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What makes advance care planning discussion so difficult? A systematic review of the factors of advance care planning in healthcare settings

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Abstract

Objectives. Existing systematic reviews related to advance care planning (ACP) largely focus on specific groups and intervention efficacy or are limited to contextual factors. This research aims to identify the modifiable factors perceived by different users of ACP in healthcare settings and inform healthcare professionals about the factors affecting ACP practice.

Methods. Five English-language databases (ProQuest, PubMed, CINAHL Plus, Scopus, and Medline) and two Chinese-language databases (CNKI and NCL) were searched up to November 2022. Empirical research identifying factors related to ACP in healthcare settings was included. ACP is defined as a discussion process on future end-of-life care. Thematic synthesis was performed on all included studies.

Results. A total of 1871 unique articles were screened; the full texts of 193 were assessed by 4 reviewers, and 45 articles were included for analysis. Twenty-two (54%) studies were qualitative, 15 (33%) were quantitative, and 6 (13%) used mixed methods. Foci varied from 28 (62%) studies on a single subject group (either patient, family, or physician), 11 (25%) on 2 subject groups (either patient and family or patient and healthcare professional), and 6 (13%) covered 3 subject groups (patient, family, and healthcare professional). Among the 17 studies involving more than 1 subject group, only 2 adopted a dyadic lens in analysis. Complex interwoven factors were categorized into (1) intrapersonal factors, (2) interpersonal factors, and (3) socio-environmental factors, with a total of 11 themes: personal belief, emotions, the burden on others, timing, responsiveness, relationship, family dynamics, experience, person taking the lead, culture, and support.

Significance of results. Patients, families, and healthcare professionals are the essential stakeholders of ACP in healthcare settings. Factors are interweaved among the intrapersonal, interpersonal, and socio-environmental dimensions. Research is warranted to examine the dynamic interactions of the 3 essential stakeholders from a multidimensional perspective, and the mechanism of the interweaving of factors.

Introduction

Over recent years, medical advancement has made various life-sustaining and life-prolonging interventions possible in the course of disease. People nowadays often have more health and social care choices when facing health challenges. The decision-making process always embeds balancing burdens and benefits with uncertain facts and more with the personal values of patients or their families. This may pose a significant challenge to the individual and family during an emotionally stressful period if it has never been discussed previously (Schubart et al. 2014), and advance care planning (hereafter ACP) has received increasing attention since the 1990s (Stoppelenburg et al. 2014). ACP is an iterative communication process in which people discuss their future end-of-life care and treatment plan with their family and healthcare providers. ACP ensures that even if the patient loses mental capacity at that time, the care provided is consistent with their personal values and preferences (Sudore et al. 2017). However, despite ACP's medical, legal, and pragmatic utility and benefits, uptake remains low (Frechman et al. 2020).

Several systematic reviews of factors related to ACP have been published in recent years. However, they tend to focus on specific groups, such as people with intellectual disabilities (Voss et al. 2017), pediatric patients (Brunetta et al. 2022), adult glioblastoma patients (Wu et al. 2021), people with dementia (Tilburgs et al. 2018), disadvantaged adults

(Brean et al. 2023), and underrepresented racial and ethnic groups (Jones et al. 2021). Some are restricted to a specific setting, such as nursing homes (Gilissen et al. 2017; Ng et al. 2022) or general practice clinics (Risk et al. 2019; Tilburgs et al. 2018). The growing understanding of ACP practices among different groups in different settings evidences the significance of the topic and provides descriptive knowledge of the activity. There are also a few systematic reviews and meta-analyses on ACP interventions, which address the efficacy of using conversation guides (Fahner et al. 2019) or generic ACP intervention (Malhotra et al. 2023). As ACP is a complex intervention, its evaluation should capture the underlying mechanism of changes or underpinning program theory and recognize its context (Skivington et al. 2021). Studies identifying impeding and facilitating factors in ACP are needed to postulate the mechanisms of change and guide the development of evidence-based or evidence-informed practice. Schichtel and colleagues (2020) published a systematic review of clinician factors among heart failure ACPs. Batchelor and colleagues (2019) and Risk and colleagues (2019) reviewed studies in Australia and identified factors of ACP in aged care settings and general practice clinics, respectively. Zhu et al. (2023) reviewed the role of acculturation in the process of ACP among Chinese immigrants. One systematic review among the general population on the factors is limited to contextual factors of ACP only (Lovell and Yates 2014). There is no comprehensive view of impeding and facilitating factors for ACP discussions among a wider range of users. The process and outcome of ACP discussion can be affected by both non-modifiable and modifiable factors. The non-modifiable factors help to identify who to target for ACP and whereas, the modifiable factors provide direction on how and what can be improved to achieve ACP. This review aims to inform professionals in healthcare settings about the modifiable factors affecting ACP practice.

Additionally, Lovell and Yates (2014) and McDermott and Selman (2018) suggested that ethnicity and culture have a role in affecting ACPs. Most published systematic reviews relate to studies reported in English. This review also expands its sources to include papers published in Chinese to increase insights for those located in communities with a significant Chinese population.

Methods

This review followed the PRISMA guidelines and was registered with PROSPERO (reference no. CRD42021229829).

Eligibility criteria

This review included only primary research reporting on ACP or ACP discussion with patients suffering from progressive illness published either in English or Chinese in peer-reviewed journals. “Factors” refers to the modifiable impeding or facilitating factors related to ACP from the perspective of the patient, their family or healthcare professional. “Health Care Settings” include both ambulatory care and in-patient care provided in hospital or community health clinics.

