new here?

- This scoping review emphasizes the multifaceted nature of ACP, categorizing its essential elements into four domains: knowledge and perception, attitudes and behaviors, values and beliefs, and cultural and ethnic considerations.
- Integrating ACP and religious among patients with cancer and their families is needed, in order to fulfill patients' and families' spiritual needs
- This scoping review highlights the importance of effective communication, trust-building, and understanding patient preferences in delivering ACP

issues, and promoting awareness of patient preferences. Further research can focus on the implementation of ACP in multi-religious or multi-faith background settings.

Authors' Contribution

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Competing Interests

The authors declare that they have no conflict of interest.

Data Availability Statement

All data generated or analysed during this study are included in this article. The datasets are available from the corresponding author on reasonable request.

Ethical Approval

Not applicable.

Funding

Not applicable.

References

- Mullick A, Martin J, Sallnow L. An introduction to advance care planning in practice. *BMJ*. 2013; 347: f6064. doi: [10.1136/bmj.f6064](https://doi.org/10.1136/bmj.f6064)
- Zwakman M, Jabbarian LJ, van Delden J, van der Heide A, Korlage IJ, Pollock K, et al. Advance care planning: a systematic review about experiences of patients with a life-threatening or life-limiting illness. *Palliat Med*. 2018; 32(8): 1305-21. doi: [10.1177/0269216318784474](https://doi.org/10.1177/0269216318784474)
- Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med*. 2014; 28(8): 1000-25. doi: [10.1177/0269216314526272](https://doi.org/10.1177/0269216314526272)
- Fritz L, Dirven L, Reijneveld JC, Koekkoek JA, Stiggelbout AM, Pasman HR, et al. Advance care planning in glioblastoma patients. *Cancers (Basel)*. 2016; 8(11): 102. doi: [10.3390/cancers8110102](https://doi.org/10.3390/cancers8110102)
- Ermers DJ, van Bussel KJH, Perry M, Engels Y, Schers HJ. Advance care planning for patients with cancer in the palliative phase in Dutch general practices. *Fam Pract*. 2019; 36(5): 587-93. doi: [10.1093/fampra/cmy124](https://doi.org/10.1093/fampra/cmy124)
- Berkowitz CM, Wolf SP, Troy J, Kamal AH. Characteristics of advance care planning in patients with cancer referred to palliative care. *JCO Oncol Pract*. 2021; 17(2): e94-100. doi: [10.1200/op.20.00657](https://doi.org/10.1200/op.20.00657)
- Serey K, Cambriel A, Pollina-Bachelier A, Lotz JP, Philippart F. Advance directives in oncology and haematology: a long way to go—a narrative review. *J Clin Med*. 2022; 11(5): 1195. doi: [10.3390/jcm11051195](https://doi.org/10.3390/jcm11051195)
- Feng C, Wu J, Li J, Deng HY, Liu J, Zhao S. Advance directives of lung cancer patients and caregivers in China: a cross sectional survey. *Thorac Cancer*. 2020; 11(2): 253-63. doi: [10.1111/1759-7714.13237](https://doi.org/10.1111/1759-7714.13237)
- Agarwal R, Shuk E, Romano D, Genoff M, Li Y, O'Reilly EM, et al. A mixed methods analysis of patients' advance care planning values in outpatient oncology: Person-Centered Oncologic Care and Choices (P-COCC). *Support Care Cancer*. 2020; 28(3): 1109-19. doi: [10.1007/s00520-019-04910-1](https://doi.org/10.1007/s00520-019-04910-1)
