BMJ Open

The Role of Patients' Family Members in End-Of-Life Communication: A Systematic Review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-067304
Article Type:	Original research
Date Submitted by the Author:	10-Aug-2022
Complete List of Authors:	Pun, Jack; City University of Hong Kong, Department of English Chow, James C. H.; Queen Elizabeth Hospital, Department of Clinical Oncology FOK, Leslie; Queen Elizabeth Hospital, Department of Clinical Oncology CHEUNG, Ka Man; Queen Elizabeth Hospital, Department of Clinical Oncology
Keywords:	PALLIATIVE CARE, ONCOLOGY, MEDICAL EDUCATION & TRAINING

TITLE PAGE

Title: The Role of Patients' Family Members in End-Of-Life Communication: A Systematic Review

Authors: Jack PUN[a], Chung Hang James CHOW[b], Leslie FOK[b], Ka Man CHEUNG[b]

Affiliations:
a-Department of English, City University of Hong Kong, Hong Kong SAR, China
b-Department of Clinical Oncology, Queen Elizabeth Hospital, Hong Kong SAR, China

Postal addresses:
a-Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong SAR, China.
b-Department of Clinical Oncology, Queen Elizabeth Hospital, 30 Gascoigne road, Kowloon, Hong Kong SAR, China.

Emails:
Jack PUN: jackpun@me.com
Leslie FOK: fl684@ha.org.hk
James Chung Hang CHOW: cch932@ha.org.hk
Ka Man CHEUNG-ckm792@ha.org.hk

Corresponding author:
Jack PUN
Email: jackpun@me.com
Postal address: Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong.

ABSTRACT

Objectives: Although a shared decision-making approach to family-clinician EOL communication is advocated among many regions, there is still a lack of clear communicative framework on communication with family caregivers. To synthesise empirical findings on the role of family in end-of-life (EOL) communication and to identify the communicative practices that are essential for EOL decision-making in family-oriented cultures.

Setting: The oncology and palliative care settings.

Participants: This systematic review followed the PRISMA guidelines. Relevant studies published between 1991 and 2021 were retrieved from four databases, including the PsycINFO, Embase, MEDLINE, and Ovid nursing databases, using keywords with meanings of “end-of-life”, “communication” and “family”. Data were then extracted and coded into themes for analysis. The search strategy yielded 53 eligible studies; all 53 included studies underwent quality assessment. Quantitative Studies were evaluated using the Quality Assessment Tool, and Joanna Briggs Institute Critical Appraisal Checklist was used for Qualitative Research.

Primary and secondary outcome measures: Research evidence on EOL communication with a focus on family.

Results: Four themes emerged from these studies: 1) Decision-making conflicts caused by families in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a “key person” who is responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Conclusions: The current review pointed towards the importance of family in EOL communication and illustrated that family participation likely leads to improved quality of life and death in patients. Future research should develop a family-oriented communication framework that targets on managing family expectations during prognosis disclosure and facilitating patients’ fulfilment of familial roles while making EOL decision-making. Clinicians should also be aware of the significance of the role of family in EOL care and manage family members’ expectations according to cultural contexts.

Keywords:
End of life; Family; Palliative care; Cancer care; Communication; Family-oriented cultures, East Asian Cultures.

Introduction

In the palliative care setting, end-of-life (EOL)[1] communication has a crucial influence on medical decision-making and the quality of care. It informs patients and their families on the current medical conditions; explores unanswered concerns and health needs; provides emotional support and practical advice; reveals what lies ahead; and allows care providers to understand how they can improve the care for the patients during their final days. Positive EOL communication during palliative care removes the stigma around death and help the patients set out their final wishes to the family [1]. In general, effective communication regarding prognoses and optimal treatment has multidimensional benefits, for instance, promoting the quality of EOL care and decreasing the stress of the carers [2]. In contrast, poorly conducted medical conversations may lead to negative treatment outcomes such as aggressive life-sustaining treatments [3-4], unsatisfactory hospital experiences [5], poor well-being [6], and unnecessary healthcare costs [2, 7]. Thorough EOL communication among clinicians, patients and carers help to alleviate anxiety and enable patients to be cared for in desired ways[2, 8].

However, empirical evidence shows that the EOL communication practice is not always performed effectively [9-10]. Many patients and carers are reported to be poorly informed about their patients' situations and that the patients were often unaware of their own risks of imminent deaths [11]. Similarly, clinicians' unawareness of patients' wishes may hinder the provision of the most appropriate healthcare options for patients. Healthcare professionals also find it challenging to directly discuss deaths with patients and caregivers, as patients and caregivers are often in denial and tend to be over-optimistic on the prognoses. It is also observed that health professionals do not have the necessary skills to communicate effectively with patients' families at the patients' EOL stage [12].

There are different expectations for palliative care in Chinese and Western cultures. Most Chinese patients rely on doctors to make the final decision regarding EOL treatments [14], the wishes of close family members are also considered. Research results show that in the broader Asian context, family members and religious beliefs heavily influences patients decisions on EOL and palliative care [15-17]. Nowadays, many developed regions such as the United States, Europe, and Australia adopt the shared decision-making approach to family–clinician EOL communication [18]. However, patients who are admitted to general wards or intensive care units (ICUs) are aggressively managed have no prior opportunities for effective disucssions with their families or clinicians about their desires and goals [19]. There is a lack of clear communication framework that sets the standard for essential information that family caregivers should receive, which will likely include patients' current medical condition and prognosis estimates, additional options of treatment and support measures available and their risks and benefits, and the preferences of patients and family to guides clinicians to reach realistic care goals [20-21]. When family members receive insufficient information, difficulties may arise during EOL communication. This occurs especially in the ICU settings, where urgent decisions about whether to pursue aggressive life-sustaining treatments for patients are required. In a study by Azoulay et al.[22], 54% of the family members of ICU patients did not have a clear understanding of the patients 'diagnoses, prognoses and treatments, and the physician–family meetings lasted for no more than 10 minutes. As a result, family members have poor understandings of the situations they were facing, which led to suboptimal decision making. In addition to time constraints, the lack of communication skills is also an important factor. Clinicians tended to discuss EOL life-sustaining treatments in a scripted, depersonalised and procedure-focused manner. Clinicians also tended not to initiate EOL conversation directly and punctually [18].

Amongst the factors affecting EOL communication as well as the engagement of patients and their family caregivers, the factor most discussed is cultural differences between the Eastern and Western countries. Chinese culture values collectivism, wherein patients prefer to make joint decisions with their family members or sometimes even rely completely on them [14]. Rooted in Confucian morality, filial piety is a very important moral tenet in Chinese culture that has been advocated and practiced for thousands of years. People of the Chinese culture are required to provide care to their parents in return for the care they received from their parents in their childhood years. Therefore, many Chinese elderly patients believe that their children may naturally understand their preferences and are able to make decisions for them in their final days[14, 23-24]. For example,

---

[1] For the purposes of clarification, palliative care and EOL are interchangeably used throughout this paper, with the estimated remaining longevity of patients having life-threatening illnesses to be within the time frame of a few months.

family members of elderly patients would request the doctors to discuss with them first, before the doctors consult the elder patient. In some cases, family members will also choose not to disclose the bad news to the patients [25]. Collusion, a scenario wherein the family wishes to hide the diagnosis from the patient, is common in Asian cultures. In a study conducted in Singapore by Low et al. [26] found that 96% of family members expressed reluctance in disclosing the prognosis to the patient. This situation is also prevalent in Hong Kong, in which its culture is heavily influenced by both Chinese and Western beliefs. In research conducted with Chinese patients, maintaining a strong connection with the family during palliative care has been reported to be one of the most important components of a "good death" for elderly patients [27]. This interdependent relationship between family caregivers and patients opposes the ideology of autonomy and self-determination that predominate in Western culture, and is to a certain extent, culturally understood and accepted by patients in the Chinese context.

Regardless of the effects of different cultural norms, recent reports have shown that healthcare professionals widely agree that EOL communication should involve both the patient and family members [28-29]. In one international survey of palliative care professionals, more than 80% of the participants agreed that more practical instructions during communication with patients' family members would enhance EOL decision-making [29-30]. Recently, the English Parliamentary and Health Service Ombudsman [31] found that the main area of health professionals' complaints about EOL care was communication failure with terminally ill patients and their family members. Without adequate family involvement, promoting the holistic care of patients during their EOL is difficult.

In response to such dissatisfaction with EOL communication, several guidelines have been established for practitioners with focus on individuals 'rights and autonomy in the medical context. Guidelines such as the COMFORT model and the SPIKES protocol provides a framework for clinicians to engage in palliative care discussion with patients [5, 32]. Meanwhile, existing recommendations mostly focus on the patient–clinician conversation rather than a family-oriented conversation. Many close family members are eager to thoroughly understand the dying process and the importance of understanding medical jargon, inclusivity, and full transparency [33] is lost in the existing recommendations.

Due to the aforementioned factors, the development of an EOL communication strategy that considers active family involvement is necessary. While previous systematic reviews on family decision-making and involvement [34], nurse to family support during withdrawal of life-sustaining treatment and imminent death [35-36], and EOL communication to patients and caregivers during the advanced stages of related illnesses [37] are present, an integrative review is lacking. As such, in this integrated review, the researchers aimed to contribute to the current literature by systematically reviewing research findings that highlights the roles of patients' families in EOL decision making. The aim of the review was to answer the following question: What is the existing research evidence regarding the role of family in EOL communication, and what themes can be derived from their synthesis?

The summarised information sheds light on the role of family in EOL communication and decision-making and contributes to future research and policy making regarding EOL communication. Although culture and its related elements regarding EOL communication and care have been heavily foregrounded thus far, it is not saliently marked in the research question because it is a prominent theme elicited after, rather than prior, the systematic review search (see also[38]).

Methods

This systematic review aimed to provide integrated information on the role of family in EOL communication using the PRISMA model (see Figure 1). The review included relevant studies published between 1st January 1991 and 31st December 2021. The purpose behind the proposed date is the majority of related studies and articles regarding familial roles in EOL communication were published since the specified date.

[**Figure 1** PRISMA flow diagram]

Eligibility

The PsycINFO, Embase, MEDLINE and the Ovid nursing databases were searched. Detailed search strategy is outlined in Appendix 1. Our investigation encompasses a broad scope. The various aspects of EOL care such as palliative care and oncology includes EOL communication studies in general (i.e. not limited to diagnosis, prognosis etc.) and focus on the involvement and roles of and between family, clinicians, and relatives. Peer-reviewed full-text journal articles such as original studies and reviews were included. The initially shortlisted articles were cross-checked by the three authors for final review and data extraction. Articles that were not peer-reviewed or written in English were excluded. Although we have a bilingual research team, EOL care articles that were written in Chinese were not included in the research due to insufficient peer-reviewed articles and the paucity of EOL communicative aspect-oriented research.

Data extraction

Three authors were involved throughout the entire title screening, data collection, and text review process. Before data extraction, the authors independently screened the titles and read the whole abstract of each paper to exclude irrelevant articles according to the inclusion criteria. The full papers were retrieved if their abstracts were considered potentially relevant. The full texts of the chosen articles were subjected to in-depth data extraction. The objectives, research design, participant characteristics and key findings were examined and recorded and appraised for quality by oncologists and palliative care practitioners to ensure that all relevant journals were included in the search. Any disagreements were resolved by discussion to reach a consensus amongst all the authors.

Quality assessment

The Quality Assessment Tool for Quantitative Studies [39] was used to assess quantitative (*n* = 15) and mixed-method studies (*n* = 2). Each article was given ratings on a 3-level ordinal scale: “weak”, “moderate”, or “strong” in eight areas such as research design and selection of study population. Qualitative (*n* = 37) and mixed-method studies (*n* = 2) were evaluated with the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research[40], which is a 10-item checklist covering components such as congruity and reflexivity, scored as “yes”, “no”, “unclear”, or “not applicable”. The quality of the included studies was evaluated independently by the first and second authors. Any disagreements in ratings were discussed and resolved with the third author.

Weight of Evidence Measure

To ensure the quality of the included studies, the papers' "weight of evidence" was measured according to three criteria: the relevance of each paper to the current review; the appropriateness of the research; and the validity of the study; and the overall contribution of the research to this review. These variables are specified in Table 1 below.

Regarding the relevance aspect of the included studies, that is, to which the degree of the topic(s) examined align with our review questions, 86% of the 53 reviewed articles were considered as either high or medium level of relevance. Appropriateness is evaluated based on whether the research designs were appropriately employed. The authors judged that 28% and 38% were deemed to be highly appropriate and fairly appropriate, respectively. 83% of the included studies were considered to have a medium-to-high level validity, where the scorings were based on the preciseness and consistency of data analysis. These ratings therefore draw an overall conclusion that 30% of the included studies were able to make a strong contribution in answering the review questions whilst 43% made a fairly significant contribution.

Table 1. Weight of Evidence of the current review

	Relevance	**Appropriateness**	**Validity**	**Overall contribution**
High	46%	28%	38%	30%
Medium	40%	38%	45%	43%
Low	13%	33%	16%	26%

Patient and Public Involvement
No patient involved.

Results

Included articles

The initial search identified 25,305 eligible studies, 25,318 of which were excluded after abstract screening. The search includes keywords and synonyms of 'end of life', 'communication' and 'family'. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevant studies, e.g. 'end of life AND communication AND family'. We have made revisions in our manuscript to address and clarify this point. The full-text screening of the remaining 109 studies were then subjected to in-depth review (see Figure 1). This led to the further exclusion of 56 articles because they: (a) focused on unrelated topics of family-oriented EOL communication; (b) lacked empirical evidence; (c) were written in other languages rather than English; or (d) were not peer reviewed. Finally, 53 studies were included in this systematic review.

The Characteristics Of The Included Studies

The characteristics of the 53 studies that met the inclusion criteria are summarised in Table 2 (See Appendix 2 for a summary of each included study). The number of studies on the role of family in EOL communication increased significantly after 2010. Most of the studies were from the United States (24), closely followed by Hong Kong (7), Canada (4), the United Kingdom (3), China (2), South Korea (2), Netherlands (2), France (2) and other countries (7). Of the 53 included studies, 37 were qualitative studies, 14 were quantitative and 2 were mixed-method.

Table 2. Main ideas of the themes emerged from the reviewed studies

Theme	Main ideas	Studies
1. Decision-making conflicts caused by families in EOL communication	There existed a certain degree of discrepancies in decision-making between the patient and family caregivers; to optimise EOL communication among the relevant stakeholders, physicians should be able to gauge and respond to the patient's psychosocial needs and to also take the family's perspective into account when having EOL conversations.	[9, 20, 23, 29, 41-51]
2. The significance of timing of EOL communication	There is typically a delay in initiating EOL communication; it is often due to the avoidance of having open physician-patient discussion about the illness. Patients were generally worried about making EOL decisions once informed about the diagnosis, whilst physicians were concerned that the negative prognostic information would impact the patients and hence, leading to a late timing of EOL communication.	[22, 26, 52-60]
3. Difficulty in identification of a "key person" responsible for decisions regarding EOL care	Some patients were found to not wish to be involved in making their own palliative care decision out of the fear and uncertainty of their EOL stage, family members or even the physicians themselves might in turn have to be responsible for decision-making; this likely leads to an unclear division of responsibility regarding EOL decision-making.	[14, 61-66]
4. Different cultural perspectives on EOL communication	Individualism is of value in the West where most patients preferred having the autonomy to make EOL decision for themselves, whilst collectivism and filial piety are the main values typically found in Eastern society; patients tended to rely on their children or discussing within the family when making palliative care decisions.	[14, 25, 67-76]

Identified themes

The authors identified and coded issues from each of the included studies, which were then synthesised into a set of broad reoccurring themes about the role of family in EOL communication. Four themes were identified: 1) Decision-making conflicts caused by families in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a "key person" responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Decision-making conflicts caused by families in EOL communication

Internationally, the involvement of family members in EOL communication has often been discussed in the context of provision of support, but very few studies have directly explored how important the role of family is and in what way the family must be involved.

Family caregivers traditionally play their own unique roles in providing emotional and financial support to contribute to a "good death" for the dying patients [20,41]. In fact, the patients expect to receive family support more than the support from healthcare workers. Furthermore, the social support from family members serves as the fulfilment of their own familial obligations and is a foundation providing quality EOL care [42-44].

Many clinicians nowadays have come to realise that the patients' and families' views and beliefs have to be considered in the decision-making process [20, 29]. In circumstances where disagreement about the medical advice arises between the doctor and the family, establishing a care plan could become difficult, and this could cause the withholding or withdrawal of treatment implementation. Family members have also noticed that healthcare staff would avoid EOL conversations. However , it is important for healthcare staff to initiate EOL conversations so that patient's needs and their family's preferences are properly addressed [29]. It was also found nthat some doctors have to follow the family's wishes, even if it was against the professional judgement of what was appropriate for the patient [45-47].

Disagreements about decisions on EOL treatments could also occur between terminally ill patients and their family members. There are contradictions between family members who wish to hold on to their loved ones for as long as possible and the patients who wish to let go and reject life-sustaining treatments[48-50]. Fan et al.[23] and Shin et al.[51] used standardised questionnaires to examine the preference and concordance among the patients with cancer, family members, and clinicians regarding EOL communication. This includes disclosure of diagnosis and prognosis, family involvement in such processes, and EOL decision-making. Findings revealed that family members' preferences do not usually align with the patients; additionally, there are discrepancies between clinicians' medical practice and the preferences of the patients and their family caregivers. For instance, rigid protocols and guidelines that inform the healthcare of the young patients created tension among family caregivers and clinicians as they did not take into account the patients' individual needs [9].

The significance of timing of EOL communication

Owing to the complexity of EOL communication, that is, the constitution of delivering exhaustive information from doctors, the complicated emotions derived from relevant stakeholders, and the dynamics of family involvement in the patient's health care, there typically appears a delay in conducting EOL communication[52-54]. Cherlin et al.[52] found that the communication between family caregivers and clinicians about the terminal illness and possible use of hospice care occurs late in the course of the illness. Some patients consistently wrestled with the thought of knowing that they were ill and trying to defer EOL decisions [55-57]. From the perspective of clinicians, there seems to be a tendency for clinicians to initiate the communication of negative prognostic information until they reach a perceived "threshold" of certainty in the accuracy of a prognosis [55]. This observation corroborates with those of Lind et al.[57], who discovered that the doctor's directive to "wait and see" may cause miscommunication between the doctor and family members. One possible reason for the delayed initiation of EOL conversations from doctors might be due to their imcompetent communication skills, in which many of them were unable to discuss EOL issues with the patients and the families in an effective and timely manner [58]. Yet, this directive to further delay diagnosis could potentially give the family a sense of false hope that the patient's situation can be improved. When miscommunication occurs, it would appear to be too late to conduct proper EOL communication, or for family members to provide input in the decision-making process about terminating treatment.