Information sources and search

Five English-language databases (ProQuest, PubMed, CINAHL Plus, Scopus, and Medline) and two Chinese-language databases (CNKI and NCL) were searched for studies meeting the inclusion criteria published from inception to November 2022. Table 1 outlines the search teams.

Screening and selection of studies

All publications identified by the search engines were exported using Endnote software, and duplicate articles were removed by the first author (MS). Initial abstract screening was performed by 4 reviewers independently (MS, RW, AC, SKY); 1 reviewer (MS) screened all articles and the other 3 reviewers (AC, SKY, RW) each screened one-third of the abstracts. The results were compared, and discrepancies in selection were resolved by discussion in 2 online meetings. Full-text screening of 45 included articles was subsequently undertaken by 3 reviewers (MS, RW, AC). MS reviewed all full-texts, and RW and AC each reviewed half. Any discrepancies were discussed between the reviewers, and consensus was achieved following 2 online meetings within 2 weeks.

Data extraction and quality appraisal

Data were extracted by 2 reviewers (MS, RW) using a standardized data extraction form to provide consistency, reduce bias, and increase the validity and reliability of the data extraction (Cumpston et al. 2022). The results were organized and sent to reviewers for verification. Methodological quality was assessed using the Mixed Method Appraisal Tool (MMAT), which can accommodate qualitative, quantitative, and mixed methods studies and has good validity and reliability (Pace et al. 2012). In general, the 3 authors (MS, AC, RW) agreed on the assessment of methodology quality. Of the 45 included articles, the 3 authors agreed that 33 (73.3%) were good, with a rating of 4 or 5 out of 5, and 12 (26.7%) were fair, with a rating of 2 or 3 out of 5.

Data analysis and synthesis

Data analysis was informed by the Framework Method involving thematic analysis (Gale et al. 2013). The first author (MS) performed the coding stages with the articles based on the standardized extraction form. The themes were identified and categorized into an analytical framework worksheet with statistical or qualitative information from the studies. An expert panel comprising 2 academic professors, a postdoctoral fellow, and 2 researchers critically reviewed the categorization. The thematic categories were further refined to derive a final set of codes to interpret the results. This study used a descriptive approach to report the findings, and given the heterogeneity of the included studies, it was not feasible to pool results or use meta-analytical approaches.

Results

Study selection

The selection process is illustrated in Figure 1 on the PRISMA diagram. Forty-five studies, 32 in English and 13 in Chinese, were included and proceeded to data extraction as listed in Table 2a and 2b.

Study characteristics

Table 3 summarizes the study design, subjects, disease types, and analytical lens of each included study. Twenty-four (53.4%) studies used quantitative methodology (cross-sectional survey or retrospective data mining), 15 studies (33.3%) used qualitative methodologies (e.g., interviews or focus groups), and the remaining 6 studies (13.3%) used mixed methods. No study utilized a randomized controlled trial.

Table 1. Database search strategy

Database	Search terms	Keywords	Search strategy syntax	Limitations
ProQuest PubMed CINAHL Plus Scopus Medline CNKI NCL	Advance Care Planning Advance Care Plan Advance Care Conversion Patient* Factors*	Advance Care Planning Factors Barriers Facilitators End-of-life	"advance* care planning*" OR "advance care discussion" OR "advance care directive" OR "chronic disease care plan" OR "end-of-life care plan" OR "communication on disease care plan" OR "advance* care conversation" AND "factor" OR "facilitators" OR "barriers" OR "enablers" AND "life-limiting" OR "life-threatening" OR "terminal disease*" OR "terminal illness" OR "serious illness" OR "seriously ill" OR "end-of-life"	Only English or Chinese language

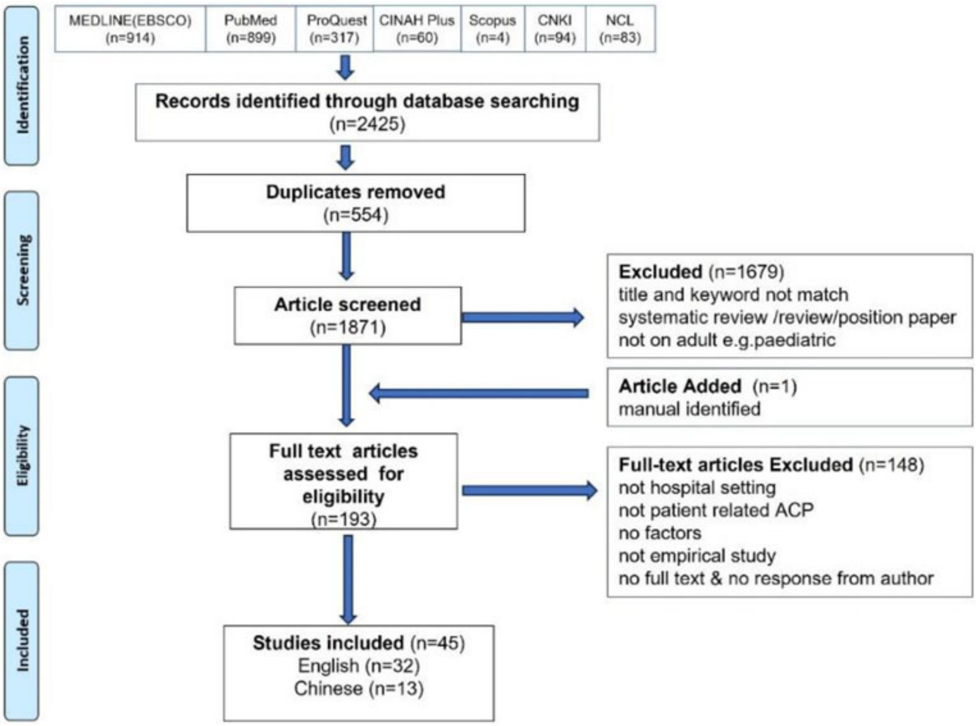

Figure 1. PRISMA diagram: barriers and facilitators of advance care planning in healthcare settings.