- Tsuruwaka M, Ikeguchi Y, Nakamura M. When do physicians and nurses start communication about advance care planning? A qualitative study at an acute care hospital in Japan. *Asian Bioeth Rev*. 2020; 12(3): 289-305. doi: [10.1007/s41649-020-00135-1](https://doi.org/10.1007/s41649-020-00135-1)
- Chow J, Harley A, Chroinin DN, Kohler F, Harlum J, Jobburn K, et al. Understanding of advance care planning in primary care: a gap analysis. *Aust J Prim Health*. 2022; 28(4): 344-9. doi: [10.1071/py21253](https://doi.org/10.1071/py21253)
- Zwakman M, van Delden JJ, Caswell G, Deliens L, Ingravallo F, Jabbarian LJ, et al. Content analysis of advance directives completed by patients with advanced cancer as part of an advance care planning intervention: insights gained from the ACTION trial. *Support Care Cancer*. 2020; 28(3): 1513-22. doi: [10.1007/s00520-019-04956-1](https://doi.org/10.1007/s00520-019-04956-1)
- Lasmarías C, Aradilla-Herrero A, Silva Fontana Rosa N, Trelis J. Perceptions and experiences of onco-haematology professionals in relation to advance care planning: a qualitative study. *Support Care Cancer*. 2024; 32(3): 180. doi: [10.1007/s00520-024-08371-z](https://doi.org/10.1007/s00520-024-08371-z)
- Cheng SY, Lin CP, Chan HY, Martina D, Mori M, Kim SH, et al. Advance care planning in Asian culture. *Jpn J Clin Oncol*. 2020; 50(9): 976-89. doi: [10.1093/jjco/hyaa131](https://doi.org/10.1093/jjco/hyaa131)
- Sudore RL, Knight SJ, McMahan RD, Feuz M, Farrell D, Miao Y, et al. A novel website to prepare diverse older adults for decision making and advance care planning: a pilot study. *J Pain Symptom Manage*. 2014; 47(4): 674-86. doi: [10.1016/j.jpainsymman.2013.05.023](https://doi.org/10.1016/j.jpainsymman.2013.05.023)
- Kuusisto A, Saranto K, Korhonen P, Haavisto E. Accessibility of information on patients' and family members' end-of-life wishes in advance care planning. *Nurs Open*. 2022; 9(1): 428-36. doi: [10.1002/nop2.1081](https://doi.org/10.1002/nop2.1081)
- Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AH. Overview of systematic reviews of advance care planning: summary of evidence and global lessons. *J Pain Symptom Manage*. 2018; 56(3): 436-59.e25. doi: [10.1016/j.jpainsymman.2018.05.016](https://doi.org/10.1016/j.jpainsymman.2018.05.016)
- Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med*. 2018; 169(7): 467-73. doi: [10.7326/m18-0850](https://doi.org/10.7326/m18-0850)
- Park HY, Kim YA, Sim JA, Lee J, Ryu H, Lee JL, et al. Attitudes of the general public, cancer patients, family caregivers, and physicians toward advance care planning: a nationwide survey before the enforcement of the life-sustaining treatment decision-making act. *J Pain Symptom Manage*. 2019; 57(4): 774-82. doi: [10.1016/j.jpainsymman.2018.12.332](https://doi.org/10.1016/j.jpainsymman.2018.12.332)
- Garrido MM, Harrington ST, Prigerson HG. End-of-life treatment preferences: a key to reducing ethnic/racial disparities in advance care planning? *Cancer*. 2014; 120(24): 3981-6. doi: [10.1002/cncr.28970](https://doi.org/10.1002/cncr.28970)
- Hu L, Chu Q, Fan Z, Chen Y. Discussion of advance care planning on end-of-life decisions with lung cancer patients in