Another potential reason why EOL communication may not be implemented in a timely fashion is the presence of physician-family collusion, a situation where family members choose to hide the diagnosis and prognosis from the patients; and it is not uncommon in the palliative care context. Notwithstanding the fact that collusion goes against medical ethics and can potentially cause various complications in EOL treatment, admittedly, collusion is widely seen across Europe and Asia[26]. This is because of the fear of disappointing the patients by informing them of their deteriorating health condition, and more prevailing in Asian countries that the social norm of holding family members to be responsible for the main body of communication about EOL care.

The failure to have patients engage in timely EOL conversations can lead to aggressive life-sustaining treatments, under-utilisation of palliative care, and negative outcomes for both patients and their families. Patients' psychological conditions, including depression scores and quality of life metrics, will be compromised without good palliative care. Moreover, introducing palliative care relieves caregiver stress and improves caregiver depression scores [22, 56]. As a result of these side effects, clinical prediction models to provide estimated remaining survival time of the patient have started to gain popularity in medical practices to aid the EOL discussion pacing of clinicians.

Proper and prompt palliative care referrals are also important. Frameworks for effective EOL communication could also encourage clinicians to identify an optimal time to refer the patient to palliative care. [59-60].

Difficulty in identification of a "key person" who is responsible for decisions regarding EOL care

Communication required to negotiate EOL care extends beyond the patients and the doctors. It also includes the patients' families, especially in the context of Asia, which family-oriented practices prevail [14]. Families may wish to take up the responsibility for the patient's EOL care. The involvement of multiple parties often lead to difficulty in identifying a main person to hold responsibility for making palliative care decisions.

Failure to identify a key person among family members in EOL care and conversations can cause confusion and misunderstanding, undermining decision making and contributing to a confused process which is already fraught with uncertainty [61-62]. Unclear responsibilities and responses can create contradictory expectations between the family members and the patient. Discrepancies have been observed between the last wishes of patients to follow the natural course comfortably and the desire of their family members to hold on to their loved ones for as long as possible [63-64]. Even when the decision-making responsibility is delegated to one family member, their decisions may be affected by contradicting opinions within the family [65]. To further complicate the matter, McDarby et al.[66] showed that elderly parents' EOL preferences may not be understood by their children. Consequently, misunderstanding and a lack of communication between the patients and their families emerge, resulting in confusion and disagreements in the EOL decision-making process.

Different cultural perspectives on EOL communication

Sociocultural factors play a significant role in EOL communication. In the West, individualism and autonomy are emphasised. EOL communication usually occurs between the doctor and the patient. Depending on the patient's wishes, family members may also be involved [25]. Although there are significant cultural differences between Chinese and Western regions, clinicians of Chinese contexts undertake the same EOL communication models adopted by clinicians from the West [25]. They would look for social cues such as the nonverbal communication behaviour including tone of voice, manner, and attitude, to determine the readiness of patients to engage in EOL conversations. However, the implications of these social cues may differ by cultures. Heavy reliance on social cues lead to miscommunication. In certain cultural contexts, understanding the non-verbal cues from patients are essential to perceiving their readiness with EOL communication, and to help (re)calibrate the conversation flow; thus, potentially making non-verbal communication even more crucial than the verbal content (see also[67-68]) . These factors influence the agencies manifested across the multiple parties, which potentially contribute further to the EOL decision-making conflicts. Meanwhile, in Chiense contexts, EOL communication is largely affected by sociocultural factors. Decisions are made as a collective family rather than between the individual patient and doctor [69]. Studies have shown that some patients do not wish to be involved in the decision-making process of their treatments even if it concerns their own life. This belief is prevalent among Chinese patients. Due to the Chinese cultural beliefs, dying Chinese patients prefer to let their children make the EOL decisions. Bowman and Singer[14] reported that the role of family in the Chinese culture emphasises interdependency, obligation, and responsibility to others. Family members in a Chinese family are expected to be responsible for protecting the patient's health, safety, and general well-being. Chinese patients believe in their children's ability to make decisions on their behalf and sees no need for advance directives about treatment or communication on EOL needs, resulting to increased miscommunication and misunderstanding about the patient' s needs.

Similar findings were observed in Eastern countries, where Asian family members typically preferred to be involved in making EOL decisions together with, or sometimes, on behalf of the elderly patients [25, 70-73]. In China and nations of proximity such as Korea, where Chinese culture poses significant impact, EOL decision-making tends to be a family-centred practice rather than an individual decision [72, 74-75]. Alternatively, Kato and Tamura [76] offered relational authority as another dynamic found within East Asian cultures, where family members will leave medical decisions to the clinicians. Kato and Tamura's [76] study also stresses that family members felt a great responsibility to care for their parents and that failure to continue the care, such as admitting their parents to a nursing home, led to feelings of guilt and abandonment among the family members. This is because the ideology behind it, which is constructed from traditional Confucianist and Buddhist beliefs, largely focuses on collectivism and familial responsibility. Filial piety is a key value to maintain social stability and familial harmony. Based on this premise, parents become the recipients of their adult children's care, and children of dying patients are highly trusted in making treatment plans and EOL decisions for their parents [70, 72, 74, 76]. In addition, in the East Asian context, immediate family members generally possess the power to decide whether to inform the patient of their current medical situations [25], creating a common phenomenon where the doctors would have consultations with the family caregivers prior to speaking with the patients.

Discussion

This review identified the significance of family members in EOL communication and how their engagement in EOL discussions can improve the quality of patients' EOL and death. Moreover, this review found that there is a need for Chinese and East Asian specific EOL communication model to address cultural needs of elderly patients. An important trend identified in the included studies is the accumulating body of knowledge on the significance of family on care, support, as well as communication with the patients. Open discussions initiated by clinicians are key to decreasing psychological side effects in patients and family members such as anxiety, psychological stress, and pressure [77].

Referencing to the research question, existing research about familial roles in EOL communication can be categorised into four different themes. As discussed, family can be a prominent source of decision-making conflict in EOL communication. Decision-making conflict could also occur between the family and clinicians, and the family and the patient. Also, The lack of identifying a key person responsible for EOL-decision making results in decision-making conflict. These conflict could result to significant delay of exercising EOL treatments.

Despite the associated challenges and issues of involving family in the decision-making process, families are an important source of support for patients who are undergoing EOL care. Family support could be manifested through providing the basic needs of the patient (i.e., helping to make the patient more comfortable, offering food and drinks, etc.), monitoring the patient's emotional status, and offering immediate support and assistance [42, 46]. Family participation in EOL matters is also found to be negatively correlated with the level of psychological distress in bereaved family caregivers, implying that the more the family members engage in the patient's EOL journey, the lesser extent they experienced psychological symptoms such as anxiety and depression after the patient has passed away [77-79]. Chui and Chan's[80] research echoes this finding, demonstrating that longer EOL discussions could significantly reduce the incidence of post-traumatic stress disorder, anxiety, and depression of thes families of patients who died in the ICU. On the other hand, Mitchell et al.'s[9] findings noted that there was insufficient time for family caregivers to consider the possibility of death, as avoiding the possibility served as a coping mechanism for the caregiver, and the life-threatening aspect of the patient's condition was only acknowledged after an episode was resolved. As for the impact on the patients, Byock's [81] clinical observation revealed that despite the typical suffering at the EOL, the quality of family input during EOL discussions, such as careful, relationship-appropriate, and goal-directed EOL communications, was important for the patient's emotional wellbeing and the overall experience towards the EOL stage. Thus, quality communication between the patients and their family members are vital in improving the quality of life of dying patients during their EOL stage [41, 43, 48].

Considering the value that familial support could have, healthcare workers must learn what is important to the patients and their families, and ensure that their preferences are adequately explored, adhered to, and respected even in cases where their preferences contradict the clinician's decision. From the clinician's point of view, EOL communication is most effective when family members participate and engage in the joint decision-making discussion [20, 82]. Fostering positivity in EOL communication as a clinician was also viewed to be important [29]. When family members and patients clearly understand one another's EOL preferences, decisions on treatments and palliative care could effectively address patients' needs [78].

There is also plenty of material to discuss with the significance of timing in EOL communication. With regards to physician-family discussions, clinicians should be equipped with the competency to explain its negative effects on the patient and family members in an empathetic and compassionate way, as well as encourage communication between family members and the patients so that family members could understand the patients' wishes and explain their diagnoses [26]. Clinicians should also be educated to take on a bridging role between family members and the patients, acting as a facilitator of communication and exploring any unspoken issues that either side are intentionally avoiding. As such, with continual training and education, healthcare professionals could develop effective communication skills for palliative care and collaborate with the patients' families to provide quality EOL care. Furthermore, healthcare providers should act as mediators and advisors to assist both parties in making appropriate treatment decisions and thus enable the patients to have a "good death" [14]. The barriers and uncertainties among the patients, family members and the clinicians should be moderated to build trust and facilitate open EOL communication [63, 83].

Moreover, healthcare providers may be capable of initiating EOL conversations at optimal timing with widespread adoption of prognostic tools. When EOL discussions are conducted at optimal timing, patients' comfort and dignity during EOL could be immensely improved [52]. The Palliative Care Chart developed by Bailey et al.[48] is a tool for clinicians to assists in generating effective EOL communication, aiming to facilitate continuity and co-ordination of care and sense of partnership between patients and their families. The chart serves as a checklist for clinicians. Together with the training on use of the tool, results showed that clinicians were able to resolve ongoing concerns occurred between the patients and family members during palliative discussions. Another means to educate health care professionals to provide better palliative care is the development of quality indicators as suggested by Raijmakers et al.[30]. Clinicians can be trained to monitor different aspects of the patient according to the quality indicators, for instance, limited need for pain control, providing palliative care accordingly, and improving the patients' quality of life towards the last stages of their lives. Educational interventions may be one way to raise the awareness and significance of patient participation in EOL planning. As suggested in this review, family participation in the process of EOL discussions should also be considered. Family participation in EOL communication were shown to have positive effects on the patients' quality of EOL treatment receptions [21, 60]. However, the degree of involvement varies between Eastern and Western countries given cultural differences, requiring a Chinese and Eastern specific communication model to address the cultural implications of different regions. Chinese patients and families commonly avoid EOL communication due to Buddhism and Confucianism beliefs, which accepts that talking about death brings death closer[14]. These beliefs also emphasise a balance of physical, emotional, and social harmony, which provides a culturally sound reason for them to evade such conversations regarding palliative care and EOL decisions [14, 60]. Also, in China specifically, filial piety plays an important role in the conduct of children. In cases of medical care, the burden of making treatment decisions and EOL choices are usually delegated to the children of elderly patients [14, 24, 56, 84]. Some elderly patients may even choose to exclude themselves from the EOL communication between clinicians and family caregivers and family members would become the first and main persons to contact during the discussion about their conditions and EOL decisions [11].

In Western countries, contrarily, patients and elderly people are generally familiar with palliative care. The awareness of setting up wills and arranging palliative care enable them to be relatively prepared to engage in early EOL conversations [64]. Furthermore, autonomy and self-determination are prevailing concepts, and patient's self-exclusion during medical consultation is rarely observed. Given the prevalence of individualism most patients of the Western contexts wish to make EOL decisions for themselves [68, 85]. In occasional circumstances, patients prefer to withhold information on diagnosis and treatments to their family members, this would lead to a lack of communication [86] as well as insufficient understanding of the illness among family members and hence, compromised preparedness in dealing with their beloved's EOL issues [80].

Prior research also addressed potential solutions to improve the quality and communicative environment of EOL care. Effective EOL communication is essential in creating a fulfilling EOL experience for the patients and their family members, while advance preparation could help achieve successful EOL conversations. As the majority of patients trust that their healthcare providers are capable of providing quality treatment, diagnosis, and other information regarding their illness. Clinicians could build good rapport over time and establish trust with patients [56]. This promotes patient-centred care, which is vital for effective EOL communication in both Eastern and Western contexts as the patients 'needs are always top priority when the doctors are developing medical plans. To attain such patient-oriented practices, clinicians must address the elements of 1) sensitivity to the patients' needs, personal experiences and perspectives; 2) self-participation of the patients' own recovery journey; and 3) enhancement of doctor-patient relationships.

It is also critical to keep the patients informed about their diseases. In a previous study [61], half of the respondents reported that neither were they notified about the diagnosis and prognoses, nor did they fully understand the information provided by doctors. Clinicians should have regular meetings with the patients and family members to keep them up to date on the disease progress and prognoses. Advance notification of the nature of the meeting, as well as the provision of a quiet and calm atmosphere could help decrease the anxiety of family members. Issues regarding the manner of delivery are present as well; when delivering bad news, clinicians were typically found not to have a specific goal, or did not consider ahead how would the news impact the receiver[68]. All these can become obstacles in conducting effective consultation as well as disclosing the unpleasant news to the patients. To balance both medical and interpersonal needs in such difficult EOL discussions, there are developed protocols to help clinicians to better approach the conversation. One example being 'COMFORT '(an acronym for Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative messages, and Team), which is a step-by-step guide on breaking bad news in a humane manner and at the same time, providing comfort to the recipient[32, 86]. 'SPIKES' (an acronym for Setting, Perception, Invitation, Knowledge, Empathetic Response, Summary), which is a six-step framework, assists doctors with proper preparation in delivering bad news while ensuring the patients' comfort and understanding of the discussion[5,87]. Whilst these protocols were developed and validated in the Western context; since sociocultural factors play a significant role in doctor-patient communication, they may not be applicable in non-Western nations due to the different traditional beliefs in the East[88]. More specifically, the Chinese philosophy of death being a taboo subject has wide influences across many Asian countries, resulting in hesitation of prognosis disclosure to dying patients. Having communication frameworks as a guideline for clinicians to navigate around EOL conversations is plausible; yet, a formulaic approach without cultural considerations of the patients could reduce patient satisfaction. Clinicians therefore need to adapt to families on a case-by-case basis while considering the nuances of patient perspective, context of the discussion, and content of the conversation so that they can adjust the communication accordingly [11].

Lastly, clinicians should attend to the family caregivers' expectations according to the cultural context. They need to understand and respect the expectations of the patient and their family regarding the treatment. Differences in preferences and the lack of communication between medical professionals and patients are known to create conflicts. Careful listening and understanding the patients' preferences enhance the quality of patients' dying process [23]. In addition, a one-size-fits-all approaches does not work in EOL communication due to the variety of factors [24]. It is essential to improvise discussions according to each patient and family needs. Moreover, keeping the general cultural guidelines in mind enables clinicians to connect with their patients more precisely in respect of different scenarios regardless of the cultural backgrounds of both parties. More research is warranted to investigate how clinicians could and should communicate with different patients, by looking for the best model to assess the need and preference in communication. Medical staff must be trained to be prepared for providing a smooth EOL communication experience to patients based on their cultural backgrounds and practice [24].

Strengths and limitations

This systematic review highlights the importance of culture and how it can affect the beliefs and roles of families in EOL decision-making. Due to limitations from the research team, only peer-reviewed articles in English were reviewed. Furthermore, only articles that have collected primary empirical data have been included in the search; other forms of research such as prior systematic reviews were not included. This may skew the overall results and findings elicited in this study. While the signposting of 'the East and West' is beneficial in distinguishing EOL communicative practices across different cultural contexts, we also acknowledge the generalisability of such labelling; there are many additional factors which contribute to the complexity of EOL communication. Lastly, we make acknowledgement that subjectivity exists to a certain extent even with the discussions on the interpretations and evaluations of each study between the four authors. Nonetheless, Table 2 presents a relatively accurate picture of the overall state of the role of family in EOL communication, and the limitations mentioned can serve as an impetus for future research.

Conclusion

This review identified the important and unique roles of family caregivers in EOL communication and the pressing need to develop an EOL communication framework designed for the Chinese and Eastern contexts. The reviewed studies indicated that family engagement in EOL discussions is beneficial for both patients and their family members. Knowledge about the patient's diagnosis and prognosis information factoring in EOL decisions will facilitate fruitful communication among healthcare providers, patients and family members. Clinicians should identify and remove barriers to enable sufficient understanding of the information desired by each party, tackle collusions tactfully, and bridge the gap between the parties if direct communication is difficult and distressing. The timing of EOL communication and communicative content are important, especially in circumstances where clinical deterioration is inevitable. Existing palliative care communication frameworks, such as the COMFORT model and SPIKES protocol could be modified according to the implications of this review to fit the family-oriented cultures in Chinese and Eastern contexts. With such guiding principles, clinicians will be able to engage and discuss EOL issues with patients confidently, thus performing a well-rounded EOL communication practice.

The current review identified four significant themes that presented the roles of family caregivers in EOL communication. Many of the articles in the systematic search in the results and discussion show the involvement of family members in EOL decision-making. Clinicians should acknowledge the significance of families' views during the decision-making process. It is paramount to respect and understand the decisions of the patient and the family, while also acting as a bridge to mediate between them and facilitate open discussions. Clinicians can also use prediction models or prognostic tools to predict the patients' survival time to ensure a timely EOL conversation to prepare for the end of their life.

Previous studies showed that programs introducing advance care planning and acculturation could successfully encourage patients to participate in EOL communication with their palliative care team and family caregivers [24, 56]. However, while previous palliative care tools have shown to improve doctor-patient interaction, a lot of them do not focus on further factors that contextualise and complicate EOL communication, such as sociocultural factors, patient-centred care, and patient autonomy. Palliative care tools can be designed to be inclusive of family involvement in EOL communication, reflecting both the role of family members and patients' individual role with respect to their families. Regarding clinicians and practitioners' EOL communication praxis, our recommendations are twofold. The first is to be continually aware of the cultural implications. The second is for clinicians to be trained so that they can help the patient negotiate personal and familial obligations while undergoing EOL treatments.

Availability of data and materials

All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate

Not applicable. All the work was developed using published data.

Consent to participate

Not applicable.

Competing interest

None.

Funding

Not applicable.

Authors' contributions

All authors contributed substantially to article search, data collection and analysis, and manuscript writing.

Acknowledgement

Not applicable.