Around one-third of the studies were conducted in North America (i.e., the United States and Canada); another third were conducted in Mainland China, and the remaining studies were conducted in other regions, such as Europe and elsewhere in Asia. Patients' illness spectrum covered both cancer and non-cancerous diseases.

Regarding the study subjects, 62% studied a single subject group. Of the studies that involved more than 1 subject group, only 2 (4%) employed a dyadic lens in the research; analysis and reporting in the remaining studies focusing on an individual group's perspective.

Factors influencing ACP discussion

The qualitative and quantitative findings were summarized into 3 thematic categories: (1) intrapersonal, (2) interpersonal, and (3) socio-environmental, and further differentiated in terms of the factors' orientation toward a particular participant group or all groups. Table 4 summarizes the factors and the direction of the force as barriers or facilitators.

Intrapersonal factors

Personal belief

Barriers reported by patients included the personal belief that the consequence of ACP discussion would be harmful or cause death (Curtis and Patrick 1997). Patients and family members both referred to the beliefs that they are powerless in facing death and that ACP discussion was unethical and uncertain on health (Cheung et al. 2020; Greutmann et al. 2013; Knauft et al. 2005; Li and Li 2016) and that concentrating on staying alive was a preferable response (Cheung et al. 2020; Greutmann et al. 2013; Knauft et al. 2005; Steiner et al. 2019; Van den Heuvel et al. 2016). Physicians' beliefs impeding their involvement in ACP included affording it lower priority and considering it to be time-consuming (Hutchison et al. 2017; Van den Heuvel et al. 2016), the role of a physician is to treat the illness (Curtis and Patrick 1997; Ladin et al. 2021) and that end-of-life care discussion was best done by other experts (Cai et al. 2023; Craig et al. 2020; Greutmann et al. 2013; Hutchison et al. 2017; Steiner et al. 2020; Van den Heuvel et al. 2016).

Table 2. (a) Summary of the included English articles ($n = 32$). (b) Summary of the included Chinese articles ($n = 13$)

Study	Site	Design	Subject	*N*	Factor	MMAT
(a)						
Abe et al. (2021)	Japan	Retrospective chart review	Seriously ill cancer and non-cancer hospitalized patients	358	Male gender, living alone, diagnosed more than 1 year	2
Bar-Sela et al. (2021)	Israeli	Mixed methods	Advanced cancer patients	109	Information and open communication with family and staff Ensure the best medical decision, avoid unnecessary procedures No close relative agrees to take up, timing	4
Betker et al. (2021)	Germany	Cross-sectional survey	Advanced cancer patients	112	Quality of life, distress (emotional burden), physical well-being	5
Brown et al. (2014)	USA	Cross-sectional survey	Gynecologic cancer patients	129	Death anxiety decreased communication between patient and family	4
Cai et al. (2023)	China	Cross-sectional survey	Clinicians caring for seriously ill patients in hospitals	285	Cultural factors (barrier) Good understanding of ACP Practice experience	4
Carr (2012)	USA	Mixed methods	Caregivers caring for chronically ill patients	138	Role model effect (witnessed death of significant others at home, free of EOL care problem, hope to avoid negative factors (pain, connection to machines, coma)	3
Carrasco et al. (2021)	Germany	Qualitative semi-structured interviews	Advanced cancer patients and caregivers in out-patient clinic	25	Action readiness, content readiness, impact on future communication and relationship	5
Cheung et al. (2020)	Hong Kong	Qualitative focus group & semi-structured interviews	Terminally ill patients and caregivers in palliative day center	30	Limited patient participation, cognitive and emotional barriers to discussion, lack of readiness and awareness of early discussion, unprepared HCP and healthcare system	4
Craig et al. (2020)	Australia	Qualitative semi-structured interviews	Health carers of patients with neurodegenerative disorder	32	Attitude of clinician (capacity to recognize approaching death, placing of relational autonomy)	4
Curtis and Patrick (1997)	USA	Qualitative focus group	AIDS patients and doctors in HIV clinics	66	Belief of causing harm or hastening death Living will obviated the need for ACP Previous experience of discrimination Wish to protect physician from uncomfortable discussion Quality of communication	5
Ding et al. 2022	Australia	Cross-sectional survey	GPs caring for seriously ill patients	61	Private residence Expectation of death for at least 3 months With PC training	4
Fenton et al. (2021)	USA	Mixed methods	Cancer patients	38	Knowledge and confidence	5
Greutmann et al. (2013)	Canada	Cross-sectional survey	Heart disease out-patients and healthcare professionals	248	Inability to reliably estimate life expectancy (doctor) More physicians than patients believed patient not ready Greater certainty of prognoses (doctor) Trust in doctor, good in taking care of patient with CHD	3
Hu et al. (2021)	USA	Cross-sectional survey	Cancer patients in oncology	272	Gender (female), tumor stage (stage III & IV), number of children (more)	3
Hutchison et al. (2017)	Canada	Qualitative semi-structured interviews	Renal disease patients, caregivers, healthcare professionals in renal center	25	Individual values of ACP Until “illness burden necessitates”	4

(*Continued*)

Table 2. (*Continued.*)