- Wuhan, China: attitude, timing and future directions. *Intern Med J.* 2021; 51(12): 2111-8. doi: [10.1111/imj.14958](https://doi.org/10.1111/imj.14958)
22. McDonald JC, du Manoir JM, Kevork N, Le LW, Zimmermann C. Advance directives in patients with advanced cancer receiving active treatment: attitudes, prevalence, and barriers. *Support Care Cancer.* 2017; 25(2): 523-31. doi: [10.1007/s00520-016-3433-6](https://doi.org/10.1007/s00520-016-3433-6)
 23. Xing YF, Lin JX, Li X, Lin Q, Ma XK, Chen J, et al. Advance directives: cancer patients' preferences and family-based decision making. *Oncotarget.* 2017; 8(28): 45391-8. doi: [10.18632/oncotarget.17525](https://doi.org/10.18632/oncotarget.17525)
 24. Falzarano F, Prigerson HG, Maciejewski PK. The role of advance care planning in cancer patient and caregiver grief resolution: helpful or harmful? *Cancers (Basel).* 2021; 13(8): 1977. doi: [10.3390/cancers13081977](https://doi.org/10.3390/cancers13081977)
 25. McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. *J Pain Symptom Manage.* 2013; 46(3): 355-65. doi: [10.1016/j.jpainsymman.2012.09.006](https://doi.org/10.1016/j.jpainsymman.2012.09.006)
 26. van Eechoud IJ, Piers RD, Van Camp S, Grypdonck M, Van Den Noortgate NJ, Deveugele M, et al. Perspectives of family members on planning end-of-life care for terminally ill and frail older people. *J Pain Symptom Manage.* 2014; 47(5): 876-86. doi: [10.1016/j.jpainsymman.2013.06.007](https://doi.org/10.1016/j.jpainsymman.2013.06.007)
 27. Carrion IV, Nedjat-Haiem FR, Marquez DX. Examining cultural factors that influence treatment decisions: a pilot study of Latino men with cancer. *J Cancer Educ.* 2013; 28(4): 729-37. doi: [10.1007/s13187-013-0522-9](https://doi.org/10.1007/s13187-013-0522-9)
 28. Carrion IV, Nedjat-Haiem FR, Martinez-Tyson D, Castañeda H. Advance care planning among Colombian, Mexican, and Puerto Rican women with a cancer diagnosis. *Support Care Cancer.* 2013; 21(5): 1233-9. doi: [10.1007/s00520-012-1652-z](https://doi.org/10.1007/s00520-012-1652-z)
 29. Voltz R, Akabayashi A, Reese C, Ohi G, Sass HM. End-of-life decisions and advance directives in palliative care: a cross-cultural survey of patients and health-care professionals. *J Pain Symptom Manage.* 1998; 16(3): 153-62. doi: [10.1016/s0885-3924\(98\)00067-0](https://doi.org/10.1016/s0885-3924(98)00067-0)
 30. Tsai WT, Chen CM, Chung MC, Tsai PY, Liu YT, Tang FC, et al. Important factors influencing willingness to participate in advance care planning among outpatients: a pilot study in central Taiwan. *Int J Environ Res Public Health.* 2022; 19(9): 5266. doi: [10.3390/ijerph19095266](https://doi.org/10.3390/ijerph19095266)
 31. Enguidanos S, Ailshire J. Timing of advance directive completion and relationship to care preferences. *J Pain Symptom Manage.* 2017; 53(1): 49-56. doi: [10.1016/j.jpainsymman.2016.08.008](https://doi.org/10.1016/j.jpainsymman.2016.08.008)
 32. Kish SK, Martin CG, Price KJ. Advance directives in critically ill cancer patients. *Crit Care Nurs Clin North Am.* 2000; 12(3): 373-83.
 33. Pautex S, Notaridis G, Déramé L, Zulian GB. Preferences of elderly cancer patients in their advance directives. *Crit Rev Oncol Hematol.* 2010; 74(1): 61-5. doi: [10.1016/j.critrevonc.2009.04.007](https://doi.org/10.1016/j.critrevonc.2009.04.007)
 34. Sahm S, Will R, Hommel G. Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff. *J Med Ethics.* 2005; 31(8): 437-40. doi: [10.1136/jme.2004.009605](https://doi.org/10.1136/jme.2004.009605)
 35. Zhang Q, Xie C, Xie S, Liu Q. the attitudes of Chinese cancer patients and family caregivers toward advance directives. *Int J Environ Res Public Health.* 2016; 13(8): 816. doi: [10.3390/ijerph13080816](https://doi.org/10.3390/ijerph13080816)
 36. Driller B, Talseth-Palmer B, Hole T, Strømskag KE, Brenne AT. Cancer patients spend more time at home and more often die at home with advance care planning conversations in primary health care: a retrospective observational cohort study. *BMC Palliat Care.* 2022; 21(1): 61. doi: [10.1186/s12904-022-00952-1](https://doi.org/10.1186/s12904-022-00952-1)