References

1. Buckman R. Communication in palliative care: a practical guide. Death, Dying and Bereavement. 2nd edn. *Sage, London.* 2000 Dec 8:146-73.
2. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA internal medicine.* 2014 Dec 1;174(12):1994-2003.
3. Clayton JM, Hancock KM, Butow PN, Tattersall MH, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia.* 2007 Jun 18;186(12):S77.
4. Odgers J, Fitzpatrick D, Penney W, Shee AW. No one said he was dying: families' experiences of end-of-life care in an acute setting. *Australian Journal of Advanced Nursing*. 2018 Mar;35(3):21-31.
5. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *The oncologist.* 2000 Aug;5(4):302-11.
6. Simpson N, Knott CI. Stress and burnout in intensive care medicine: an Australian perspective. *Med J Aust.* 2017 Feb 20;206(3):107-8.
7. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: associations with end-of-life conversations. *Archives of internal medicine.* 2009 Mar 9;169(5):480-8.
8. Maubach N, Batten M, Jones S, Chen J, Scholz B, Davis A, Bromley J, Burke B, Tan R, Hurwitz M, Rodgers H. End-of-life care in an Australian acute hospital: a retrospective observational study. *Internal medicine journal.* 2019 Nov;49(11):1400-5.
9. Mitchell S, Slowther AM, Coad J, Dale J. Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation. Archives of Disease in Childhood. 2020 Nov 16; 106:570-576.
10. Ng GW, Pun JK, So EH, Chiu WW, Leung AS, Stone YH, Lam CL, Lai SP, Leung RP, Luk HW, Leung AK. Speak-up culture in an intensive care unit in Hong Kong: a cross-sectional survey exploring the communication openness perceptions of Chinese doctors and nurses. *BMJ open.* 2017 Aug 1;7(8):e015721.
11. Pun JK, Cheung KM, Chow JC, Chan WL. Chinese perspective on end-of-life communication: a systematic review. *BMJ Supportive & Palliative Care.* 2020 Jul 9.
12. Hawryluck L. Communication with patients and families. *Ian Anderson Continuing Education Program in End-of-Life Care.* 2000.
13. Food and Health Bureau. End-of-life Care: Legislative Proposals on Advanced Directives and Dying in Place – Consultation Document. 2019 Sep https://www.fhb.gov.hk/download/press_and_publications/consultation/190900_eolcare/e_EOL_care_legisiative_proposals.pdf.
14. Bowman KW, Singer PA. Chinese seniors' perspectives on end-of-life decisions. *Social science & medicine.* 2001 Aug 1;53(4):455-64.
15. Wang X, Huang Y, Radha Krishna L, Puvanendran R. Role of the Nasogastric Tube and Lingzhi (Ganoderma lucidum) in Palliative Care. *Journal of Pain and Symptom Management*. 2016 Apr;51(4):794-9.
16. Peng NH, Liu HL, Chen CH, Bachman J. Cultural practices and end-of-life decision making in the neonatal intensive care unit in Taiwan. *Journal of Transcultural Nursing*. 2012 Jul;23(3):320-6.
17. Miljeteig I, Johansson KA, Sayeed SA, Norheim OF. End-of-life decisions as bedside rationing. An ethical analysis of life support restrictions in an Indian neonatal unit. *Journal of Medical Ethics*. 2010 Aug;36(8):473-8.
18. Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *General hospital psychiatry.* 2010 Jul 1;32(4):433-42.
19. Leung DY, Chan HY, Yau SZ, Chiu PK, Tang FW, Kwan JS. A video-supported nurse-led advance care planning on end-of-life decision-making among frail older patients: Protocol for a randomized controlled trial. *Journal of advanced nursing.* 2019 Jun;75(6):1360-9.
20. Ohs JE, Trees AR, Gibson C. Holding on and letting go: Making sense of end-of-life care decisions in families. *Southern Communication Journal.* 2015 Oct 20;80(5):353-64.
21. Keeley MP. Family communication at the end of life. Behavioral Sciences, 7, 45.

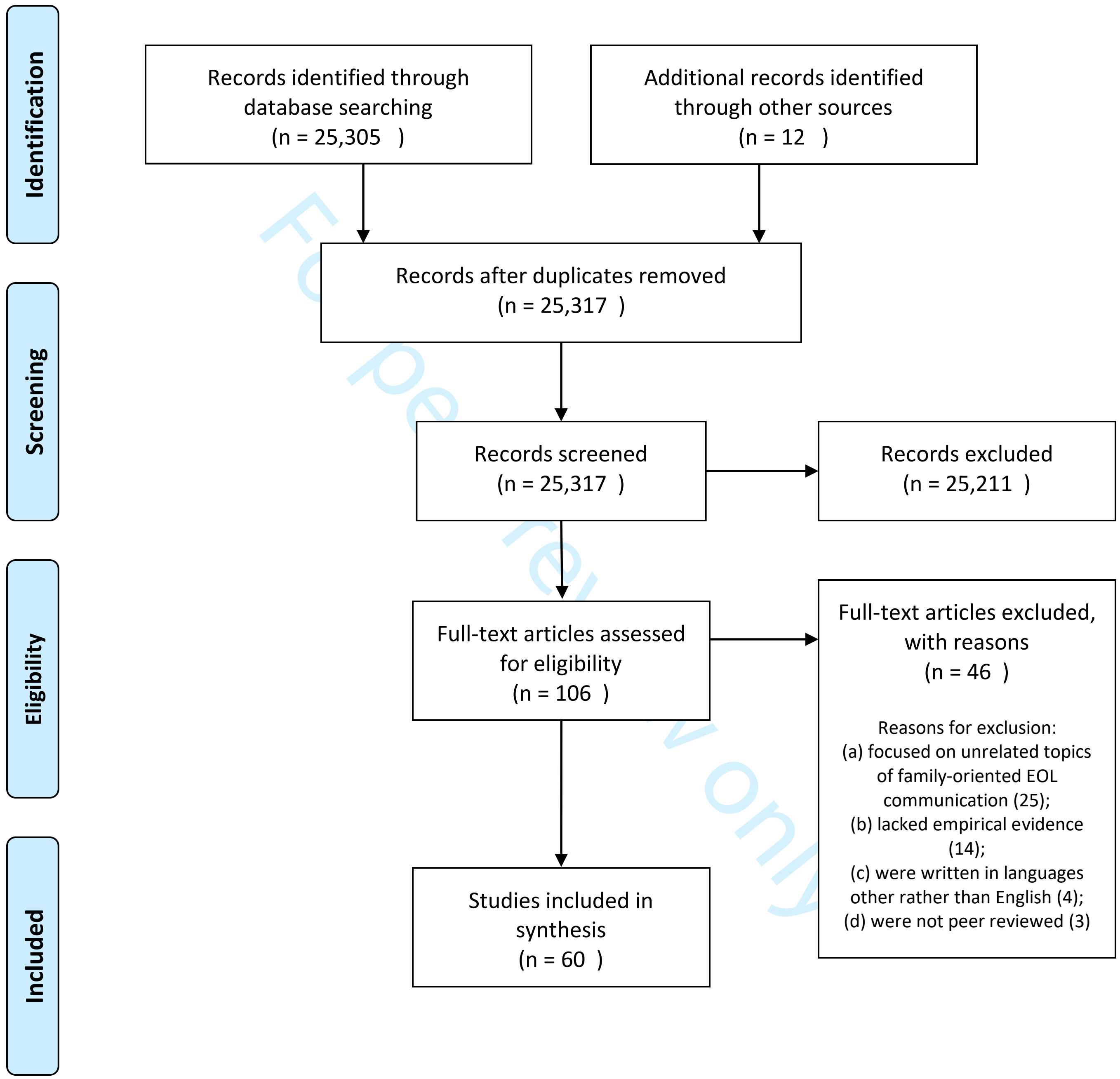
22. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C, Canoui P, Le Gall JR, Schlemmer B. Half the families of intensive care unit patients experience inadequate communication with clinicians. *Critical care medicine.* 2000 Aug 1;28(8):3044-9.
23. Fan Z, Chen L, Meng L, Jiang H, Zhao Q, Zhang L, Fang CK. Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff. *Supportive Care in Cancer.* 2019 Feb 1;27(2):583-9.
24. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The gerontologist.* 2005 Oct 1;45(5):634-41.
25. Wang Q. Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US. 2010.
26. Low JA, Kiow SL, Main N, Luan KK, Sun PW, Lim M. Reducing collusion between family members and clinicians of patients referred to the palliative care team. *The Permanente Journal.* 2009;13(4):11.
27. Lo RS, Woo J, Zhoc KC, Li CY, Yeo W, Johnson P, Mak Y. Cross-cultural validation of the McGill Quality of Life questionnaire in Hong Kong Chinese. *Palliative medicine.* 2001 Jul;15(5):387-97.
28. Almack K, Cox K, Moghaddam N, Pollock K, Seymour J. After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC palliative care.* 2012 Dec;11(1):1-0.
29. Kastbom L, Karlsson M, Falk M, Milberg A. Elephant in the room - Family members' perspectives on advance care planning. *Scandinavian journal of primary health care*. 2020 Nov 11;38(4):421-429.
30. Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, Popa-Velea O, Romotzky V, Schuler S, Ellershaw J, Ostgathe, on behalf of OPCARE9 C. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. *Journal of palliative medicine.* 2012 Mar 1;15(3):308-16.
31. The English Parliamentary and Health Service Ombudsman. *The Ombudsman's Annual Report and Accounts 2015-16* (Rep.). 2016 Nov 3. Retrieved https://www.ombudsman.org.uk/sites/default/files/PHSO_Annual_Report_2015-16.pdf.
32. Wittenberg E, Goldsmith JV, Ragan SL, Parnell TA. Communication in palliative nursing: The COMFORT Model. *Oxford University Press.* 2019 Dec 24.
33. Paré K, Grudziak J, Lavin K, Sten MB, Huegerich A, Umble K, Twer E, Reid T. Family perceptions of palliative care and communication in the surgical intensive care unit. *Journal of Patient Experience*. 2021 July 14;8.
34. Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative medicine*. 2019 Sep;33(8):926-41.
35. Coombs MA, Parker R, Ranse K, Endacott R, Bloomer MJ. An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care. *Journal of advanced nursing*. 2017 Jan;73(1):39-55.
36. Lowey, SE. Communication between the Nurse and Family Caregiver in End-of-Life Care: A Review of the Literature. *Journal of hospice and palliative nursing*. 2008 Jan;10(1):35-45.
37. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*. 2007 Jul;34(1):81-93.
38. Pun JKH, Chan EA, Wang S, Slade D. Health professional-patient communication practices in East Asia: An integrative review of an emerging field of research and practice in Hong Kong, South Korea, Japan, Taiwan, and Mainland China. *Patient education and counselling*. 2018 Jul;101(7):1193-1206.
39. Thomas H, Ciliska D, Dobbins M. Quality assessment tool for quantitative studies. Toronto: Effective Public Health Practice Project McMaster University. 2003.
40. Joanna Briggs Institute. JBI critical appraisal checklist for qualitative research. Retrieved from http://joannabriggs.org/assets/docs/criticalappraisal-tools/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017. pdf. 2017.
41. Githaiga JN, Swartz L. Socio-cultural contexts of end-of-life conversations and decisions: bereaved family cancer caregivers' retrospective co-constructions. *BMC palliative care.* 2017 Dec;16(1):1-8.
42. Lee MK, Yun YH. Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study. *Cancer nursing.* 2018 May 1;41(3):E1-0.

43. Royak-Schaler R, Gadalla SM, Lemkau JP, Ross DD. Family perspectives on communication with healthcare providers during end-of-life cancer care. In Oncology nursing forum 2006 Jul 1 (Vol. 33, No. 4, p. 753). Oncology Nursing Society.
44. Towsley GL, Hirschman KB, Madden C. Conversations about end of life: perspectives of nursing home residents, family, and staff. *Journal of Palliative Medicine.* 2015 May 1;18(5):421-8. doi:10.1089/jpm.2014.0316
45. Shaunfield SL. "IT'SA VERY TRICKY COMMUNICATION SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN. *Theses and Dissertations--Communication* 2015;43. https://uknowledge.uky.edu/comm_etds/43.
46. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.
47. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
48. Bailey S, Sellick SM, Setliff AE, Linkewich B, Kelley ML, Poling M. Communication at life's end [A patient held palliative care chart facilitates communication]. *The Canadian Nurse.* 1999 May 1;95(5):41.
49. Kramer BJ, Kavanaugh M, Trentham-Dietz A, Walsh M, Yonker JA. Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer. *The Gerontologist.* 2010 Apr 1;50(2):215-25.
50. Kotecho M, Adamek ME. Gender differences in quality of life of urban elders in Ethiopia. *Innovation in Aging.* 2017 Jul;1(Suppl 1):879.
51. Shin DW, Cho J, Kim SY, Chung IJ, Kim SS, Yang HK, Ahn E, Park BR, Seo H, Park JH. Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. *Psycho-Oncology.* 2015 Feb;24(2):212-9.
52. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between clinicians and family caregivers about care at the end of life: when do discussions occur and what is said?. *Journal of palliative medicine.* 2005 Dec 1;8(6):1176-85.
53. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.
54. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
55. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation: benefit or harm?. *Jama.* 1995 Sep 13;274(10):826-9.
56. Huang HL, Chiu TY, Lee LT, Yao CA, Chen CY, Hu WY. Family experience with difficult decisions in end-of-life care. *Psycho-Oncology.* 2012 Jul;21(7):785-91. Doi: 10.1002/pon.3107
57. Lind R, Lorem GF, Nortvedt P, Hevrøy O. Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. *Intensive care medicine.* 2011 Jul;37(7):1143-50.
58. El-Jawahri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, Kamdar M, Jacobsen J, Chittenden EH, Rinaldi SP, Gallagher ER. Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial. *The oncologist.* 2017 Dec;22(12):1528. Doi: 10.1634/theoncologist.2017-0227
59. Hui D, Kim SH, Roquemore J, Dev R, Chisholm G, Bruera E. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer.* 2014 Jun 1;120(11):1743-9.
60. Rhoads S, Amass T. Communication at the End-of-Life in the Intensive Care Unit: A Review of Evidence-Based Best Practices. *Rhode Island Medical Journal.* 2019 Dec 1;102(10).
61. Biola H, Sloane PD, Williams CS, Daaleman TP, Williams SW, Zimmerman S. Physician communication with family caregivers of long-term care residents at the end of life. *Journal of the American Geriatrics Society.* 2007 Jun;55(6):846-56.
62. Chan WC. Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?. *Journal of palliative medicine.* 2011 Sep 1;14(9):997-1003.

63. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. Patient and Family Related Barriers of Integrating End-of-Life Communication into Advanced Illness Management. *Journal of Pain and Symptom Management.* 2018 Dec 1;56(6):e58-9.
64. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. "Whatever happens, happens" challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study. *BMC palliative care.* 2019 Dec;18(1):1-9.
65. Trees AR, Ohs JE, Murray MC. Family communication about end-of-life decisions and the enactment of the decision-maker role. *Behavioral Sciences.* 2017 Jun;7(2):36.
66. McDarby M, Picchiello M, Kozlov EK, Ju C, Worthalter D, Carpenter B. ADULT CHILDREN'S UNDERSTANDING OF PARENTS'CARE AND LIVING PREFERENCES AT END OF LIFE. *Innovation in Aging.* 2019 Nov;3(Supplement_1):S668-9. doi:10.1093/geroni/igz038.2473
67. McElroy JA, Proulx CM, Johnson L, et al. Breaking bad news of a breast cancer diagnosis over the telephone: an emerging trend. *Supportive care in cancer* 2019 Mar; 27(3): 943-950.
68. Schonfeld TL, Stevens EA, Lampman MA, et al. Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities. *American journal of hospice and palliative medicine* 2012 Jun; 29(4): 260-267.
69. Ayers NE, Vydelingum V, Arber A. An ethnography of managing emotions when talking about life-threatening illness. *International nursing review.* 2017 Dec;64(4):486-93.
70. Chan WC, Epstein I, Reese D, Chan CL. Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the "support paradox". *Social Work in Health Care.* 2009 Jul 8;48(5):519-32.
71. Ho AH, Chan CL, Leung PP, Chochinov HM, Neimeyer RA, Pang SM, Tse DM. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age and ageing.* 2013 Jul 1;42(4):455-61.
72. Tse CY, Chong A, Fok SY. Breaking bad news: a Chinese perspective. *Palliative medicine.* 2003 Jun;17(4):339-43. Doi: 10.1191/0269216303pm751oa
73. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
74. Ko E, Roh S, Higgins D. Do older Korean immigrants engage in end-of-life communication?. *Educational Gerontology.* 2013 Aug 1;39(8):613-22.
75. Zheng RS, Guo QH, Dong FQ, Owens RG. Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study. *International journal of nursing studies.* 2015 Jan 1;52(1):288-96.
76. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
77. Abbey JG. Communication about end-of-life topics between terminally ill cancer patients and their family members. 2008
78. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of the American Geriatrics Society.* 1997 Nov;45(11):1339-44.
79. Scott AM. Family conversations about end-of-life health decisions. University of Illinois at Urbana-Champaign; 2010.
80. Chui WY, Chan SW. Stress and coping of Hong Kong Chinese family members during a critical illness. *Journal of clinical nursing.* 2007 Feb;16(2):372-81.
81. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clinics in geriatric medicine.* 1996 May 1;12(2):237-52.
82. Ohs JE, Trees AR, Kurian N. Problematic integration and family communication about decisions at the end of life. *Journal of Family Communication.* 2017 Oct 2;17(4):356-71.
83. Van den Heuvel LA, Hoving C, Schols JM, Spruit MA, Wouters EF, Janssen DJ. Barriers and facilitators to end-of-life communication in advanced chronic organ failure. *International journal of palliative nursing.* 2016 May 2;22(5):222-9.

84. Peterson LJ, Hyer K, Meng H, Dobbs D, Gamaldo A, O'Neil K. Factors associated with whether older adults discuss their EOL care preferences with family members. *Innovation in Aging.* 2018 Nov;2(suppl_1):843. doi:10.1093/geroni/igy023.3141
85. Colletti L, Gruppen L, Barclay M, Stern D. Teaching students to break bad news. *The American journal of surgery.* 2001 Jul 1;182(1):20-3.
86. Villagran M, Goldsmith J, Wittenberg-Lyles E, Baldwin P. Creating COMFORT: A communication-based model for breaking bad news. *Communication Education.* 2010 Jul 1;59(3):220-34.
87. Schapira L. Delivering bad news to patients and their families. *Tumors of the Chest* 2006 (pp. 597-605). Springer, Berlin, Heidelberg.
88. Labaf A, Jahanshir A, Shahvaraninasab A. Difficulties in using Western guidelines for breaking bad news in the emergency department: the necessity of indigenizing guidelines for non-Western countries. *Journal of Medical Ethics & History of Medicine.* 2014 Jan 1;7(1).