Study	Site	Design	Subject	*N*	Factor	MMAT
Jia et al. (2022)	USA	Qualitative semi-structured interviews	Chinese advanced cancer patients and caregivers in cancer center	28	Trust in clinician, clinician's professional responsibilities, and uncertain future hinder open discussion	5
Kalluri et al. (2022)	Canada	Qualitative semi-structured interviews	IPF patients, caregivers, and healthcare professionals	20	Insufficient information Too late	5
Knauft et al. (2005)	USA	Mixed methods	COPD patients, caregivers, and healthcare professionals in clinics	219	Prefer to concentrate on staying alive Not sure which doctor will be taking care of patient	2
Ladin et al. (2021)	USA	Qualitative semi-structured interviews	CKD patients, caregivers, and healthcare professionals in clinics	68	Minority group (clinician), cultural or religious barriers Role ambiguity and responsibility for ACP Questioning the value of ACP Institutional barriers (time, training, reimbursement, electronic records) Consequences of avoiding ACP (disparities in ACP access, overconfidence that wishes are known to others)	4
Lall et al. (2021)	Singapore	Qualitative interviews	Chronically ill patients and caregivers in 6 hospitals	28	Engagement with death (individual experience, inter-relational, environmental) Formation of preference (personal health concerns, familial care concerns) Choice of proxy (values, personality, proximity) Legacy solidification (financial, needs of other relatives)	4
Maragh-Bass et al. (2021)	USA	Mixed methods (qualitative part)	African American HIV patients and caregivers of a HIV specialty clinic	11	More ACP knowledge (women) Spend more time caregiving (men)	3
Saranza et al. (2021)	Canada	Cross-sectional survey	Parkinson disease patients in movement disorder clinic	90	Prefer when disease has progressed Spirituality and religion decreased the odds of discussion	4
Schichtel et al. (2021)	UK	Qualitative semi-structured interviews	Healthcare professionals (nurses and GPs caring for patients with heart failure	24	Barriers include HCP's fear of death and failure, lack of disease-specific knowledge, uncertainty about professional role, lack of time Facilitators include HF disease-specific training, shared decision-making tools, synchronized communication across specialties, prioritizing time for ACP in HF	4
Simon et al. (2015)	Canada	Qualitative interviews	Seriously ill, older hospitalized patients and their family members in various centers	503	Personal belief, attitude, experience, health status Access to doctor and HCP, information Tools and infrastructure to communicate ACP Interaction, location, timing, quality of communication, relationship with doctor	4
Steiner et al. (2020)	USA	Cross-sectional survey	Adult CHD patients	150	Married, anticipating a shorter lifespan Discussed with ACHD clinician	5
Steiner et al. (2019)	USA	Qualitative semi-structured interviews	CHD patients	25	Arrange logistics Reduce burden on loved one(s) Ensure preferences are honored Cost of creating document Lack of resources to make informed decision Denial and avoidance are easier	5

(*Continued*)

Table 2. (*Continued.*)

Study	Site	Design	Subject	*N*	Factor	MMAT
Tang et al. (2014)	Taiwan	Cross-sectional survey	Cancer patients in 23 teaching hospitals in Taiwan	2467	Patient accurately understands their prognosis Preference for comfort-oriented care and hospice care	5
Toguri et al. (2020)	Canada	Qualitative semi-structured interviews	Advanced cancer patients, caregivers, and healthcare professionals in oncology unit	18	Positive attitudes toward ACO HCPs lack understanding of patients' and families' informational needs during the ACP process Limited access to services and support Poor communication between HCPs Initiation approach Patient-family dynamics Limited formal training, team approach, coordinated system	5
Van den Heuvel et al. (2016)	Netherlands	Cross-sectional survey	Advanced organ failure patients and caregivers in dyads in outpatient clinics in 6 hospitals	318	Trust in physician's competence Earlier experiences with death in their social environment Family and patient fair agreement	5
Yang et al. (2021a)	China	Mixed methods (qualitative part)	Caregivers caring for patients with chronic disease at health centers	14	Attitude toward death Quality of life Family support Past medical experience	4
Yang et al. (2021b)	Singapore	Qualitative semi-structured interviews	Advanced cancer patients, caregivers, and healthcare professionals in 2 hospitals	31	Variation in preference for decision-making (patient vs doctor-led vs shared) Diagnosis disclosure not culturally appropriate	5
Yoo et al. (2020)	Korea	Cross-sectional survey	Advanced cancer inpatients and outpatients and caregivers in 9 hospitals	251	Patients with understanding of illness Caregivers understand patient's illness	2
(b)						
Dai and Zhang (2021)	China	Cross-sectional survey	HIV hospitalized patients	113	Natural acceptance and death escape in death attitude, family support and friend support in understanding social support are influencing factors	3
Ding et al. (2020)	China	Cross-sectional survey	Seriously ill hospitalized patients	205	Education level, religion, income, residence, bereavement experience, CPR experience, awareness of ACP are influencing factors	3
Han et al. (2021)	China	Cross-sectional survey	CVA patients in hospital	177	Disease perception, health literacy, attitude toward death, education, stroke history, degree of trust in medical and nursing care are influencing factors	4
Li and Li (2016)	China	Cross-sectional survey	Advanced cancer patients and caregivers in a hospital	220	Long-term illnesses, autonomy of patient, ethics and morals, not fulfilling the wishes are influencing factors	4
Shen and Yang (2020)	China	Cross-sectional survey	Hospitalized patients with chronic heart failure	356	Subject support, object support, support utilization positively related to readiness for ACP Education level, religion, death attitude, doctor–patient relationship, social support score are influencing factors	4
Wang et al. (2022)	China	Cross-sectional survey	Hospitalized cancer patients	235	Gender, involvement in EOL medical decision-making, awareness of life-sustaining treatment and ACP, level of disease uncertainty, level of active coping are influencing factors	3
Wang and Sheng (2020)	China	Cross-sectional survey	Patients with chronic disease in community health clinics	168	Coping (negative and positive), trust in physicians during illness, experience of previous EOL care for family members are influencing factors	3