 37. Hou XT, Lu YH, Yang H, Guo RX, Wang Y, Wen LH, et al. The knowledge and attitude towards advance care planning among Chinese patients with advanced cancer. *J Cancer Educ.* 2021; 36(3): 603-10. doi: [10.1007/s13187-019-01670-8](https://doi.org/10.1007/s13187-019-01670-8)
 38. Michael N, O'Callaghan C, Baird A, Hiscock N, Clayton J. Cancer caregivers advocate a patient- and family-centered approach to advance care planning. *J Pain Symptom Manage.* 2014; 47(6): 1064-77. doi: [10.1016/j.jpainsymman.2013.07.009](https://doi.org/10.1016/j.jpainsymman.2013.07.009)
 39. Abu Al Hamayel N, Isenberg SR, Sixon J, Smith KC, Pitts SI, Dy SM, et al. Preparing older patients with serious illness for advance care planning discussions in primary care. *J Pain Symptom Manage.* 2019; 58(2): 244-51.e1. doi: [10.1016/j.jpainsymman.2019.04.032](https://doi.org/10.1016/j.jpainsymman.2019.04.032)
 40. Andreassen P, Neergaard MA, Brogaard T, Skorstengaard MH, Jensen AB. The diverse impact of advance care planning: a long-term follow-up study on patients' and relatives' experiences. *BMJ Support Palliat Care.* 2017; 7(3): 335-40. doi: [10.1136/bmjspcare-2015-000886](https://doi.org/10.1136/bmjspcare-2015-000886)
 41. Johnson SB, Butow PN, Kerridge I, Tattersall MH. What do patients with cancer and their families value most at the end of life? A critical analysis of advance care planning. *Int J Palliat Nurs.* 2017; 23(12): 596-604. doi: [10.12968/ijpn.2017.23.12.596](https://doi.org/10.12968/ijpn.2017.23.12.596)
 42. Barnes S, Gardiner C, Gott M, Payne S, Chady B, Small N, et al. Enhancing patient-professional communication about end-of-life issues in life-limiting conditions: a critical review of the literature. *J Pain Symptom Manage.* 2012; 44(6): 866-79. doi: [10.1016/j.jpainsymman.2011.11.009](https://doi.org/10.1016/j.jpainsymman.2011.11.009)
 43. Chiang FM, Wang YW, Hsieh JG. How acculturation influences attitudes about advance care planning and end-of-life care among Chinese living in Taiwan, Hong Kong, Singapore, and Australia. *Healthcare (Basel).* 2021; 9(11): 1477. doi: [10.3390/healthcare9111477](https://doi.org/10.3390/healthcare9111477)
 44. Lipnick D, Green M, Thiede E, Smith TJ, Lehman EB, Johnson R, et al. Surrogate decision maker stress in advance care planning conversations: a mixed-methods analysis from a randomized controlled trial. *J Pain Symptom Manage.* 2020; 60(6): 1117-26. doi: [10.1016/j.jpainsymman.2020.07.001](https://doi.org/10.1016/j.jpainsymman.2020.07.001)
 45. Karches KE, Chung GS, Arora V, Meltzer DO, Curlin FA. Religiosity, spirituality, and end-of-life planning: a single-site survey of medical inpatients. *J Pain Symptom Manage.* 2012; 44(6): 843-51. doi: [10.1016/j.jpainsymman.2011.12.277](https://doi.org/10.1016/j.jpainsymman.2011.12.277)
 46. Kubi B, Istl AC, Lee KT, Conca-Cheng A, Johnston FM. Advance care planning in cancer: patient preferences for personnel and timing. *JCO Oncol Pract.* 2020; 16(9): e875-83. doi: [10.1200/jop.19.00367](https://doi.org/10.1200/jop.19.00367)
 47. Zheng RJ, Fu Y, Xiang QF, Yang M, Chen L, Shi YK, et al. Knowledge, attitudes, and influencing factors of cancer patients toward approving advance directives in China. *Support Care Cancer.* 2016; 24(10): 4097-103. doi: [10.1007/s00520-016-3223-1](https://doi.org/10.1007/s00520-016-3223-1)
 48. Menon S, Kars MC, Malhotra C, Campbell AV, van Delden JJM. Advance care planning in a multicultural family centric community: a qualitative study of health care professionals', patients', and caregivers' perspectives. *J Pain Symptom Manage.* 2018; 56(2): 213-21.e4. doi: [10.1016/j.jpainsymman.2018.05.007](https://doi.org/10.1016/j.jpainsymman.2018.05.007)
 49. Shen MJ, Manna R, Banerjee SC, Nelson CJ, Alexander K, Alici Y, et al. Incorporating shared decision making into communication with older adults with cancer and their caregivers: development and evaluation of a geriatric shared decision-making communication skills training module. *Patient Educ Couns.* 2020; 103(11): 2328-34. doi: [10.1016/j.pec.2020.04.032](https://doi.org/10.1016/j.pec.2020.04.032)
 50. Epstein AS, Shuk E, O'Reilly EM, Gary KA, Volandes AE. 'We have to discuss it': cancer patients' advance care planning impressions following educational information about