PRISMA 2009 Flow Diagram



Records identified through database searching
(n = 25,305)

Additional records identified through other sources
(n = 12)

Records after duplicates removed
(n = 25,317)

Records screened
(n = 25,317)

Records excluded
(n = 25,211)

Full-text articles assessed for eligibility
(n = 106)

Full-text articles excluded, with reasons
(n = 46)

Reasons for exclusion:
(a) focused on unrelated topics of family-oriented EOL communication (25);
(b) lacked empirical evidence (14);
(c) were written in languages other rather than English (4);
(d) were not peer reviewed (3)

Studies included in synthesis
(n = 60)

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix 1. Search strategy

The current review search includes keywords and synonyms of ‘end of life’, ‘communication’ and ‘family’. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevantstudies, e.g. ‘end of life AND communication AND family’.

Appendix 2 Summary of each included study.

Theme	Author(s)	Article	Objective(s)	Research design	Sample
1	Abbey, 2008 [41]	Communication about end-of-life topics between terminally ill cancer patients and their family members	To explore EOL communication by addressing patient-family communications	Quantitative - Questionnaire	369 patients
1	Bailey et al., 1999 [55]	Communication at life's end [A patient held palliative care chart facilitates communication]	To promote effective communication, the continuity and co-ordination of care, and sense of partnership for patients and their families through developing a care chart relating to palliative communication	Qualitative - Interviews	40 families and health care providers
1	Byock, 1996 [42]	The nature of suffering and the nature of opportunity at the end of life	To explore the personal experience of suffering in life-limiting illness and to understand the nature of opportunity at the end of life.	Qualitative - Clinical observation	N/A
1	Chui & Chan, 2007 [43]	Stress and coping of Hong Kong Chinese family members during a critical illness	To assess how families cope with stress during a family members’ admission to ICU and the relationships between stress and coping	Qualitative - Structured interview	133 participants
1	Fan et al., 2019 [23]	Preference of cancer patients and family	To study the preferences of cancer patients and	Quantitative - Questionnaire	216 cancer patients

		members regarding delivery of bad news and differences in clinical practice among medical staff	their families in way of being informed of their conditions and explore the factors in the underlying preferences		242 family caregivers 176 clinical staff members
1	Githaiga & Swartz, 2017 [44]	Socio-cultural contexts of end-of-life conversations and decisions: bereaved family caregivers' retrospective co-constructions	To examine the content and context of EOL conversations and decisions based on family caregivers of cancer patients in resource-limited areas.	Qualitative - Focus group interview	13 participants
1	Hanson et al., 1997 [45]	What is wrong with end-of-life care? Opinions of bereaved family members	To explore family perceptions of EOL care and communication	Qualitative - Interview	461 family members
1	Kastbom et al., 2020 [29]	Elephant in the room - Family members' perspectives on advance care planning	To explore family members' experiences of advance care planning and EOL communication	Qualitative - Interview	18 family members of deceased nursing home patients
1	Kotecho & Adamek, 2017 [57]	Gender differences in quality of life of urban elders in Ethiopia	To explore how death of a resident affects Certified Nursing Assistants in terms of impacts and support they received.	Qualitative - Semi-structured interviews	140 participants
1	Kramer et al., 2010 [56]	Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer	To examine the correlates and predictors of family conflict at the end of life	Quantitative - Surveys	155 participants
1	Lee & Yun, 2018 [46]	Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study	To determine whether family caregiver functioning predicts EOL Quality of life received by terminally ill patients with cancer	Quantitative - Questionnaire	264 family caregivers of terminally ill patients

1	Mitchell et al., 2020 [9]	Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation	To understand experiences of healthcare services concerning children with life-limiting conditions and their family members	Qualitative - Interview	31 family members including 10 children
1	Ohs et al., 2015 [20]	Holding on and letting go: Making sense of end-of-life care decisions in families	To understand how family members make EOL care decisions and their discursive contradictions that appears during the process	Qualitative - Interview	15 family caregivers of cancer patients
1	Ohs et al., 2017 [47]	Problematic integration and family communication about decisions at the end of life	To examine how families make decisions on behalf of their dying family members at the end of life and how they manage the stressful situation	Qualitative - Interview	22 family members who engaged in EOL conversations
1	Royak-Schaler et al., 2006 [48]	Family perspectives on communication with healthcare providers during end-of-life cancer care	To assess healthcare provider communication on EOL with patients and their family members	Mixed method - Focus group discussions and questionnaires	24 family members of deceased patients
1	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
1	Shaunfield, 2016 [51]	“IT’S A VERY TRICKY COMMUNICATION	To explore the communication stressors experienced by	Qualitative - Interviews	40 caregivers

		SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN	family caregivers to examine why communication tasks are perceived as difficult		
1	Shin et al., 2015 [49]	Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices	To assess cancer patient preferences, family caregiver preferences, and family caregiver predictions of patient preferences regarding the disclosure of terminal status, family involvement in the disclosure process, and EOL choices	Quantitative - Cross-sectional survey	990 patients
1	Towsley et al., 2015 [22]	Conversations about End of Life: Perspectives of Nursing Home Residents, Family, and Staff	To describe the communication, content and process related to EOL conversations among nursing home residents, family and staff	Qualitative - Semi-structured interview	16 residents 12 family members 10 staff members
1	Wong & Chan, 2006 [53]	The qualitative experience of Chinese parents with children diagnosed of cancer	To describe the coping experience of Chinese parents with children diagnosed as having cancer during the treatment stage	Qualitative - Interview	9 parents with children diagnosed with cancer
1	Zhang & Siminoff, 2003 [54]	Silence and Cancer: Why Do Families and Patients Fail To Communicate?	To examine how patients with cancer and their family members make treatment decisions together, and to explore the avoidance of communication and issues families face	Qualitative - Interview	64 participants

2	Azoulay et al., 2000 [22]	Half the families of intensive care unit patients experience inadequate communication with physicians	To explore the needs of family members of patients with terminal illness in order to improve communication and ease their burden	Quantitative - Prospective study	102 ICU patients
2	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
2	Carrese & Rhodes, 1995 [60]	Western bioethics on the Navajo Reservation: Benefit or harm?	To explore the influence of Western biomedical and ethical principles on Navajo values, and how it affects the quality of health care	Qualitative - Interview	34 Navajo people
2	Cherlin et al., 2005 [61]	Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said?	To examine family caregivers' communication with physicians on illness, life expectancy, hospice, EOL discussion timing and their understanding on these issues.	Qualitative - Survey and interviews	218 family caregivers
2	El-Jawahri et al., 2017 [62]	Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial	To explore the influence of early integrated palliative care on patients and evaluate caregivers' stress and quality of life	Quantitative - Clinical trail	350 patients
2	Gamble et al., 1991 [63]	Knowledge, attitudes, and behavior of elderly persons	To explore elderly's knowledge, attitude and behavior	Quantitative - Questionnaire	75 elders

		regarding living wills	regarding living wills		
2	Gonella et al., 2020 [87]	A qualitative study of family carers views on how end-of-life communication contributes to palliative-oriented care in nursing home	To explore how EOL communication may contribute to palliative care in nursing homes.	Qualitative - Interview	32 bereaved family carers from 13 different nursing homes
2	Gutierrez, 2013 [64]	Prognostic categories and timing of negative prognostic communication from critical care physicians to family members at end- of-life in an intensive care unit	To explore how physicians communicate negative prognoses to families and the influence of timing	Qualitative - Observations and interviews	7 critical care attending physicians 3 critical care fellows 20 family members of patients
2	Huang et al., 2012 [65]	Family experience with difficult decisions in end-of-life care	To determine the frequency and difficulty of decision making in EOL care and its related factors	Quantitative - Questionnaires	302 family caregivers
2	Hui et al., 2014 [58]	Impact of timing and setting of palliative care referral on quality of end- of-life care in cancer patients	To examine the association between timing and setting of palliative care referral and the quality of EOL care	Quantitative – Retrospective cohort study	366 adult patients who died of advanced cancer
2	Lind et al., 2011 [66]	Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions	To examine patients' family members experience of EOL decision making and the process of making the decisions	Qualitative - Interviews	27 family members
2	Low et al., 2009 [26]	Reducing collusion between family members and clinicians of patients referred to the palliative care team	To explore the rate of collusion among family members and clinicians. And to reduce the rate of collusion through the project	Qualitative - Clinical practice improvement project (defining the problem, establish	655 patients

				strategies for intervention)	
2	Ohs et al., 2017 [47]	Problematic integration and family communication about decisions at the end of life	To examine how families make decisions on behalf of their dying family members at the end of life and how they manage the stressful situation	Qualitative - Interview	22 family members who engaged in EOL conversations
2	Rhoads & Amass, 2013 [59]	Communication at the End-of- Life in the Intensive Care Unit: A Review of Evidence- Based Best Practices	To explore the current data and recommendations on the care of patients in ICU at the end of life	Qualitative	N/A
2	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
3	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
3	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors
3	Chan, 2011 [68]	Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members	To explore the relationships among the patient's awareness of the prognosis, the family's awareness of the prognosis, the patient's anxiety,	Qualitative - Clinical records of deceased cancer patients in a palliative care unit of a public hospital	935 Patients

		in the Hong Kong Chinese context?	and difficulty in communicating with family members		
3	Im et al., 2018 [69]	Patient and Family Related Barriers of Integrating End-of-Life Communication into Advanced Illness Management	To explore the barriers EOL communication from the perspective of the patients and their family members	Qualitative - Semi-structured interviews	19 patients with advanced heart failures and their family caregivers
3	Im et al., 2019 [70]	"Whatever happens, happens" challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study	To explore the challenges of EOL communication among older adults and their family care-givers, as well as to understand the illness and goals of care among patients in advanced heart failure.	Qualitative - Semi-structured interviews	22 participants
3	McDarby et al., 2019 [71]	Adult Children's Understanding of Parents' Care and Living Preferences at End of Life	To examine how contact between patients and adult children relate to EOL conversations	Quantitative - Questionnaires	66 adult children 36 older adult patients
3	Trees et al., 2017 [72]	Family communication about end-of-life decisions and the enactment of the decision- maker role	To explore how families enacts their roles as decision makers for their family members who are at the end of their lives	Qualitative - Interview	22 participants
3	Van den Heuvel et al., 2016 [73]	Barriers and facilitators to end-of-life communication in advanced chronic organ failure	To identify the challenges, facilitators and agreement to EOL communication among family members and patients	Qualitative - Interview	158 patients and family caregiver
4	Ayers et al., 2017 [74]	An ethnography of managing emotions when talking about life-threatening illness	To explore how dying patients, palliative care staff and family caregivers	Qualitative - Observations and ethnographic interviews	4 patients. 6 family caregivers and 5 palliative care staff

			communicate about life-threatening illness in Ethiopia		
4	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors
4	Chan et al., 2009 [75]	Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the "support paradox"	To explore the relationship of family- related factors and psychosocial outcomes among HK Chinese cancer patients in palliative care.	Qualitative - Clinical records and interviews	935 patients
4	Fielding & Hung, 1996 [76]	Preferences for information and involvement in decisions during cancer care among a Hong Kong Chinese population	To assess differences that between Western and Asia cancer patients' preferences for information on diagnosis, prognosis and treatment options and involvement in treatment decision making	Quantitative - Telephone survey	1136 cancer patients
4	Ho et al., 2013 [79]	Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong	To examine the concept of 'living and dying with dignity' in Chinese context; and how the dignity model influenced older terminal patients in Hong Kong	Qualitative - Interview	16 patients
4	Kato & Tamura, 2020 [88]	Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive	To explain the meaning of continuous EOL discussion for family members	Qualitative - Semi-structured interviews	13 family members of residents from 3 nursing homes in Kyoto

		Study of Family Members' Narratives			
4	Ko et al., 2013 [77]	Do Older Korean Immigrants Engage in End-of-Life Communication?	To understand patients' communication with family and their healthcare providers on EOL care among older Korean immigrants	Quantitative - Questionnaire	195 older Korean immigrants
4	Peterson et al., 2018 [78]	Factors associated with whether older adults discuss their EOL care preferences with family members	To examine the factors associated with EOL care wishes discussions with family, especially race and ethnicity	Quantitative - Survey	364 participants
4	Tse et al., 2003 [80]	Breaking bad news: a Chinese perspective	To address this difference in attitudes, the ethical principles for and against disclosure are analysed, considering the views in Chinese philosophy, sociological studies and traditional Chinese medicine	Qualitative	N/A
4	Wang, 2010 [25]	Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US	To examine the relationship between doctor and patient in the Chinese context and the differences with the US	Mixed method -Survey and interview	Survey: 1097 Chinese and 1280 Americans Interview: 26 Chinese
4	Zheng et al., 2015 [81]	Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study	To elucidate Chinese oncology nurses' experience of caring for dying cancer patients	Qualitative - Interview	28 nurses

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	N/A
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	4-6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	4-6
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	4-6
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	4-6
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	4-6
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	4-6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	4-6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	4-6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	4-6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	4-6
Certainty	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	4-6

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	6-10
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	6-10
Study characteristics	17	Cite each included study and present its characteristics.	6-10
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	6-10
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	6-10
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	6-10
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	6-10
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	6-10
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	6-10
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	6-10
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	6-10
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	10-12
	23b	Discuss any limitations of the evidence included in the review.	10-12
	23c	Discuss any limitations of the review processes used.	10-12
	23d	Discuss implications of the results for practice, policy, and future research.	10-12
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

PRISMA 2020 Checklist

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

BMJ Open

The Role of Patients’ Family Members in End-Of-Life Communication: An Integrated Review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-067304.R1
Article Type:	Original research
Date Submitted by the Author:	07-Nov-2022
Complete List of Authors:	Pun, Jack; City University of Hong Kong, Department of English Chow, James C. H.; Queen Elizabeth Hospital, Department of Clinical Oncology FOK, Leslie; Queen Elizabeth Hospital, Department of Clinical Oncology CHEUNG, Ka Man; Queen Elizabeth Hospital, Department of Clinical Oncology
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health services research, Patient-centred medicine
Keywords:	PALLIATIVE CARE, ONCOLOGY, MEDICAL EDUCATION & TRAINING

TITLE PAGE

Title: The Role of Patients' Family Members in End-Of-Life Communication: An Integrated Review

Authors: Jack PUN[a], Chung Hang James CHOW[b], Leslie FOK[b], Ka Man CHEUNG[b]

Affiliations:
a-Department of English, City University of Hong Kong, Hong Kong SAR, China
b-Department of Clinical Oncology, Queen Elizabeth Hospital, Hong Kong SAR, China

Postal addresses:
a-Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong SAR, China.
b-Department of Clinical Oncology, Queen Elizabeth Hospital, 30 Gascoigne road, Kowloon, Hong Kong SAR, China.

Emails:
Jack PUN: jackpun@me.com
Leslie FOK: fl684@ha.org.hk
James Chung Hang CHOW: cch932@ha.org.hk
Ka Man CHEUNG-ckm792@ha.org.hk

Corresponding author:
Jack PUN
Email: jackpun@me.com
Postal address: Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong.

ABSTRACT

Objectives: To synthesise empirical findings on the role of family in end-of-life (EOL) communication and to identify the communicative practices that are essential for EOL decision-making in family-oriented cultures.

Setting: The end-of-life (EOL) communication settings.

Participants: This Integrated review followed the PRISMA reporting guideline. Relevant studies published between 1st January 1991 and 31st December 2021 were retrieved from four databases, including the PsycINFO, Embase, MEDLINE, and Ovid nursing databases, using keywords with meanings of "end-of-life", "communication" and "family". Data were then extracted and coded into themes for analysis. The search strategy yielded 53 eligible studies; all 53 included studies underwent quality assessment. Quantitative Studies were evaluated using the Quality Assessment Tool, and Joanna Briggs Institute Critical Appraisal Checklist was used for Qualitative Research.

Primary and secondary outcome measures: Research evidence on EOL communication with a focus on family.

Results: Four themes emerged from these studies: 1) Conflicts in family decision-making in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a "key person" who is responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Conclusions: The current review pointed towards the importance of family in EOL communication and illustrated that family participation likely leads to improved quality of life and death in patients. Future research should develop a family-oriented communication framework which is designed for the Chinese and Eastern contexts that targets on managing family expectations during prognosis disclosure and facilitating patients' fulfilment of familial roles while making EOL decision-making. Clinicians should also be aware of the significance of the role of family in EOL care and manage family members' expectations according to cultural contexts.

Keywords:
End of life; Family; Palliative care; Cancer care; Communication; Family-oriented cultures, East Asian Cultures.

Introduction

End-of-life (EOL)[1] communication has a crucial influence on medical decision-making and the quality of care at the final stage of a patient journey. It informs patients and their families on the current medical conditions; explores unanswered concerns and health needs; provides emotional support and practical advice; reveals what lies ahead; and allows care providers to understand how they can improve the care for the patients during their final days. ~~Positive~~ EOL communication during palliative care removes the stigma around death and help the patients set out their final wishes to the family [1]. In general, effective communication regarding prognoses and optimal treatment has multidimensional benefits, for instance, promoting the quality of EOL care and decreasing the stress of the carers [2]. In contrast, poorly conducted medical conversations may lead to negative treatment outcomes such as aggressive life-sustaining treatments [3-4], unsatisfactory hospital experiences [5], poor well-being [6], and unnecessary healthcare costs [2, 7]. Thorough EOL communication among clinicians, patients and carers help to alleviate anxiety and enable patients to be cared for in desired ways[2, 8].

However, empirical evidence shows that the EOL communication practice is not always performed effectively [9-10]. Many patients and carers are reported to be poorly informed about their patients' situations and that the patients were often unaware of their own risks of imminent deaths [11]. Similarly, clinicians' unawareness of patients' wishes may hinder the provision of the most appropriate healthcare options for patients. Healthcare professionals also find it challenging to directly discuss deaths with patients and caregivers, as patients and caregivers are often being ill informed and tend to be over-optimistic on the prognoses [12]. There are different expectations for palliative care in Chinese and Western cultures. Most Chinese patients rely on doctors to make the final decision regarding EOL treatments [13-14], the wishes of close family members are also considered. Research results show that in the broader Asian context, family members and religious beliefs heavily influences patients decisions on EOL and palliative care [15-17].