(*Continued*)

Table 2. (*Continued.*)

Study	Site	Design	Subject	*N*	Factor	MMAT
Yin et al. (2022)	China	Cross-sectional survey	Hospitalized cancer patients	426	Religion, course of disease, degree of pain, medical trust, death attitude are influencing factors	3
Yuan et al. (2022)	China	Qualitative semi-structured interviews	Seriously ill patients, caregivers, and healthcare professionals	41	Timing, evolving patient status Nurses attitude, knowledge Patient's personal experience and preference Family attitude	4
Yuan and Liu (2020)	China	Cross-sectional survey	Hospitalized patients with chronic heart failure	190	Education level, religion, perceived quality of life, attitudes toward death are influencing factors	5
Zhao and Zhao (2019)	China	Cross-sectional survey	Hemodialysis patients in hospitals	196	Education level, religion, discussion with others about death, understanding of life support therapy	4
Zhu and Xu (2014)	China	Cross-sectional survey	Advanced cancer patients	112	Worry over follow-up treatment, fear of death, psychological burden are influencing factors	4
Zhang et al. (2021)	China	Cross-sectional survey	Advanced cancer patients in 4 hospitals	355	Meaning of life, benefit discovery, self-esteem, length of disease, education level are predictors	5

Patients' beliefs in self-autonomy (Li and Li 2016; Steiner et al. 2020; Van den Heuvel et al. 2016) or believing that ACP discussion would result in a better quality of life for them (Carr 2012; Curtis and Patrick 1997; Greutmann et al. 2013; Knauft et al. 2005; Steiner et al. 2019; Van den Heuvel et al. 2016; Yang et al. 2021b; Yuan and Liu 2020) have positive influence on ACP discussion. Most studies reporting this focused on Western populations.

Emotions

Patient, family, and physician groups reported the emotions induced by talking about death and dying. A negative attitude toward death is correlated to less acceptance of ACP discussion among Chinese patients and families (Brown et al. 2014; Schichtel et al. 2021; Shen and Yang 2020; Yin 2022; Yuan et al. 2022; Zhu and Xu 2014). Feeling a psychological burden and discomfort was reported by patients in 5 studies (Betker et al. 2021; Curtis and Patrick 1997; Fenton et al. 2021; Yuan et al. 2022; Zhu and Xu 2014), and the topic was not welcoming. Emotional burden can also be a barrier for healthcare professionals. Physicians referred to their fear of facing a patient's death and not being ready to let the patient die (Cheung et al. 2020; Schichtel et al. 2021). Emotional distress would encourage avoiding the discussion, and when other parties feel the same, ACP would never be initiated.

Burden to others

Patients avoided ACP because of concern that such discussion would burden their significant other(s) (Carr 2012; Cheung et al. 2020). Patients' significant others did not include family members only. In 2 studies, patients felt that discussing their end-of-life care would upset their physician (Curtis and Patrick 1997; Knauft et al. 2005). Families sometimes requested keeping such discussions from the patient, and physicians worried that discussing ACP would undermine the patient's hope. Intent to protect became a hurdle for patients' participation in ACP discussions (Abe et al. 2021; Cheung et al. 2020). While some studies reported intent to avoid emotionally burdening others as a barrier, other studies found participants had different views, perceiving that advance discussion would lessen other parties' emotional burden, especially in end-of-life decision-making (Steiner et al. 2019).

Preference of timing

Inappropriate timing was identified as a barrier in ACP discussion; however, perceptions of appropriateness differed among participant groups. Some studies reported that patients thought "too early" and "not sick enough" were indictors of inappropriateness (Carr 2012; Cheung et al. 2020; Curtis and Patrick 1997; Yuan et al. 2022). However, "too late for discussion" was also presented as a barrier, rendering ACP unrealistic (Kalluri et al. 2022; Steiner et al. 2020). The deliberation of "not too early" was also differed. Some studies elaborated by the person had experienced a very sick time, had but some studies referred to a long duration of sickness or occurrence of significant illness burden (Ding et al. 2020; Han et al. 2021; Hutchison et al. 2017; Wang and Sheng 2020; Zhao and Zhao 2019).

Interpersonal factors

Responsiveness of others

Almost all studies reported physicians' response as a factor determining patients' participation in ACP. Besides skills and clinical knowledge, a physician's attitude, such as empathic care, sensitivity to the patient's cultural characteristics, and addressing their needs can facilitate patient participation (Greutmann et al. 2013; Knauft et al. 2005; Van den Heuvel et al. 2016). Patients' perceptions of the physician as in a rush and having no time for such discussion impeded their participation in ACP (Greutmann et al. 2013; Knauft et al. 2005; Steiner et al. 2019). In any event, physicians would not proceed if they judged the patient not suitable or not ready to discuss ACP (Abe et al. 2021; Greutmann et al. 2013). The responses of patients and physicians mutually influenced each other in ACP discussions.