- cardiopulmonary resuscitation. *Psychooncology*. 2015; 24(12): 1767-73. doi: [10.1002/pon.3786](https://doi.org/10.1002/pon.3786)
51. Chu D, Yen YF, Hu HY, Lai YJ, Sun WJ, Ko MC, et al. Factors associated with advance directives completion among patients with advance care planning communication in Taipei, Taiwan. *PLoS One*. 2018; 13(7): e0197552. doi: [10.1371/journal.pone.0197552](https://doi.org/10.1371/journal.pone.0197552)
52. Martina D, Kustanti CY, Dewantari R, Sutandyo N, Putranto R, Shatri H, et al. Advance care planning for patients with cancer and family caregivers in Indonesia: a qualitative study. *BMC Palliat Care*. 2022; 21(1): 204. doi: [10.1186/s12904-022-01086-0](https://doi.org/10.1186/s12904-022-01086-0)
53. Anaka M, Lee M, Lim E, Ghosh S, Cheung WY, Spratlin J. Changing rates of goals of care designations in patients with advanced pancreatic cancer during a multifactorial advanced care planning initiative: a real-world evidence study. *JCO Oncol Pract*. 2022; 18(6): e869-76. doi: [10.1200/op.21.00649](https://doi.org/10.1200/op.21.00649)
54. Huepenbecker SP, Lewis S, Valentine MC, Palisoul ML, Thaker PH, Hagemann AR, et al. Gynecologic oncology patient perspectives and knowledge on advance care planning: a quality improvement intervention. *Gynecol Oncol Rep*. 2022; 43: 101060. doi: [10.1016/j.gore.2022.101060](https://doi.org/10.1016/j.gore.2022.101060)
55. Misbah M, Saadat Al Husaini SM, Mujtaba S. An analysis of concept of suffering from a philosophical perspective. *Journal of Hikmat-e-Islami*. 2015; 2(1): 9-31. [Persian].
56. Zhang Y, Cui C, Wang Y, Wang L. Effects of stigma, hope and social support on quality of life among Chinese patients diagnosed with oral cancer: a cross-sectional study. *Health Qual Life Outcomes*. 2020; 18(1): 112. doi: [10.1186/s12955-020-01353-9](https://doi.org/10.1186/s12955-020-01353-9)
57. Crooks J, Trotter S, Clarke G. How does ethnicity affect presence of advance care planning in care records for individuals with advanced disease? A mixed-methods systematic review. *BMC Palliat Care*. 2023; 22(1): 43. doi: [10.1186/s12904-023-01168-7](https://doi.org/10.1186/s12904-023-01168-7)