Nowadays, many developed regions such as the United States, Europe, and Australia adopt the shared decision-making approach to family–clinician EOL communication [18]. However, patients who are admitted to general wards or intensive care units (ICUs) which are aggressively managed have no prior opportunities for effective discussions with their families or clinicians about their desires and goals [19]. There is a lack of clear communication framework that sets the standard for essential information that family caregivers should receive, which will likely include patients' current medical condition and prognosis estimates, additional options of treatment and support measures available and their risks and benefits, and the preferences of patients and family to guides clinicians to reach realistic care goals [20-21]. When family members receive insufficient information, difficulties may arise during EOL communication. This occurs especially in the ICU settings, where urgent decisions about whether to pursue aggressive life-sustaining treatments for patients are required. In a study by Azoulay et al.[22], 54% of the family members of ICU patients did not have a clear understanding of the patients ' diagnoses, prognoses and treatments, and the physician–family meetings lasted for no more than 10 minutes. As a result, family members have poor understandings of the situations they were facing, which led to suboptimal decision making. In addition to time constraints, the lack of communication skills is also an important factor. Clinicians tended to discuss EOL life-sustaining treatments in a scripted, depersonalised and procedure-focused manner. Clinicians also tended not to initiate EOL conversation directly and in a timely manner [18].

Amongst the factors affecting EOL communication as well as the engagement of patients and their family caregivers, the factor most discussed is cultural differences between the Eastern and Western countries. Chinese culture values collectivism, wherein patients prefer to make joint decisions with their family members or sometimes even rely completely on them [14]. Rooted in Confucian morality, filial piety is a very important moral tenet in Chinese culture that has been advocated and practiced for thousands of years. People of the Chinese culture are required to provide care to their parents in return for the care they received from their parents in their childhood years. Therefore, many Chinese elderly patients believe that their children may naturally understand their preferences and are able to make decisions for them in their final days[14, 23-24]. For example, family members of elderly patients would request the doctors to discuss with them first, before the doctors consult the elder patient. In some cases, family members will also choose not to disclose the bad news to the

---

patients [25]. Collusion, a scenario wherein the family wishes to hide the diagnosis from the patient, is common in Asian cultures. In a study conducted in Singapore by Low et al. [26] found that 96% of family members expressed reluctance in disclosing the prognosis to the patient. This situation is also prevalent in Hong Kong, in which its culture is heavily influenced by both Chinese and Western beliefs. In research conducted with Chinese patients, maintaining a strong connection with the family during palliative care has been reported to be one of the most important components of a "good death" for elderly patients [27]. This interdependent relationship between family caregivers and patients opposes the ideology of autonomy and self-determination that predominate in Western culture, and is to a certain extent, culturally understood and accepted by patients in the Chinese context.

Regardless of the effects of different cultural norms, recent reports have shown that healthcare professionals widely agree that EOL communication should involve both the patient and family members [28-29]. In one international survey of palliative care professionals, more than 80% of the participants agreed that more practical instructions during communication with patients' family members would enhance EOL decision-making [29-30]. Recently, the English Parliamentary and Health Service Ombudsman [31] found that the main area of health professionals' complaints about EOL care was communication failure with terminally ill patients and their family members. Without adequate family involvement, promoting the holistic care of patients during their EOL is difficult.

In response to such dissatisfaction with EOL communication, several guidelines have been established for practitioners with focus on individuals 'rights and autonomy in the medical context. Guidelines such as the COMFORT model and the SPIKES protocol provides a framework for clinicians to engage in palliative care discussion with patients [5, 32]. Meanwhile, existing recommendations mostly focus on the patient–clinician conversation rather than a family-oriented conversation. Many close family members are eager to thoroughly understand the dying process and the importance of understanding medical jargon, inclusivity, and full transparency [33] is lost in the existing recommendations.

Due to the aforementioned factors, the development of an EOL communication strategy that considers active family involvement is necessary. While previous systematic reviews on family decision-making and involvement [34], nurse to family support during withdrawal of life-sustaining treatment and imminent death [35-36], and EOL communication to patients and caregivers during the advanced stages of related illnesses [37] are present, an integrative review is lacking. As such, in this integrated review, the researchers aimed to contribute to the current literature by systematically reviewing research findings that highlights the roles of patients' families in EOL decision making. The aim of the review was to answer the following question: What is the existing research evidence regarding the role of family in EOL communication, and what themes can be derived from their synthesis?

The summarised information sheds light on the role of family in EOL communication and decision-making and contributes to future research and policy making regarding EOL communication. Although culture and its related elements regarding EOL communication and care have been heavily foregrounded thus far, it is not saliently marked in the research question because it is a prominent theme elicited after, rather than prior, the systematic review search (see also[38]).

Methods

This integrated review aimed to provide integrated information on the role of family in EOL communication using the PRISMA guideline as reporting system (see Figure 1). The review included relevant studies published between 1st January 1991 and 31st December 2021. The purpose behind the proposed date is the majority of related studies and articles regarding familial roles in EOL communication were published since the specified date.

[Figure 1 PRISMA flow diagram]

Search strategy

PsycINFO, Embase, MEDLINE and the Ovid nursing databases were searched in the initial screening process to identify relevant articles using the following keywords and synonyms of ‘end of life’, ‘communication’ and ‘family’. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevant studies, e.g. ‘end of life AND communication AND family’ (See Appendix 1). In addition, a manual search was made of relevant journals, and the bibliographies of relevant articles and reviews were also cross-checked for potential eligible studies. Studies that met the inclusion criteria were included for further review and duplicated articles were removed.

Inclusion and exclusion criteria

An initial search was carried out to identify relevant articles on EOL communication that were published between 1st January 1991 and 31st December 2021. Studies were included if they were peer-reviewed and concerned EOL communication and family. Studies were excluded for the following reasons: (a) having a focus on topics that were unrelated to EOL communication (e.g., religious studies of EOL care); (b) not being original research based on empirical findings (e.g., literature reviews, opinion pieces); (c) being non-English language articles; (d) being non-peer reviewed studies.

Our investigation encompasses a broad scope. The various aspects of EOL care includes EOL communication studies in general (i.e. not limited to diagnosis, prognosis etc.)[1] and focus on the involvement and roles of and between family, clinicians, and relatives. Peer-reviewed full-text journal articles such as original studies and reviews were included. The initially shortlisted articles were cross-checked by the three authors for final review and data extraction. Articles that were not peer-reviewed or written in English were excluded. Although we have a bilingual research team, EOL care articles that were written in Chinese were not included in the research due to insufficient peer-reviewed articles and the paucity of EOL communicative aspect-oriented research.

Data extraction

Three authors were involved throughout the entire title screening, data collection, and text review process. Before data extraction, the authors independently screened the titles and read the whole abstract of each paper to exclude irrelevant articles according to the inclusion criteria. The full papers were retrieved if their abstracts were considered potentially relevant. The full texts of the chosen articles were subjected to in-depth data extraction. The objectives, research design, participant characteristics and key findings were examined and recorded and appraised for quality by oncologists and palliative care practitioners to ensure that all relevant journals were included in the search. Any disagreements were resolved by discussion to reach a consensus amongst all the authors.

Patient and Public Involvement

No patient involved.

Results

Quality assessment

The Quality Assessment Tool for Quantitative Studies [39] was used to assess quantitative (*n* = 15) and mixed-method studies (*n* = 2). Each article was given ratings on a 3-level ordinal scale: "weak", "moderate", or "strong" in eight areas such as research design and selection of study population. Qualitative (*n* = 37) and mixed-method studies (*n* = 2) were evaluated with the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research[40], which is a 10-item checklist covering components such as congruity and reflexivity, scored as "yes", "no", "unclear", or "not applicable". The quality of the included studies was evaluated independently by the first and second authors. Any disagreements in ratings were discussed and resolved with the third author.

Weight of Evidence Measure

To ensure the quality of the included studies, the papers' "weight of evidence" was measured according to three criteria: the relevance of each paper to the current review; the appropriateness of the research; and the validity of the study; and the overall contribution of the research to this review. These variables are specified in Table 1 below.

Regarding the relevance aspect of the included studies, that is, to which the degree of the topic(s) examined align with our review questions, 86% of the 53 reviewed articles were considered as either high or medium level of relevance. Appropriateness is evaluated based on whether the research designs were appropriately employed. The authors judged that 28% and 38% were deemed to be highly appropriate and fairly appropriate, respectively. 83% of the included studies were considered to have a medium-to-high level validity, where the scorings were based on the preciseness and consistency of data analysis. These ratings therefore draw an overall conclusion that 30% of the included studies were able to make a strong contribution in answering the review questions whilst 43% made a fairly significant contribution.

Table 1. Weight of Evidence of the current review

	Relevance	**Appropriateness**	**Validity**	**Overall contribution**
High	46%	28%	38%	30%
Medium	40%	38%	45%	43%
Low	13%	33%	16%	26%

Included articles

The initial search identified 25,305 eligible studies, 25,318 of which were excluded after abstract screening. The search includes keywords and synonyms of ‘end of life’, ‘communication’ and ‘family’. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevant studies, e.g. ‘end of life AND communication AND family’. The full-text screening of the remaining 109 studies were then subjected to in-depth review (see Figure 1). This led to the further exclusion of 56 articles because they: (a) focused on unrelated topics of family-oriented EOL communication; (b) lacked empirical evidence; (c) were written in other languages rather than English; or (d) were not peer reviewed. Finally, 53 studies were included in this review.

The Characteristics Of The Included Studies

The characteristics of the 53 studies that met the inclusion criteria are summarised in Table 2 (See Appendix 2 for a summary of each included study). The number of studies on the role of family in EOL communication increased significantly after 2010. Most of the studies were from the United States (24), closely followed by Hong Kong (7), Canada (4), the United Kingdom (3), China (2), South Korea (2), Netherlands (2), France (2) and other countries (7). Of the 53 included studies, 37 were qualitative studies, 14 were quantitative and 2 were mixed-method.

Table 2. Main ideas of the themes emerged from the reviewed studies

Theme	Main ideas	Studies
1. Conflicts in family decision-making in EOL communication	There existed a certain degree of discrepancies in decision-making between the patient and family caregivers; to optimise EOL communication among the relevant stakeholders, physicians should be able to gauge and respond to the patient’s psychosocial needs and to also take the family’s perspective into account when having EOL conversations.	[9, 20, 23, 29, 41-51]
2. The significance of timing of EOL communication	There is typically a delay in initiating EOL communication; it is often due to the avoidance of having open physician-patient discussion about the illness. Patients were generally worried about making EOL decisions once informed about the diagnosis, whilst physicians were concerned that the negative prognostic information would impact the patients and hence, leading to a late timing of EOL communication.	[22, 26, 52-60]
3. Difficulty in identification of a “key person” responsible for decisions regarding EOL care	Some patients were found to not wish to be involved in making their own palliative care decision out of the fear and uncertainty of their EOL stage, family members or even the physicians themselves might in turn have to be responsible for decision-making; this likely leads to an unclear division of responsibility regarding EOL decision-making.	[14, 61-66]

4. Different cultural perspectives on EOL communication	Individualism is of value in the West where most patients preferred having the autonomy to make EOL decision for themselves, whilst collectivism and filial piety are the main values typically found in Eastern society; patients tended to rely on their children or discussing within the family when making palliative care decisions.	[14, 25, 67-76]

Identified themes

Thematic analysis was conducted to capture any re-occurring topics in the included studies. To do this, all the authors will first read through the transcripts carefully and give an initial free-coding to all segments relevant to the role of family in EOL communication. We then conducted several review rounds to compare, sort, and recode, as we look for connections among the coded segments and compared analyses from the other included papers. In this way, the authors identified and coded issues from each of the included studies, which were then synthesised into a set of broad reoccurring themes about the role of family in EOL communication. Four themes were identified: 1) Conflict in family decision-making in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a “key person” responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Conflicts in family decision-making in EOL communication

Internationally, the involvement of family members in EOL communication has often been discussed in the context of provision of support, but very few studies have directly explored how important the role of family is and in what way the family must be involved.

Family caregivers traditionally play their own unique roles in providing emotional and financial support to contribute to a “good death”— a pain-free situation during the last phase of life and not on exhausting possible treatments to prolong life unnecessarily--- for the dying patients [20,41]. In fact, the patients expect to receive family support more than the support from healthcare workers. Furthermore, the social support from family members serves as the fulfilment of their own familial obligations and is a foundation providing quality EOL care [42-44].

Many clinicians nowadays have come to realise that the patients’ and families’ views and beliefs have to be considered in the decision-making process [20, 29]. In circumstances where disagreement about the medical advice arises between the doctor and the family, establishing a care plan could become difficult, and this could cause the withholding or withdrawal of treatment implementation. Family members have also noticed that healthcare staff would avoid EOL conversations. However, it is important for healthcare staff to initiate EOL conversations so that patient’s needs and their family’s preferences are properly addressed [29]. It was also found that some doctors have to follow the family’s wishes, even if it was against the professional judgement of what was appropriate for the patient [45-47]. For instance, against the doctors’ recommendations, some family ~~desired~~ might still desire more unnecessary treatments ~~that doctors did not recommend~~ just to sustain a dying patient’s life when he or she could not make an EOL decision.

Disagreements about decisions on EOL treatments could also occur between terminally ill patients and their family members. There are contradictions between family members who wish to hold on to their loved ones for as long as possible and the patients who wish to let go and reject life-sustaining treatments [48-50]. Fan et al.[23] and Shin et al.[51] used standardised questionnaires to examine the preference and concordance among the patients with cancer, family members, and clinicians regarding EOL communication. This includes the disclosure of diagnosis and prognosis, family involvement in such processes, and EOL decision-making. Findings revealed that family members’ preferences did not ~~usually~~ always align with that of the patients in some cultural contexts such as China and Korea [23; 51]. For example, Shin et al. [51] found that discussions between patients and their family regarding treatment preferences might not always end in agreement, since patients’ family tended to opt for life-sustaining treatments when the patients desired otherwise. Fan et al. [23] suggested that mainland Chinese patients depended largely on their families and doctors tended to substitute patients' consents with that of their families. Additionally, there are discrepancies between clinicians’ medical practice and the preferences of the patients and their family caregivers. For instance, rigid protocols and guidelines that inform the healthcare of the young patients created tension among family caregivers and clinicians as they did not take into account the patients’ individual needs [9].

The significance of timing of EOL communication

Owing to the complexity of EOL communication, that is, the constitution of delivering exhaustive information from doctors, the complicated emotions derived from relevant stakeholders, and the dynamics of family involvement in the patient's health care, there typically appears a delay in conducting EOL communication [52-54]. Cherlin et al. [52] found that the communication between family caregivers and clinicians about the terminal illness and possible use of hospice care occurs late in the course of the illness. Some patients consistently wrestled with the thought of knowing that they were ill and trying to defer EOL decisions [55-57]. From the perspective of clinicians, there seems to be a tendency for clinicians to initiate the communication of negative prognostic information until they reach a perceived "threshold" of certainty in the accuracy of a prognosis [55]. This observation corroborates with those of Lind et al. [57], who discovered that the doctor's directive to "wait and see" may cause miscommunication between the doctor and family members. One possible reason for the delayed initiation of EOL conversations from doctors might be due to their incompetent communication skills, in which many of them were unable to discuss EOL issues with the patients and the families in an effective and timely manner [58]. Yet, this directive to further delay diagnosis could potentially give the family a sense of false hope that the patient's situation can be improved. When miscommunication occurs, it would appear to be too late to conduct proper EOL communication, or for family members to provide input in the decision-making process about terminating treatment.

Another potential reason why EOL communication may not be implemented in a timely fashion is the presence of physician-family collusion, a situation where family members choose to hide the diagnosis and prognosis from the patients; ~~and it is not uncommon in the palliative care context~~. Notwithstanding the fact that collusion goes against medical ethics and can potentially cause various complications in EOL treatment, admittedly, collusion is widely seen across Europe and Asia [26]. This is because of the fear of disappointing the patients by informing them of their deteriorating health condition, and more prevailing in Asian countries that the social norm of holding family members to be responsible for the main body of communication about EOL care.

The failure to have patients engage in timely EOL conversations can lead to aggressive life-sustaining treatments, under-utilisation of palliative care, and negative outcomes for both patients and their families. Patients' psychological conditions, including depression scores and quality of life metrics, will be compromised without good palliative care. Moreover, introducing palliative care relieves caregiver stress and improves caregiver depression scores [22, 56]. As a result of these side effects, clinical prediction models to provide estimated remaining survival time of the patient have started to gain popularity in medical practices to aid the EOL discussion pacing of clinicians.

~~Proper and~~ Prompt palliative care referrals are also important. Frameworks for effective EOL communication could also encourage clinicians to identify an optimal time to refer the patient to palliative care. [59-60].

Difficulty in identification of a "key person" who is responsible for decisions regarding EOL care

Communication required to negotiate EOL care extends beyond the patients and the doctors. It also includes the patients' families, especially in the context of Asia, which family-oriented practices prevail [14]. Families may wish to take up the responsibility for the patient's EOL care. The involvement of multiple parties often leads to difficulty in identifying a main person to hold responsibility for making palliative care decisions.

Failure to identify a key person among family members in EOL care and conversations can cause confusion and misunderstanding, undermining decision making and contributing to a confused process which is already fraught with uncertainty [61-62]. Unclear responsibilities and responses can create contradictory expectations between the family members and the patient. Discrepancies have been observed between the last wishes of patients to follow the natural course comfortably and the desire of their family members to hold on to their loved ones for as long as possible [63-64]. Even when the decision-making responsibility is delegated to one family member, their decisions may be affected by contradicting opinions within the family [65]. To further complicate the matter, McDarby et al. [66] showed that elderly parents' EOL preferences may not be understood by their children. Consequently, misunderstanding and a lack of communication between the patients and their families emerge, resulting in confusion and disagreements in the EOL decision-making process.