Table 3. Characteristics of the included studies

Characteristics		*N*	%
Study design			
	Qualitative	22	54%
	Quantitative	15	33%
	Mixed method	6	13%
Study site			
	North America (United States, Canada)	17	37.8%
	China	16	35.6%
	Other areas in Asia (Singapore, Japan, Taiwan, South Korea, Hong Kong, Israel)	7	15.5%
	Europe (United Kingdom, Germany, Netherlands)	4	8.9%
	Australia	1	2.2%
Quality rating MMAT			
	Fair	12	26.7%
	Good	33	73.3%
Study subject			
	Patient	23	51%
	Patient & family/caregiver	8	18%
	Patient & family/caregiver & healthcare professional	6	13%
	Healthcare professional	4	9%
	Patient & healthcare professional	3	7%
	Family/caregiver	1	2%
Illness type			
	Non-cancer	23	51%
	Cancer	17	38%
	Not specified serious illness	5	11%
Analysis lens			
	Individual	43	96%
	Dyadic	2	4%

Relationship

A trustful relationship can be a facilitator or a barrier in ACP. Firm trust in the physician increased patients' confidence to share their preference for end-of-life care (Greutmann et al. 2013; Jia et al. 2022; Shen and Yang 2020; Van den Heuvel et al. 2016; Yang et al. 2021a). Nevertheless, firm trust in the physician or family was also a barrier that lowered a patient's incentive for ACP because they were confident that the other parties understood their wishes and were willing to place total trust and leave all decisions to them (Carrasco et al. 2021; Cheung et al. 2020; Hutchison et al. 2017; Ladin et al. 2021; Yuan et al. 2022).

Family dynamics

Physicians' readiness to engage in ACP discussions was reduced when families experienced preexisting conflict as they felt they did not have either the skills or the time to manage difficult family dynamics. Patients avoided ACP discussion if they anticipated the discussion would arouse conflicts in the family (Carr 2012; Carrasco et al. 2021; Cheung et al. 2020; Jia et al. 2022; Lall et al. 2021; Toguri et al. 2020; Van den Heuvel et al. 2016; Zhu and Xu 2014). Chinese physicians reported that their reluctance to initiate ACP was due to the fear of being misunderstood by the family for not making sufficient effort to treat the patient (Yuan et al. 2022).

Previous experience of end-of-life care

Eight studies reported that experiencing the death of someone close or providing end-of-life care for such a person positively influenced their perception of the value of ACP. Experience of a family member's death with palliative care support, free from suffering, positively influenced their own ACP discussions (Bar-Sela et al. 2021; Carrasco et al. 2021; Curtis and Patrick 1997; Fenton et al. 2021; Lall et al. 2021; Van den Heuvel et al. 2016; Wang and Sheng 2020; Yuan et al. 2022; Zhao and Zhao 2019).

Person to lead ACP discussion

The views on the person to lead ACP discussion varied and impeded the kickoff of ACP discussion. Physicians preferred the patient to initiate the discussion (Hutchison et al. 2017), while patients expected healthcare professionals to take the lead (Jia et al. 2022). Adopting a passive role and waiting for someone else to initiate ACP was one reason for the low uptake of ACP (Curtis and Patrick 1997).

Socio-environmental factors

Cultural characteristics

Different cultural beliefs and practices were reported in 6 studies. Four of these were conducted in Asia and one study on a minority group. Some studies reported rejection of ACP discussion due to cultural taboos regarding talking about death (Cai et al. 2023; Lall et al. 2021; Yuan et al. 2022). Some studies also mentioned that the decision-making role of the family in the decision-making process was also different in different cultures (Hutchison et al. 2017; Yang et al. 2021b). Lack of sensitivity to cultural characteristics is the barrier to ACP rather than cultural differences.

Support

Patients and families were reluctant to discuss ACP when subsequent continuity of care for the patient was uncertain, including not knowing where to get support (Cheung et al. 2020; Zhu and Xu 2014). Lack of communication between clinical departments also diminished patients' readiness to discuss ACP (Schichtel et al. 2021). Healthcare professionals reported that organizational support such as having protected time for discussion, training on skills and tools, and policies, a standardized protocol and documentation were helping factors (Ding et al. 2022; Ladin et al. 2021; Simon et al. 2015; Toguri et al. 2020; Yuan et al. 2022). Other than the infrastructural support from the healthcare system, topic-specific support, such as having someone in the social environment to accommodate dialogue about end-of-life care, can facilitate patients and families in preparing for ACP discussion (Dai and

Table 4. Summary of themes and direction of the force of the included studies

Themes	Sub-themes	Barrier	Facilitator
Intrapersonal	**Personal belief**	Discussion may cause harm or death (Curtis and Patrick 1997) Unnecessary if there is a living will (Curtis and Patrick 1997) Sense of powerlessness, uncertainty about future (Cheung et al. 2020) ACP will be "set in stone" (Curtis and Patrick 1997; Wang et al. 2022) Concentrate on staying alive not death (Cheung et al. 2020; Hutchison et al. 2017; Knauft et al. 2005; Steiner et al. 2020; Van den Heuvel et al. 2016) Unable to estimate life expectancy (Craig et al. 2020; Greutmann et al. 2013) Incompetent in communication skills (Cai et al. 2023; Hutchison et al. 2017; Steiner et al. 2019; Van den Heuvel et al. 2016)	Autonomy and preference honored (Li 2016; Steiner et al. 2019) Quality of life (Carr 2012; Curtis and Patrick 1997; Knauft et al. 2005; Steiner et al. 2020; Van den Heuvel et al. 2016; Yang et al. 2021b; Yuan et al. 2020)
	Emotions	Fear of death, death anxiety (Brown et al. 2014; Schichtel et al. 2021; Shen and Wang 2020; Yin et al. 2022; Yuan et al. 2022; Zhu and Xu 2014) Emotional burden (Betker et al. 2021; Zhu and Xu 2014) Discomfort about discussion (Curtis and Patrick 1997; Fenton et al. 2021; Yuan et al. 2022)	Emotional relief (Ladin et al. 2021) Peace of mind (Craig et al. 2020)
	Burden to others	Adding to family's emotional burden (Carr 2012; Cheung et al. 2020) Upset HCP (Knauft et al. 2005) Undermining patient's hope (Cheung et al. 2020) Burdening the patient if they know (Abe et al. 2021)	Lessen family's emotional burden (Steiner et al. 2020)
	Preference of timing	Not felt sick enough for ACP (Carr 2012; Curtis and Patrick 1997) Too early (Cheung et al. 2020; Yuan et al. 2022) Too late (Kalluri et al. 2022; Steiner et al. 2019)	When sick for long time (Han et al. 2021; Wang and Sheng 2020; Yin et al. 2022) When someone had experienced being very sick (Ding et al. 2020)
Interpersonal	**Responsiveness of others**	Staff in a rush (Greutmann et al. 2013; Knauft et al. 2005; Steiner et al. 2019; Van den Heuvel et al. 2016) Staff judge patient (Abe et al. 2021; Greutmann et al. 2013)	HCP caring attitude (Greutmann et al. 2013; Knauft et al. 2005; Van den Heuvel et al. 2016)
	Relationship	Strong trust in doctor (Carrasco et al. 2021; Cheung et al. 2020; Ladin et al. 2021) Strong trust in family (Cheung et al. 2020; Hutchison et al. 2017; Yuan et al. 2022) Reputation of institution (Jia et al. 2022)	Good rapport with and trustful HCP (Greutmann et al. 2013; Jia et al. 2022; Shen and Wang 2020; Yang et al. 2021a; Van den Heuvel et al. 2016)
	Family dynamics	Avoid decision conflict (Carr 2012; Cheung et al. 2020) Family dynamics (Carrasco et al. 2021; Jia et al. 2022; Toguri et al. 2020; Zhu and Xu 2014) Family request to withhold discussion from patient (Cai et al. 2023)	
	Previous experience of EOL care		Experience of family EOL care (Bar-Sela et al. 2021; Carrasco et al. 2021; Curtis and Patrick 1997; Fenton et al. 2021; Lall et al. 2021; Van den Heuvel et al. 2016; Wang and Sheng 2020; Yuan et al. 2022)

(*Continued*)

Table 4. (*Continued.*)

Themes	Sub-themes	Barrier	Facilitator
	Person to lead ACP discussion	Wait for someone else to initiate ACP (Curtis and Patrick 1997) Wait for patient to initiate ACP (Hutchison et al. 2017)	Clinician to initiate ACP (Jia et al. 2022)
Social environmental	**Cultural characteristics**	Not culturally appropriate (Yang et al. 2021b) Culturally taboo (Cai et al. 2023; Lall et al. 2021; Yuan et al. 2022) Cultural differences (Hutchison et al. 2017)	
	Support	Lack of clear continuity of care (Cheung et al. 2020; Zhu and Xu 2014) Limited access to services and support of ACP, e.g., time team approach (Ding et al. 2022; Toguri et al. 2020; Yuan et al. 2022)	Synchronized communication across specialties (Schichtel et al. 2021) Opportunity to discuss ACP with someone other than HCP (Knauft et al. 2005; Zhao and Zhao 2019)

Zhang 2021; Knauft et al. 2005; Shen and Yang 2020; Zhao and Zhao 2019).

Discussion

The interweaving of systemic and dynamic factors

Factors elicited from the reviewed studies were not unidimensional but included intrapersonal, interpersonal, and socio-environmental level which reflected the interactive and dynamic characteristics of the different factors.

The intrapersonal factors identified in this study were more than matters about individuals but comprised the personal belief of self and others, one's own emotions, and the perceived emotions of others. Moreover, personal beliefs or emotions toward ACP interacted with the external world and contributed to the outcomes of the interpersonal factors. In this study, the interpersonal factors of "trustful relationship" and "family dynamics" are examples of reciprocal influence resulting in bidirectional outcomes as facilitators or barriers to ACP. This bidirectional nature of interpersonal factors was consistently found in other studies (Rhee et al. 2013). The factor, relationship, can be an impeding or facilitating factor shaped by the context, the relationship, and the individual belief. The interaction process and direction are chaotic and messier than a linear model. There is a need for further exploration. The motive to protect oneself from the negative consequences of relationship disintegration may generate a perception of ACP as a risk. Conversely, the motive to enhance the relationship by actively handling disagreement and conflicts may welcome ACP as an opportunity. The direction and magnitude of "trust" and "burden" may be determined by the individual's underlying motives.

Socio-environmental factors such as culture and social support are interweaved with intrapersonal and interpersonal factors. Discussing death and dying may still be taboo in some cultures; research indicates Asians tend to adopt culture-specific beliefs such as fatalism to cope with death (Yen 2013). When the social environment discourages talking about death, the mystery of death and dying accelerate a person's fear, and subsequently reconfirmed such discussion as burdensome both to the person and other people around them. The study suggested an interweaving relationship of the 3 categories of factors in considering ACP discussion as illustrated in Figure 2.

The interweaving of factors among the intrapersonal, interpersonal, and socio-environmental dimension suggest ACP is a complex dynamic interplay within the person and in relation to others. However, the dynamic interplay among patients, family and healthcare professionals, and the core elements that drive their force toward or against ACP have not been explored. ACP is a communication process involving these 3 parties regarding the patient's preferences of end-of-life care, which not only affects the patient's quality of care but also has significant impacts on family and caring professionals. A deeper understanding of their interactions and impacts in ACP can not only help to formulate strategies to enhance ACP uptake but also provide a feasible channel for constructive participation to improve end-of-life care communication.