Different cultural perspectives on EOL communication

Sociocultural factors play a significant role in EOL communication. In the West, individualism and autonomy are emphasised. EOL communication usually occurs between the doctor and the patient. Depending on the patient's wishes, family members may also be involved [25]. Although there are significant cultural differences between Chinese and Western regions, clinicians of Chinese contexts undertake the same EOL communication models adopted by clinicians from the West [25]. They would look for social cues such as the nonverbal communication behaviour including tone of voice, manner, and attitude, to determine the readiness of patients to engage in EOL conversations. However, the implications of these social cues may differ by cultures. Heavy reliance on social cues lead to miscommunication. In certain cultural contexts, understanding the non-verbal cues from patients are essential to perceiving their readiness with EOL communication, and to help (re)calibrate the conversation flow; thus, potentially making non-verbal communication even more crucial than the verbal content (see also [67-68]) . These factors influence the agencies manifested across the multiple parties, which potentially contribute further to the EOL decision-making conflicts. Meanwhile, in Chinese contexts, EOL communication is largely affected by sociocultural factors. Decisions are made as a collective family rather than between the individual patient and doctor [69]. Studies have shown that some patients do not wish to be involved in the decision-making process of their treatments even if it concerns their own life. This belief is prevalent among Chinese patients. Due to the Chinese cultural beliefs, dying Chinese patients prefer to let their children make the EOL decisions. Bowman and Singer [14] reported that the role of family in the Chinese culture emphasises interdependency, obligation, and responsibility to others. Family members in a Chinese family are expected to be responsible for protecting the patient's health, safety, and general well-being. Chinese patients believe in their children's ability to make decisions on their behalf and sees no need for advance directives about treatment or communication on EOL needs, resulting to increased miscommunication and misunderstanding about the patient' s needs.

Similar findings were observed in Eastern countries, where Asian family members typically preferred to be involved in making EOL decisions together with, or sometimes, on behalf of the elderly patients [25, 70-73]. In China and nations of proximity such as Korea, where Chinese culture poses significant impact, EOL decision-making tends to be a family-centred practice rather than an individual decision [72, 74-75]. Alternatively, Kato and Tamura [76] offered relational authority as another dynamic found within East Asian cultures, where family members will leave medical decisions to the clinicians. Kato and Tamura's [76] study also stresses that family members felt a great responsibility to care for their parents and that failure to continue the care, such as admitting their parents to a nursing home, led to feelings of guilt and abandonment among the family members. This is because the ideology behind it, which is constructed from traditional Confucianist and Buddhist beliefs, largely focuses on collectivism and familial responsibility. Filial piety is a key value to maintain social stability and familial harmony. Based on this premise, parents become the recipients of their adult children's care, and children of dying patients are highly trusted in making treatment plans and EOL decisions for their parents [70, 72, 74, 76]. In addition, in the East Asian context, immediate family members generally possess the power to decide whether to inform the patient of their current medical situations [25], creating a common phenomenon where the doctors would have consultations with the family caregivers prior to speaking with the patients.

Discussion

This review identified the significance of family members in EOL communication and how their engagement in EOL discussions can improve the quality of patients' EOL and death. Moreover, this review found that there is a need for Chinese and East Asian specific EOL communication model to address cultural needs of elderly patients. An important trend identified in the included studies is the accumulating body of knowledge on the significance of family on care, support, as well as communication with the patients. Open discussions initiated by clinicians are key to decreasing psychological side effects in patients and family members such as anxiety, psychological stress, and pressure [77].

Referencing to the research question, existing research about familial roles in EOL communication can be categorised into four different themes. As discussed, family can be a prominent source of decision-making conflict in EOL communication. For instance, family caregivers may have to perform the role of the patient's 'doctor' in home-based care by assessing the patient's symptoms, administering drugs, and providing hands-on care. With little to no support from professional healthcare staff, home care becomes the very source of anxiety and stress for the carer [78]. Decision-making conflicts could also occur between the family and clinicians, and the family and the patient, particularly if resources for support from professionals were limited. It goes without saying that these conflicts do affect the provision of holistic and effective care for the patient [78]. Not only that, the lack of identifying a key person responsible for EOL-decision making results in decision-making conflict. These conflicts could result in significant delays of exercising EOL treatments.

Despite the associated challenges and issues of involving family in the decision-making process, families are an important source of support for patients who are undergoing EOL care. Family support could be manifested through providing the basic needs of the patient (i.e., helping to make the patient more comfortable, offering food and drinks, etc.), monitoring the patient's emotional status, and offering immediate support and assistance [42, 46]. Family participation in EOL matters is also found to be negatively correlated with the level of psychological distress in bereaved family caregivers, implying that the more the family members engage in the patient's EOL journey, the lesser extent they experienced psychological symptoms such as anxiety and depression after the patient has found dead [77,79-80]. Chui and Chan's [81] research echoes this finding, demonstrating that longer EOL discussions could significantly reduce the incidence of post-traumatic stress disorder, anxiety, and depression of the families of patients who died in the ICU. On the other hand, Mitchell et al.'s [9] findings noted that there was insufficient time for family caregivers to consider the possibility of death, as avoiding the possibility served as a coping mechanism for the caregiver, and the life-threatening aspect of the patient's condition was only acknowledged after an episode was resolved. As for the impact on the patients, Byock's [82] clinical observation revealed that despite the typical suffering at the EOL, the quality of family input during EOL discussions, such as careful, relationship-appropriate, and goal-directed EOL communications, was important for the patient's emotional wellbeing and the overall experience towards the EOL stage. Thus, quality communication between the patients and their family members are vital in improving the quality of life of dying patients during their EOL stage [41, 43, 48].

Considering the value that familial support could have, healthcare workers must learn what is important to the patients and their families, and ensure that their preferences are adequately explored, adhered to, and respected even in cases where their preferences contradict the clinician's decision. From the clinician's point of view, EOL communication is most effective when family members participate and engage in the joint decision-making discussion [20, 83]. Fostering positivity in EOL communication as a clinician was also viewed to be important [29]. When family members and patients clearly understand one another's EOL preferences, decisions on treatments and palliative care could effectively address patients' needs [79].

There is also plenty of material to discuss with the significance of timing in EOL communication. With regards to physician-family discussions, clinicians should be equipped with the competency to explain its negative effects on the patient and family members in an empathetic and compassionate way, as well as encourage communication between family members and the patients so that family members could understand the patients' wishes and explain their diagnoses [26]. Clinicians should also be educated to take on a bridging role between family members and the patients, acting as a facilitator of communication and exploring any unspoken issues that either side are intentionally avoiding. As such, with continual training and education, healthcare professionals could develop effective communication skills for palliative care and collaborate with the patients' families to provide quality EOL care. Furthermore, healthcare providers should act as mediators and advisors to assist both parties in making appropriate treatment decisions and thus enable the patients to have a "good death" [14]. The barriers and uncertainties among the patients, family members and the clinicians should be moderated to build trust and facilitate open EOL communication [63, 84].

Moreover, healthcare providers may be capable of initiating EOL conversations at optimal timing with widespread adoption of prognostic tools. When EOL discussions are conducted at optimal timing, patients' comfort and dignity during EOL could be immensely improved [52]. The Palliative Care Chart developed by Bailey et al. [48] is a tool for clinicians to assists in generating effective EOL communication, aiming to facilitate continuity and co-ordination of care and sense of partnership between patients and their families. The chart serves as a checklist for clinicians. Together with the training on use of the tool, results showed that clinicians were able to resolve ongoing concerns occurred between the patients and family members during palliative discussions. Another means to educate health care professionals to provide better palliative care is the development of quality indicators as suggested by Raijmakers et al. [30]. Clinicians can be trained to monitor different aspects of the patient according to the quality indicators, for instance, limited need for pain control, providing palliative care accordingly, and improving the patients' quality of life towards the last stages of their lives. Educational interventions may be one way to raise the awareness and significance of patient participation in EOL planning. As suggested in this review, family participation in the process of EOL discussions should also be considered. Family participation in EOL communication were shown to have positive effects on the patients' quality of EOL treatment receptions [21, 60]. However, the degree of involvement varies between Eastern and Western countries given cultural differences, requiring a Chinese and Eastern specific communication model to address the cultural implications of different regions. Chinese patients and families commonly avoid EOL communication due to Buddhism and Confucianism beliefs, which accepts that talking about death brings death closer [14]. These beliefs also emphasise a balance of physical, emotional, and social harmony, which provides a culturally sound reason for them to evade such conversations regarding palliative care and EOL decisions [14, 60]. Also, in China specifically, filial piety plays an important role in the conduct of children. In cases of medical care, the burden of making treatment decisions and EOL choices are usually delegated to the children of elderly patients [14, 24, 56, 85]. Some elderly patients may even choose to exclude themselves from the EOL communication between clinicians and family caregivers and family members would become the first and main persons to contact during the discussion about their conditions and EOL decisions [11].

In Western countries, contrarily, patients and elderly people are generally familiar with palliative care. The awareness of setting up wills and arranging palliative care enable them to be relatively prepared to engage in early EOL conversations [64]. Furthermore, autonomy and self-determination are prevailing concepts, and patient's self-exclusion during medical consultation is rarely observed. Given the prevalence of individualism most patients of the Western contexts wish to make EOL decisions for themselves [68, 86]. In occasional circumstances, patients prefer to withhold information on diagnosis and treatments to their family members, this would lead to a lack of communication [87] as well as insufficient understanding of the illness among family members and hence, compromised preparedness in dealing with their beloved's EOL issues [81].

Prior research also addressed potential solutions to improve the quality and communicative environment of EOL care. Effective EOL communication is essential in creating a fulfilling EOL experience for the patients and their family members, while advance preparation could help achieve successful EOL conversations. As the majority of patients trust that their healthcare providers are capable of providing quality treatment, diagnosis, and other information regarding their illness. Clinicians could build good rapport over time and establish trust with patients [56]. This promotes patient-centred care, which is vital for effective EOL communication in both Eastern and Western contexts as the patients 'needs are always top priority when the doctors are developing medical plans. To attain such patient-oriented practices, clinicians must address the elements of 1) sensitivity to the patients' needs, personal experiences and perspectives; 2) self-participation of the patients' own recovery journey; and 3) enhancement of doctor-patient relationships.

It is also critical to keep the patients informed about their diseases. In a previous study [61], half of the respondents reported that neither were they notified about the diagnosis and prognoses, nor did they fully understand the information provided by doctors. Clinicians should have regular meetings with the patients and family members to keep them up to date on the disease progress and prognoses. Advance notification of the nature of the meeting, as well as the provision of a quiet and calm atmosphere could help decrease the anxiety of family members. Issues regarding the manner of delivery are present as well; when delivering bad news, clinicians were typically found not to have a specific goal or did not consider ahead how would the news impact the receiver [68]. All these can become obstacles in conducting effective consultation as well as disclosing the unpleasant news to the patients. To balance both medical and interpersonal needs in such difficult EOL discussions, there are developed protocols to help clinicians to better approach the conversation. One example being 'COMFORT model, which is a step-by-step guide on breaking bad news in a humane manner and at the same time, providing comfort to the recipient [32, 87]. 'SPIKES' protocol, which is a six-step framework, assists doctors with proper preparation in delivering bad news while ensuring the patients' comfort and understanding of the discussion[5,88]. Whilst these protocols were developed and validated in the Western context; since sociocultural factors play a significant role in doctor-patient communication, they may not be applicable in non-Western nations due to the different traditional beliefs in the East [89]. More specifically, the Chinese philosophy of death being a taboo subject has wide influences across many Asian countries, resulting in hesitation of prognosis disclosure to dying patients. Having communication frameworks as a guideline for clinicians to navigate around EOL conversations is plausible; yet, a formulaic approach without cultural considerations of the patients could reduce patient satisfaction. Clinicians therefore need to adapt to families on a case-by-case basis while considering the nuances of patient perspective, context of the discussion, and content of the conversation so that they can adjust the communication accordingly [11].

Lastly, clinicians should attend to the family caregivers' expectations according to the cultural context. They need to understand and respect the expectations of the patient and their family regarding the treatment. Differences in preferences and the lack of communication between medical professionals and patients are known to create conflicts. Careful listening and understanding the patients' preferences enhance the quality of patients' dying process [23]. In addition, a one-size-fits-all approaches does not work in EOL communication due to the variety of factors [24]. It is essential to improvise discussions according to each patient and family needs. Moreover, keeping the general cultural guidelines in mind enables clinicians to connect with their patients more precisely in respect of different scenarios regardless of the cultural backgrounds of both parties. More research is warranted to investigate how clinicians could and should communicate with different patients, by looking for the best model to assess the need and preference in communication. Medical staff must be trained to be prepared for providing a smooth EOL communication experience to patients based on their cultural backgrounds and practice [24].

Strengths and limitations of the study

- To our best ~~of~~ knowledge, since there is limited research on exploring the role of family in EOL communication, this review fills in the gap by highlighting the importance of culture and how it can affect the beliefs and roles of families in EOL decision-making.
- Better family-oriented EOL communication suggests that family participation will likely lead to improved quality of life and death in patients, managing family expectations during prognosis disclosure and facilitating patients' fulfilment of familial roles while making EOL decision-making.
- While patients from the East depend on their family members to make EOL decisions, this paper urges for a family-oriented framework which helps patients ~~to~~ fulfil their social role in the family.
- While the signposting of 'the East and the West' is beneficial in distinguishing EOL communicative practices across different cultural contexts, we also acknowledge the generalisability of such labelling; there are many additional factors which contribute to the complexity of EOL communication.

Conclusion

This review identified the important and unique roles of family caregivers in EOL communication and the pressing need to develop an EOL communication framework designed for the Chinese and Eastern contexts. The reviewed studies indicated that family engagement in EOL discussions is beneficial for both patients and their family members. Knowledge about the patient's diagnosis and prognosis information factoring in EOL decisions will facilitate fruitful communication among healthcare providers, patients and family members. Clinicians should identify and remove barriers to enable sufficient understanding of the information desired by each party, tackle collusions tactfully, and bridge the gap between the parties if direct communication is difficult and distressing. The timing of EOL communication and communicative content are important, especially in circumstances where clinical deterioration is inevitable. Existing palliative care communication frameworks, such as the COMFORT model (an acronym for Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative messages, and Team) and SPIKES protocol (an acronym for Setting, Perception, Invitation, Knowledge, Empathetic Response, Summary) could be modified according to the implications of this review to fit the family-oriented cultures in Chinese and Eastern contexts. With such guiding principles, clinicians will be able to engage and discuss EOL issues with patients confidently, thus performing a well-rounded EOL communication practice.

The current review identified four significant themes that presented the roles of family caregivers in EOL communication. Many of the articles in the review search in the results and discussion show the involvement of family members in EOL decision-making. Clinicians should acknowledge the significance of families' views during the decision-making process. It is paramount to respect and understand the decisions of the patient and the family, while also acting as a bridge to mediate between them and facilitate open discussions. Clinicians can also use prediction models or prognostic tools to predict the patients' survival time to ensure a timely EOL conversation to prepare for the end of their life.

Previous studies showed that programs introducing advance care planning and acculturation could successfully encourage patients to participate in EOL communication with their palliative care team and family caregivers [24, 56]. However, while previous palliative care tools have shown to improve doctor-patient interaction, a lot of them do not focus on further factors that contextualise and complicate EOL communication, such as sociocultural factors, patient-centred care, and patient autonomy. Palliative care tools can be designed to be inclusive of family involvement in EOL communication, reflecting both the role of family members and patients' individual role with respect to their families. Regarding clinicians and practitioners' EOL communication praxis, our recommendations are twofold. The first is to be continually aware of the cultural implications. The second is for clinicians to be trained so that they can help the patient negotiate personal and familial obligations while undergoing EOL treatments.

Availability of data and materials
All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate
Not applicable. All the work was developed using published data.

Consent to participate
Not applicable.

Competing interest
None.

Funding
Not applicable.

Authors' contributions
JKHP contributed to the conception and design of the study. KMC, LF and CHJC revised the study protocol. JKHP, KMC, LF and CHJC contributed to the acquisition and analysis of data. JKHP evaluated the risk of bias of the included studies. JKHP and KMC interpreted the data. JKHP, LF and KMC drafted the manuscript. All the authors critically revised the manuscript and gave the final approval of the version to be published.

Acknowledgement
Not applicable.

References
1. Buckman R. Communication in palliative care: a practical guide. Death, Dying and Bereavement. 2nd edn. *Sage, London.* 2000 Dec 8:146-73.
2. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA internal medicine.* 2014 Dec 1;174(12):1994-2003.

3. Clayton JM, Hancock KM, Butow PN, Tattersall MH, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia.* 2007 Jun 18;186(12):S77.
4. Odgers J, Fitzpatrick D, Penney W, Shee AW. No one said he was dying: families' experiences of end-of-life care in an acute setting. *Australian Journal of Advanced Nursing*. 2018 Mar;35(3):21-31.
5. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *The oncologist.* 2000 Aug;5(4):302-11.
6. Simpson N, Knott CI. Stress and burnout in intensive care medicine: an Australian perspective. *Med J Aust.* 2017 Feb 20;206(3):107-8.
7. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: associations with end-of-life conversations. *Archives of internal medicine.* 2009 Mar 9;169(5):480-8.
8. Maubach N, Batten M, Jones S, Chen J, Scholz B, Davis A, Bromley J, Burke B, Tan R, Hurwitz M, Rodgers H. End-of-life care in an Australian acute hospital: a retrospective observational study. *Internal medicine journal.* 2019 Nov;49(11):1400-5.
9. Mitchell S, Slowther AM, Coad J, Dale J. Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation. Archives of Disease in Childhood. 2020 Nov 16; 106:570-576.
10. Ng GW, Pun JK, So EH, Chiu WW, Leung AS, Stone YH, Lam CL, Lai SP, Leung RP, Luk HW, Leung AK. Speak-up culture in an intensive care unit in Hong Kong: a cross-sectional survey exploring the communication openness perceptions of Chinese doctors and nurses. *BMJ open.* 2017 Aug 1;7(8):e015721.
11. Pun JK, Cheung KM, Chow JC, Chan WL. Chinese perspective on end-of-life communication: a systematic review. *BMJ Supportive & Palliative Care.* 2020 Jul 9.
12. Hawryluck L. Communication with patients and families. *Ian Anderson Continuing Education Program in End-of-Life Care.* 2000.
13. Food and Health Bureau. End-of-life Care: Legislative Proposals on Advanced Directives and Dying in Place – Consultation Document. 2019 Sep https://www.fhb.gov.hk/download/press_and_publications/consultation/190900_eolcare/e_EOL_care_legisiative_proposals.pdf.
14. Bowman KW, Singer PA. Chinese seniors’ perspectives on end-of-life decisions. *Social science & medicine.* 2001 Aug 1;53(4):455-64.
15. Wang X, Huang Y, Radha Krishna L, Puvanendran R. Role of the Nasogastric Tube and Lingzhi (Ganoderma lucidum) in Palliative Care. *Journal of Pain and Symptom Management.* 2016 Apr;51(4):794-9.
16. Peng NH, Liu HL, Chen CH, Bachman J. Cultural practices and end-of-life decision making in the neonatal intensive care unit in Taiwan. *Journal of Transcultural Nursing*. 2012 Jul;23(3):320-6.
17. Miljeteig I, Johansson KA, Sayeed SA, Norheim OF. End-of-life decisions as bedside rationing. An ethical analysis of life support restrictions in an Indian neonatal unit. *Journal of Medical Ethics*. 2010 Aug;36(8):473-8.
18. Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *General hospital psychiatry.* 2010 Jul 1;32(4):433-42.
19. Leung DY, Chan HY, Yau SZ, Chiu PK, Tang FW, Kwan JS. A video-supported nurse-led advance care planning on end-of-life decision-making among frail older patients: Protocol for a randomized controlled trial. *Journal of advanced nursing.* 2019 Jun;75(6):1360-9.
20. Ohs JE, Trees AR, Gibson C. Holding on and letting go: Making sense of end-of-life care decisions in families. *Southern Communication Journal.* 2015 Oct 20;80(5):353-64.
21. Keeley MP. Family communication at the end of life. Behavioral Sciences, 7, 45.
22. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C, Canoui P, Le Gall JR, Schlemmer B. Half the families of intensive care unit patients experience inadequate communication with clinicians. *Critical care medicine.* 2000 Aug 1;28(8):3044-9.
23. Fan Z, Chen L, Meng L, Jiang H, Zhao Q, Zhang L, Fang CK. Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff. *Supportive Care in Cancer.* 2019 Feb 1;27(2):583-9.

24. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The gerontologist.* 2005 Oct 1;45(5):634-41.
25. Wang Q. Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US. 2010.
26. Low JA, Kiow SL, Main N, Luan KK, Sun PW, Lim M. Reducing collusion between family members and clinicians of patients referred to the palliative care team. *The Permanente Journal.* 2009;13(4):11.
27. Lo RS, Woo J, Zhoc KC, Li CY, Yeo W, Johnson P, Mak Y. Cross-cultural validation of the McGill Quality of Life questionnaire in Hong Kong Chinese. *Palliative medicine.* 2001 Jul;15(5):387-97.
28. Almack K, Cox K, Moghaddam N, Pollock K, Seymour J. After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC palliative care.* 2012 Dec;11(1):1-0.
29. Kastbom L, Karlsson M, Falk M, Milberg A. Elephant in the room - Family members' perspectives on advance care planning. *Scandinavian journal of primary health care*. 2020 Nov 11;38(4):421-429.
30. Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, Popa-Velea O, Romotzky V, Schuler S, Ellershaw J, Ostgathe, on behalf of OPCARE9 C. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. *Journal of palliative medicine.* 2012 Mar 1;15(3):308-16.
31. The English Parliamentary and Health Service Ombudsman. *The Ombudsman's Annual Report and Accounts 2015-16* (Rep.). 2016 Nov 3. Retrieved https://www.ombudsman.org.uk/sites/default/files/PHSO_Annual_Report_2015-16.pdf.
32. Wittenberg E, Goldsmith JV, Ragan SL, Parnell TA. Communication in palliative nursing: The COMFORT Model. *Oxford University Press.* 2019 Dec 24.
33. Paré K, Grudziak J, Lavin K, Sten MB, Huegerich A, Umble K, Twer E, Reid T. Family perceptions of palliative care and communication in the surgical intensive care unit. *Journal of Patient Experience*. 2021 July 14;8.
34. Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative medicine*. 2019 Sep;33(8):926-41.
35. Coombs MA, Parker R, Ranse K, Endacott R, Bloomer MJ. An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care. *Journal of advanced nursing*. 2017 Jan;73(1):39-55.
36. Lowey, SE. Communication between the Nurse and Family Caregiver in End-of-Life Care: A Review of the Literature. *Journal of hospice and palliative nursing*. 2008 Jan;10(1):35-45.
37. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*. 2007 Jul;34(1):81-93.
38. Pun JKH, Chan EA, Wang S, Slade D. Health professional-patient communication practices in East Asia: An integrative review of an emerging field of research and practice in Hong Kong, South Korea, Japan, Taiwan, and Mainland China. *Patient education and counselling*. 2018 Jul;101(7):1193-1206.
39. Thomas H, Ciliska D, Dobbins M. Quality assessment tool for quantitative studies. Toronto: Effective Public Health Practice Project McMaster University. 2003.
40. Joanna Briggs Institute. JBI critical appraisal checklist for qualitative research. Retrieved from http://joannabriggs.org/assets/docs/criticalappraisal-tools/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017. pdf. 2017.
41. Githaiga JN, Swartz L. Socio-cultural contexts of end-of-life conversations and decisions: bereaved family cancer caregivers' retrospective co-constructions. *BMC palliative care.* 2017 Dec;16(1):1-8.
42. Lee MK, Yun YH. Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study. *Cancer nursing.* 2018 May 1;41(3):E1-0.
43. Royak-Schaler R, Gadalla SM, Lemkau JP, Ross DD. Family perspectives on communication with healthcare providers during end-of-life cancer care. In Oncology nursing forum 2006 Jul 1 (Vol. 33, No. 4, p. 753). Oncology Nursing Society.
44. Towsley GL, Hirschman KB, Madden C. Conversations about end of life: perspectives of nursing home residents, family, and staff. *Journal of Palliative Medicine.* 2015 May 1;18(5):421-8. doi:10.1089/jpm.2014.0316

45. Shaunfield SL. “IT’SA VERY TRICKY COMMUNICATION SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN. *Theses and Dissertations--Communication* 2015;43. https://uknowledge.uky.edu/comm_etds/43.
46. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.
47. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
48. Bailey S, Sellick SM, Setliff AE, Linkewich B, Kelley ML, Poling M. Communication at life's end [A patient held palliative care chart facilitates communication]. *The Canadian Nurse.* 1999 May 1;95(5):41.
49. Kramer BJ, Kavanaugh M, Trentham-Dietz A, Walsh M, Yonker JA. Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer. *The Gerontologist.* 2010 Apr 1;50(2):215-25.
50. Kotecho M, Adamek ME. Gender differences in quality of life of urban elders in Ethiopia. *Innovation in Aging.* 2017 Jul;1(Suppl 1):879.
51. Shin DW, Cho J, Kim SY, Chung IJ, Kim SS, Yang HK, Ahn E, Park BR, Seo H, Park JH. Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. *Psycho-Oncology.* 2015 Feb;24(2):212-9.
52. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between clinicians and family caregivers about care at the end of life: when do discussions occur and what is said?. *Journal of palliative medicine.* 2005 Dec 1;8(6):1176-85.
53. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.
54. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
55. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation: benefit or harm?. *Jama.* 1995 Sep 13;274(10):826-9.
56. Huang HL, Chiu TY, Lee LT, Yao CA, Chen CY, Hu WY. Family experience with difficult decisions in end-of-life care. *Psycho-Oncology.* 2012 Jul;21(7):785-91. Doi: 10.1002/pon.3107
57. Lind R, Lorem GF, Nortvedt P, Hevrøy O. Family members’ experiences of “wait and see” as a communication strategy in end-of-life decisions. *Intensive care medicine.* 2011 Jul;37(7):1143-50.
58. El-Jawahri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, Kamdar M, Jacobsen J, Chittenden EH, Rinaldi SP, Gallagher ER. Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial. *The oncologist.* 2017 Dec;22(12):1528. Doi: 10.1634/theoncologist.2017-0227
59. Hui D, Kim SH, Roquemore J, Dev R, Chisholm G, Bruera E. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer.* 2014 Jun 1;120(11):1743-9.
60. Rhoads S, Amass T. Communication at the End-of-Life in the Intensive Care Unit: A Review of Evidence-Based Best Practices. *Rhode Island Medical Journal.* 2019 Dec 1;102(10).
61. Biola H, Sloane PD, Williams CS, Daaleman TP, Williams SW, Zimmerman S. Physician communication with family caregivers of long-term care residents at the end of life. *Journal of the American Geriatrics Society.* 2007 Jun;55(6):846-56.
62. Chan WC. Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?. *Journal of palliative medicine.* 2011 Sep 1;14(9):997-1003.
63. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. Patient and Family Related Barriers of Integrating End-of-Life Communication into Advanced Illness Management. *Journal of Pain and Symptom Management.* 2018 Dec 1;56(6):e58-9.
64. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. “Whatever happens, happens” challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study. *BMC palliative care.* 2019 Dec;18(1):1-9.
65. Trees AR, Ohs JE, Murray MC. Family communication about end-of-life decisions and the enactment of the decision-maker role. *Behavioral Sciences.* 2017 Jun;7(2):36.

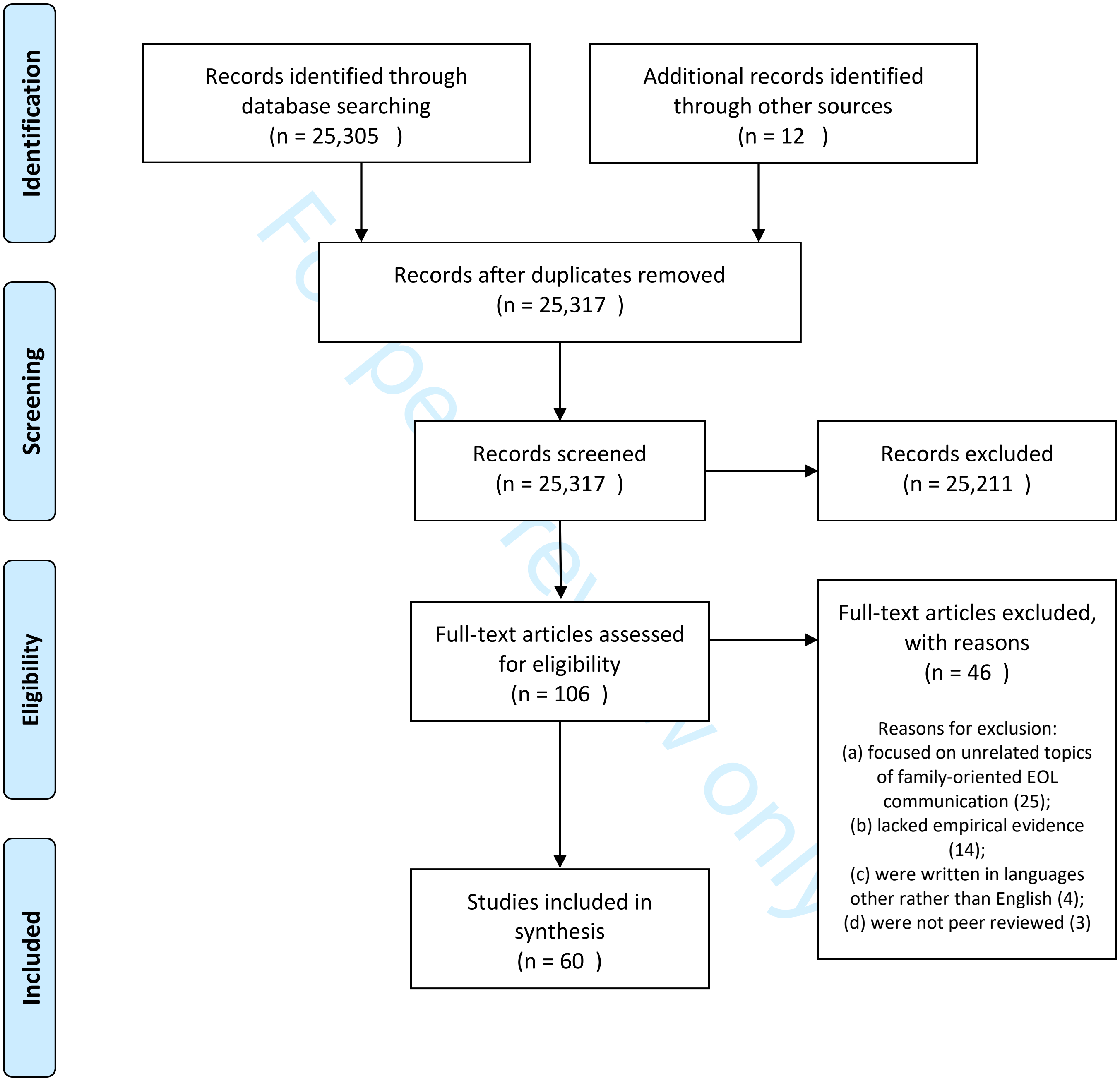
66. McDarby M, Picchiello M, Kozlov EK, Ju C, Worthalter D, Carpenter B. ADULT CHILDREN'S UNDERSTANDING OF PARENTS'CARE AND LIVING PREFERENCES AT END OF LIFE. *Innovation in Aging.* 2019 Nov;3(Supplement_1):S668-9. doi:10.1093/geroni/igz038.2473
67. McElroy JA, Proulx CM, Johnson L, et al. Breaking bad news of a breast cancer diagnosis over the telephone: an emerging trend. *Supportive care in cancer* 2019 Mar; 27(3): 943-950.
68. Schonfeld TL, Stevens EA, Lampman MA, et al. Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities. *American journal of hospice and palliative medicine* 2012 Jun; 29(4): 260-267.
69. Ayers NE, Vydelingum V, Arber A. An ethnography of managing emotions when talking about life-threatening illness. *International nursing review.* 2017 Dec;64(4):486-93.
70. Chan WC, Epstein I, Reese D, Chan CL. Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the "support paradox". *Social Work in Health Care.* 2009 Jul 8;48(5):519-32.
71. Ho AH, Chan CL, Leung PP, Chochinov HM, Neimeyer RA, Pang SM, Tse DM. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age and ageing.* 2013 Jul 1;42(4):455-61.
72. Tse CY, Chong A, Fok SY. Breaking bad news: a Chinese perspective. *Palliative medicine.* 2003 Jun;17(4):339-43. Doi: 10.1191/0269216303pm751oa
73. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
74. Ko E, Roh S, Higgins D. Do older Korean immigrants engage in end-of-life communication?. *Educational Gerontology.* 2013 Aug 1;39(8):613-22.
75. Zheng RS, Guo QH, Dong FQ, Owens RG. Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study. *International journal of nursing studies.* 2015 Jan 1;52(1):288-96.
76. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
77. Abbey JG. Communication about end-of-life topics between terminally ill cancer patients and their family members. 2008.
78. Salifu Y, Almack K, Caswell G. 'My wife is my doctor at home': A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative medicine.* 2021 Jan;35(1):97-108.
79. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of the American Geriatrics Society.* 1997 Nov;45(11):1339-44.
80. Scott AM. Family conversations about end-of-life health decisions. University of Illinois at Urbana-Champaign; 2010.
81. Chui WY, Chan SW. Stress and coping of Hong Kong Chinese family members during a critical illness. *Journal of clinical nursing.* 2007 Feb;16(2):372-81.
82. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clinics in geriatric medicine.* 1996 May 1;12(2):237-52.
83. Ohs JE, Trees AR, Kurian N. Problematic integration and family communication about decisions at the end of life. *Journal of Family Communication.* 2017 Oct 2;17(4):356-71.
84. Van den Heuvel LA, Hoving C, Schols JM, Spruit MA, Wouters EF, Janssen DJ. Barriers and facilitators to end-of-life communication in advanced chronic organ failure. *International journal of palliative nursing.* 2016 May 2;22(5):222-9.
85. Peterson LJ, Hyer K, Meng H, Dobbs D, Gamaldo A, O'Neil K. Factors associated with whether older adults discuss their EOL care preferences with family members. *Innovation in Aging.* 2018 Nov;2(suppl_1):843. doi:10.1093/geroni/igy023.3141
86. Colletti L, Gruppen L, Barclay M, Stern D. Teaching students to break bad news. *The American journal of surgery.* 2001 Jul 1;182(1):20-3.
87. Villagran M, Goldsmith J, Wittenberg-Lyles E, Baldwin P. Creating COMFORT: A communication-based model for breaking bad news. *Communication Education.* 2010 Jul 1;59(3):220-34.

88. Schapira L. Delivering bad news to patients and their families. *Tumors of the Chest* 2006 (pp. 597-605). Springer, Berlin, Heidelberg.
89. Labaf A, Jahanshir A, Shahvaraninasab A. Difficulties in using Western guidelines for breaking bad news in the emergency department: the necessity of indigenizing guidelines for non-Western countries. *Journal of Medical Ethics & History of Medicine.* 2014 Jan 1;7(1).

---

[1] To avoid conflating EOL and palliative care, we mainly include studies that are primary focus on EOL topic but we note that some EOL studies may contain topic such as palliative care.

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix 1. Search strategy

The current review search includes keywords and synonyms of ‘end of life’, ‘communication’ and ‘family’. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevantstudies, e.g. ‘end of life AND communication AND family’.

Appendix 2 Summary of each included study.