The missing piece of a triadic perspective

ACP is a communication process between at least 3 parties: the persons involved, their family members, and their healthcare professionals. Nevertheless, only 2 studies examined participants in patient and family dyads. All other studies were conducted through the lens of a single stakeholder group, resulting in an incomplete understanding of the phenomenon. Fletcher (2012) suggests the dyadic-level concept between patient and caregiver on "communication," "reciprocal influence," and "caregiver-patient congruence" in facing the course of illness. Another study also found a correlation between patients' and their partners' distress, suggesting they reacted as an emotional system rather than as individuals (Kershaw et al. 2015). Healthcare professionals are a core stakeholder group in ACP, particularly when ACP is discussed in healthcare settings. Understanding of the communication, reciprocal influence, and congruence needs to be triadic among patients, families, and healthcare professionals.

Universality and distinctiveness of factors between the Chinese societies and the West

One of the expected contributions of this review is to offer a more comprehensive view of the factors by including studies for Chinese, for a wider range of targets, and in different settings. Among the 45 studies, 16 of them researched on the Chinese population in different regions including Hong Kong, Taiwan, and mainland China.

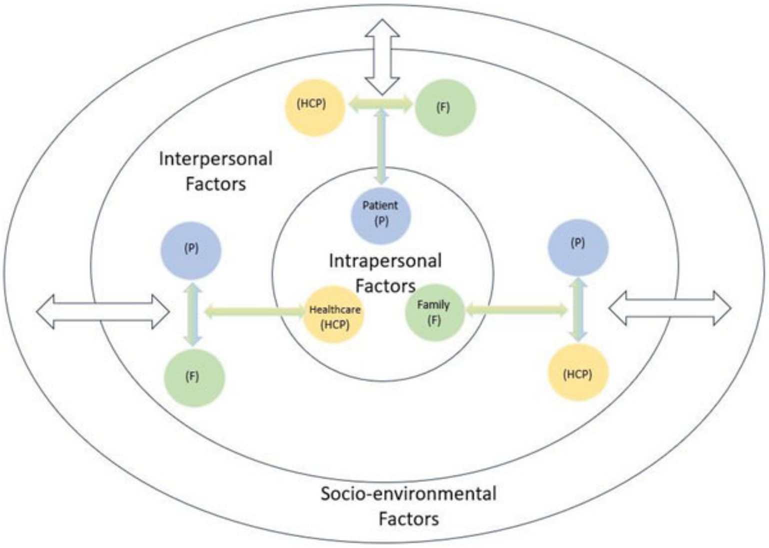

Figure 2. Interweaving of intrapersonal, interpersonal, and socio-environmental factors.

Disregarding the study regions, appropriate time to initiate the ACP discussion is shared even with different perceptions on appropriateness. Emotional burdens on self and others were another shared challenge faced by the patient, the family, and healthcare professionals. Accessible emotional support pre- and post-ACP discussion is as important as the support during the discussion.

While a sense of autonomy and quality of life was the dominant focus of the intrapersonal factors in Western society, death belief, illness condition, and information about ACP had a more significant influence on participation in ACP in the Chinese communities. Culture, family, and social support were reported more often in the research on Chinese population. Although majority of the included Chinese studies are from China, the findings on the essential role of family and relationship are consistent with other literature reported (Martina et al. 2021). In a collectivist Asian culture, sociocultural factors pose an important barrier; discussing end-of-life issues is considered taboo and against cultural values, such as filial piety (Ali et al. 2021).

Family is a linchpin in Chinese society, and harmonious relations are of paramount importance in making major decisions (Leung et al. 2011). Although some studies in this systematic review did include family members in studying the factors affecting ACP, they were researched as a patient proxy or supplemented the patient's perspective rather than focusing on the interactions of family and other stakeholders in the initiation or discussion process.

Conclusion

This study draws a comprehensive picture of existing knowledge of the modifiable factors of ACP in healthcare settings for patients with a progressive illness. It has several implications for clinical practice and future research. First, it provided a systemic and dynamic lens on the modifiable factors affecting ACP discussion. Factors can be bidirectional and not absolutely a barrier or facilitator, and they are interweaving among intrapersonal, interpersonal, and socio-environmental dimensions. However, little was known about the interplay and warrant research on the dynamic interactions from a tripartite perspective. Second, apart from the universal factors affecting the uptake of ACP, more attention needs to be paid to the distinctive factors reflecting the population's characteristics. Family concerns may be weighted more important than the individual in some cultures and the decision making may vary in different populations. Being sensitive to the cultural issues and honor the uniqueness of the population characteristics would enable continuous communication. For instance, some societies address death and dying openly while it remains a taboo in the others. Pre-ACP preparation is necessary to explore the concerns and needs in the context, healthcare professionals can exercise flexibility to accommodate the cultural practice in engaging patients and their families in ACP discussion.

Contributions & limitations

Given the heterogeneity of the included studies, a meta-analysis was not appropriate. Therefore, thematic synthesis was performed.

To the best of our knowledge, this is the first study to include both Chinese-language and English-language publications on studies of the barriers and facilitators of ACP in healthcare settings. This study also adopted a new framework to structure the factors from the intrapersonal, interpersonal, and socio-environmental dimensions and explained the interweaving nature and the bidirectional force of the factors. Healthcare settings is a common location for ACP discussion, yet there is no systematic review on factors affecting ACP discussion in such settings and this study addresses this research gap and offers valuable information to clinical practice and future research.

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