Theme	Author(s)	Article	Objective(s)	Research design	Sample
1	Abbey, 2008 [41]	Communication about end-of-life topics between terminally ill cancer patients and their family members	To explore EOL communication by addressing patient-family communications	Quantitative - Questionnaire	369 patients
1	Bailey et al., 1999 [55]	Communication at life's end [A patient held palliative care chart facilitates communication]	To promote effective communication, the continuity and co-ordination of care, and sense of partnership for patients and their families through developing a care chart relating to palliative communication	Qualitative - Interviews	40 families and health care providers
1	Byock, 1996 [42]	The nature of suffering and the nature of opportunity at the end of life	To explore the personal experience of suffering in life-limiting illness and to understand the nature of opportunity at the end of life.	Qualitative - Clinical observation	N/A
1	Chui & Chan, 2007 [43]	Stress and coping of Hong Kong Chinese family members during a critical illness	To assess how families cope with stress during a family members’ admission to ICU and the relationships between stress and coping	Qualitative - Structured interview	133 participants
1	Fan et al., 2019 [23]	Preference of cancer patients and family	To study the preferences of cancer patients and	Quantitative - Questionnaire	216 cancer patients

		members regarding delivery of bad news and differences in clinical practice among medical staff	their families in way of being informed of their conditions and explore the factors in the underlying preferences		242 family caregivers 176 clinical staff members
1	Githaiga & Swartz, 2017 [44]	Socio-cultural contexts of end-of-life conversations and decisions: bereaved family caregivers' retrospective co-constructions	To examine the content and context of EOL conversations and decisions based on family caregivers of cancer patients in resource-limited areas.	Qualitative - Focus group interview	13 participants
1	Hanson et al., 1997 [45]	What is wrong with end-of-life care? Opinions of bereaved family members	To explore family perceptions of EOL care and communication	Qualitative - Interview	461 family members
1	Kastbom et al., 2020 [29]	Elephant in the room - Family members' perspectives on advance care planning	To explore family members' experiences of advance care planning and EOL communication	Qualitative - Interview	18 family members of deceased nursing home patients
1	Kotecho & Adamek, 2017 [57]	Gender differences in quality of life of urban elders in Ethiopia	To explore how death of a resident affects Certified Nursing Assistants in terms of impacts and support they received.	Qualitative - Semi-structured interviews	140 participants
1	Kramer et al., 2010 [56]	Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer	To examine the correlates and predictors of family conflict at the end of life	Quantitative - Surveys	155 participants
1	Lee & Yun, 2018 [46]	Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study	To determine whether family caregiver functioning predicts EOL Quality of life received by terminally ill patients with cancer	Quantitative - Questionnaire	264 family caregivers of terminally ill patients

1	Mitchell et al., 2020 [9]	Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation	To understand experiences of healthcare services concerning children with life-limiting conditions and their family members	Qualitative - Interview	31 family members including 10 children
1	Ohs et al., 2015 [20]	Holding on and letting go: Making sense of end-of-life care decisions in families	To understand how family members make EOL care decisions and their discursive contradictions that appears during the process	Qualitative - Interview	15 family caregivers of cancer patients
1	Ohs et al., 2017 [47]	Problematic integration and family communication about decisions at the end of life	To examine how families make decisions on behalf of their dying family members at the end of life and how they manage the stressful situation	Qualitative - Interview	22 family members who engaged in EOL conversations
1	Royak-Schaler et al., 2006 [48]	Family perspectives on communication with healthcare providers during end-of-life cancer care	To assess healthcare provider communication on EOL with patients and their family members	Mixed method - Focus group discussions and questionnaires	24 family members of deceased patients
1	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
1	Shaunfield, 2016 [51]	"IT'S A VERY TRICKY COMMUNICATION	To explore the communication stressors experienced by	Qualitative - Interviews	40 caregivers

		SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN	family caregivers to examine why communication tasks are perceived as difficult		
1	Shin et al., 2015 [49]	Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices	To assess cancer patient preferences, family caregiver preferences, and family caregiver predictions of patient preferences regarding the disclosure of terminal status, family involvement in the disclosure process, and EOL choices	Quantitative - Cross-sectional survey	990 patients
1	Towsley et al., 2015 [22]	Conversations about End of Life: Perspectives of Nursing Home Residents, Family, and Staff	To describe the communication, content and process related to EOL conversations among nursing home residents, family and staff	Qualitative - Semi-structured interview	16 residents 12 family members 10 staff members
1	Wong & Chan, 2006 [53]	The qualitative experience of Chinese parents with children diagnosed of cancer	To describe the coping experience of Chinese parents with children diagnosed as having cancer during the treatment stage	Qualitative - Interview	9 parents with children diagnosed with cancer
1	Zhang & Siminoff, 2003 [54]	Silence and Cancer: Why Do Families and Patients Fail To Communicate?	To examine how patients with cancer and their family members make treatment decisions together, and to explore the avoidance of communication and issues families face	Qualitative - Interview	64 participants

2	Azoulay et al., 2000 [22]	Half the families of intensive care unit patients experience inadequate communication with physicians	To explore the needs of family members of patients with terminal illness in order to improve communication and ease their burden	Quantitative - Prospective study	102 ICU patients
2	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
2	Carrese & Rhodes, 1995 [60]	Western bioethics on the Navajo Reservation: Benefit or harm?	To explore the influence of Western biomedical and ethical principles on Navajo values, and how it affects the quality of health care	Qualitative - Interview	34 Navajo people
2	Cherlin et al., 2005 [61]	Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said?	To examine family caregivers' communication with physicians on illness, life expectancy, hospice, EOL discussion timing and their understanding on these issues.	Qualitative - Survey and interviews	218 family caregivers
2	El-Jawahri et al., 2017 [62]	Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial	To explore the influence of early integrated palliative care on patients and evaluate caregivers' stress and quality of life	Quantitative - Clinical trail	350 patients
2	Gamble et al., 1991 [63]	Knowledge, attitudes, and behavior of elderly persons	To explore elderly's knowledge, attitude and behavior	Quantitative - Questionnaire	75 elders

		regarding living wills	regarding living wills		
2	Gonella et al., 2020 [87]	A qualitative study of family carers views on how end-of-life communication contributes to palliative-oriented care in nursing home	To explore how EOL communication may contribute to palliative care in nursing homes.	Qualitative - Interview	32 bereaved family carers from 13 different nursing homes
2	Gutierrez, 2013 [64]	Prognostic categories and timing of negative prognostic communication from critical care physicians to family members at end- of-life in an intensive care unit	To explore how physicians communicate negative prognoses to families and the influence of timing	Qualitative - Observations and interviews	7 critical care attending physicians 3 critical care fellows 20 family members of patients
2	Huang et al., 2012 [65]	Family experience with difficult decisions in end-of-life care	To determine the frequency and difficulty of decision making in EOL care and its related factors	Quantitative - Questionnaires	302 family caregivers
2	Hui et al., 2014 [58]	Impact of timing and setting of palliative care referral on quality of end- of-life care in cancer patients	To examine the association between timing and setting of palliative care referral and the quality of EOL care	Quantitative – Retrospective cohort study	366 adult patients who died of advanced cancer
2	Lind et al., 2011 [66]	Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions	To examine patients' family members experience of EOL decision making and the process of making the decisions	Qualitative - Interviews	27 family members
2	Low et al., 2009 [26]	Reducing collusion between family members and clinicians of patients referred to the palliative care team	To explore the rate of collusion among family members and clinicians. And to reduce the rate of collusion through the project	Qualitative - Clinical practice improvement project (defining the problem, establish	655 patients

				strategies for intervention)	
2	Ohs et al., 2017 [47]	Problematic integration and family communication about decisions at the end of life	To examine how families make decisions on behalf of their dying family members at the end of life and how they manage the stressful situation	Qualitative - Interview	22 family members who engaged in EOL conversations
2	Rhoads & Amass, 2013 [59]	Communication at the End-of- Life in the Intensive Care Unit: A Review of Evidence- Based Best Practices	To explore the current data and recommendations on the care of patients in ICU at the end of life	Qualitative	N/A
2	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
3	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
3	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors
3	Chan, 2011 [68]	Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members	To explore the relationships among the patient's awareness of the prognosis, the family's awareness of the prognosis, the patient's anxiety,	Qualitative - Clinical records of deceased cancer patients in a palliative care unit of a public hospital	935 Patients

		in the Hong Kong Chinese context?	and difficulty in communicating with family members		
3	Im et al., 2018 [69]	Patient and Family Related Barriers of Integrating End-of-Life Communication into Advanced Illness Management	To explore the barriers EOL communication from the perspective of the patients and their family members	Qualitative - Semi-structured interviews	19 patients with advanced heart failures and their family caregivers
3	Im et al., 2019 [70]	"Whatever happens, happens" challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study	To explore the challenges of EOL communication among older adults and their family care-givers, as well as to understand the illness and goals of care among patients in advanced heart failure.	Qualitative - Semi-structured interviews	22 participants
3	McDarby et al., 2019 [71]	Adult Children's Understanding of Parents' Care and Living Preferences at End of Life	To examine how contact between patients and adult children relate to EOL conversations	Quantitative - Questionnaires	66 adult children 36 older adult patients
3	Trees et al., 2017 [72]	Family communication about end-of-life decisions and the enactment of the decision- maker role	To explore how families enacts their roles as decision makers for their family members who are at the end of their lives	Qualitative - Interview	22 participants
3	Van den Heuvel et al., 2016 [73]	Barriers and facilitators to end-of-life communication in advanced chronic organ failure	To identify the challenges, facilitators and agreement to EOL communication among family members and patients	Qualitative - Interview	158 patients and family caregiver
4	Ayers et al., 2017 [74]	An ethnography of managing emotions when talking about life-threatening illness	To explore how dying patients, palliative care staff and family caregivers	Qualitative - Observations and ethnographic interviews	4 patients. 6 family caregivers and 5 palliative care staff

			communicate about life-threatening illness in Ethiopia		
4	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors
4	Chan et al., 2009 [75]	Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the "support paradox"	To explore the relationship of family- related factors and psychosocial outcomes among HK Chinese cancer patients in palliative care.	Qualitative - Clinical records and interviews	935 patients
4	Fielding & Hung, 1996 [76]	Preferences for information and involvement in decisions during cancer care among a Hong Kong Chinese population	To assess differences that between Western and Asia cancer patients' preferences for information on diagnosis, prognosis and treatment options and involvement in treatment decision making	Quantitative - Telephone survey	1136 cancer patients
4	Ho et al., 2013 [79]	Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong	To examine the concept of 'living and dying with dignity' in Chinese context; and how the dignity model influenced older terminal patients in Hong Kong	Qualitative - Interview	16 patients
4	Kato & Tamura, 2020 [88]	Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive	To explain the meaning of continuous EOL discussion for family members	Qualitative - Semi-structured interviews	13 family members of residents from 3 nursing homes in Kyoto

		Study of Family Members' Narratives			
4	Ko et al., 2013 [77]	Do Older Korean Immigrants Engage in End-of-Life Communication ?	To understand patients' communication with family and their healthcare providers on EOL care among older Korean immigrants	Quantitative - Questionnaire	195 older Korean immigrants
4	Peterson et al., 2018 [78]	Factors associated with whether older adults discuss their EOL care preferences with family members	To examine the factors associated with EOL care wishes discussions with family, especially race and ethnicity	Quantitative - Survey	364 participants
4	Tse et al., 2003 [80]	Breaking bad news: a Chinese perspective	To address this difference in attitudes, the ethical principles for and against disclosure are analysed, considering the views in Chinese philosophy, sociological studies and traditional Chinese medicine	Qualitative	N/A
4	Wang, 2010 [25]	Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US	To examine the relationship between doctor and patient in the Chinese context and the differences with the US	Mixed method -Survey and interview	Survey: 1097 Chinese and 1280 Americans Interview: 26 Chinese
4	Zheng et al., 2015 [81]	Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study	To elucidate Chinese oncology nurses' experience of caring for dying cancer patients	Qualitative - Interview	28 nurses

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	N/A
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	4-6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	4-6
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	4-6
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	4-6
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	4-6
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	4-6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	4-6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	4-6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	4-6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	4-6
Certainty	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	4-6

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	6-10
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	6-10
Study characteristics	17	Cite each included study and present its characteristics.	6-10
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	6-10
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	6-10
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	6-10
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	6-10
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	6-10
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	6-10
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	6-10
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	6-10
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	10-12
	23b	Discuss any limitations of the evidence included in the review.	10-12
	23c	Discuss any limitations of the review processes used.	10-12
	23d	Discuss implications of the results for practice, policy, and future research.	10-12
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

PRISMA 2020 Checklist

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

The Role of Patients' Family Members in End-Of-Life Communication: An Integrative Review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-067304.R2
Article Type:	Original research
Date Submitted by the Author:	23-Nov-2022
Complete List of Authors:	Pun, Jack; City University of Hong Kong, Department of English Chow, James C. H.; Queen Elizabeth Hospital, Department of Clinical Oncology FOK, Leslie; Queen Elizabeth Hospital, Department of Clinical Oncology CHEUNG, Ka Man; Queen Elizabeth Hospital, Department of Clinical Oncology
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health services research, Patient-centred medicine
Keywords:	PALLIATIVE CARE, ONCOLOGY, MEDICAL EDUCATION & TRAINING

TITLE PAGE

Title: The Role of Patients' Family Members in End-Of-Life Communication: An Integrative Review

Authors: Jack PUN[a], Chung Hang James CHOW[b], Leslie FOK[b], Ka Man CHEUNG[b]

Affiliations:
a-Department of English, City University of Hong Kong, Hong Kong SAR, China
b-Department of Clinical Oncology, Queen Elizabeth Hospital, Hong Kong SAR, China

Postal addresses:
a-Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong SAR, China.
b-Department of Clinical Oncology, Queen Elizabeth Hospital, 30 Gascoigne road, Kowloon, Hong Kong SAR, China.

Emails:
Jack PUN: jackpun@me.com
Leslie FOK: fl684@ha.org.hk
James Chung Hang CHOW: cch932@ha.org.hk
Ka Man CHEUNG-ckm792@ha.org.hk

Corresponding author:
Jack PUN
Email: jackpun@me.com
Postal address: Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong.

ABSTRACT

Objectives: To synthesise empirical findings on the role of family in end-of-life (EOL) communication and to identify the communicative practices that are essential for EOL decision-making in family-oriented cultures.

Setting: The end-of-life (EOL) communication settings.

Participants: This integrative review followed the PRISMA reporting guideline. Relevant studies published between 1st January 1991 and 31st December 2021 were retrieved from four databases, including the PsycINFO, Embase, MEDLINE, and Ovid nursing databases, using keywords with meanings of “end-of-life”, “communication” and “family”. Data were then extracted and coded into themes for analysis. The search strategy yielded 53 eligible studies; all 53 included studies underwent quality assessment. Quantitative Studies were evaluated using the Quality Assessment Tool, and Joanna Briggs Institute Critical Appraisal Checklist was used for Qualitative Research.

Primary and secondary outcome measures: Research evidence on EOL communication with a focus on family.

Results: Four themes emerged from these studies: 1) Conflicts in family decision-making in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a “key person” who is responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Conclusions: The current review pointed towards the importance of family in EOL communication and illustrated that family participation likely leads to improved quality of life and death in patients. Future research should develop a family-oriented communication framework which is designed for the Chinese and Eastern contexts that targets on managing family expectations during prognosis disclosure and facilitating patients’ fulfilment of familial roles while making EOL decision-making. Clinicians should also be aware of the significance of the role of family in EOL care and manage family members’ expectations according to cultural contexts.

Keywords:
End of life; Family; Palliative care; Communication; Family-oriented cultures, East Asian Cultures.

Strengths and limitations of this study

- This review offers a timely synthesis of research evidence of the role of family in end-of-life communication.
- The search strategy was developed in collaboration with frontline clinicians, academics, and librarians to offer a diversified view towards a holistic understanding of the topic, study methodologies and study settings.
- This review includes different research designs and methods including quantitative, qualitative and mixed-methods studies within the topic of family role in end-of-life communication.
- As an integrative review, the themes emerged from the included studies can inform future research on developing a family-oriented communication framework that targets on managing family expectations when making EOL decision-making
- Findings have to be interpreted cautiously due to a number of studies included in this review are emerged from Chinese context.

Introduction

End-of-life (EOL)[1] communication has a crucial influence on medical decision-making and the quality of care at the final stage of a patient journey. It informs patients and their families on the current medical conditions; explores unanswered concerns and health needs; provides emotional support and practical advice; reveals what lies ahead; and allows care providers to understand how they can improve the care for the patients during their final days. EOL communication during palliative care removes the stigma around death and help the patients set out their final wishes to the family [1]. In general, effective communication regarding prognoses and optimal treatment has multidimensional benefits, for instance, promoting the quality of EOL care and decreasing the stress of the carers [2]. In contrast, poorly conducted medical conversations may lead to negative treatment outcomes such as aggressive life-sustaining treatments [3-4], unsatisfactory hospital experiences [5], poor well-being [6], and unnecessary healthcare costs [2, 7]. Thorough EOL communication among clinicians, patients and carers help to alleviate anxiety and enable patients to be cared for in desired ways [2, 8].

However, empirical evidence shows that the EOL communication practice is not always performed effectively [9-10]. Many patients and carers are reported to be poorly informed about their patients' situations and that the patients were often unaware of their own risks of imminent deaths [11]. Similarly, clinicians' unawareness of patients' wishes may hinder the provision of the most appropriate healthcare options for patients. Healthcare professionals also find it challenging to directly discuss deaths with patients and caregivers, as patients and caregivers are often being ill informed and tend to be over-optimistic on the prognoses [12]. There are different expectations for palliative care in Chinese and Western cultures. Most Chinese patients rely on doctors to make the final decision regarding EOL treatments [13-14], the wishes of close family members are also considered. Research results show that in the broader Asian context, family members and religious beliefs heavily influences patients decisions on EOL and palliative care [15-17].

Nowadays, many developed regions such as the United States, Europe, and Australia adopt the shared decision-making approach to family–clinician EOL communication [18]. However, patients who are admitted to general wards or intensive care units (ICUs) which are aggressively managed have no prior opportunities for effective discussions with their families or clinicians about their desires and goals [19]. There is a lack of clear communication framework that sets the standard for essential information that family caregivers should receive, which will likely include patients' current medical condition and prognosis estimates, additional options of treatment and support measures available and their risks and benefits, and the preferences of patients and family to guides clinicians to reach realistic care goals [20-21]. When family members receive insufficient information, difficulties may arise during EOL communication. This occurs especially in the ICU settings, where urgent decisions about whether to pursue aggressive life-sustaining treatments for patients are required. In a study by Azoulay et al.[22], 54% of the family members of ICU patients did not have a clear understanding of the patients ' diagnoses, prognoses and treatments, and the physician–family meetings lasted for no more than 10 minutes. As a result, family members have poor understandings of the situations they were facing, which led to suboptimal decision making. In addition to time constraints, the lack of communication skills is also an important factor. Clinicians tended to discuss EOL life-sustaining treatments in a scripted, depersonalised and procedure-focused manner. Clinicians also tended not to initiate EOL conversation directly and in a timely manner [18].

Amongst the factors affecting EOL communication as well as the engagement of patients and their family caregivers, the factor most discussed is cultural differences between the Eastern and Western

---

countries. Chinese culture values collectivism, wherein patients prefer to make joint decisions with their family members or sometimes even rely completely on them [14]. Rooted in Confucian morality, filial piety is a very important moral tenet in Chinese culture that has been advocated and practiced for thousands of years. People of the Chinese culture are required to provide care to their parents in return for the care they received from their parents in their childhood years. Therefore, many Chinese elderly patients believe that their children may naturally understand their preferences and are able to make decisions for them in their final days [14, 23-24]. For example, family members of elderly patients would request the doctors to discuss with them first, before the doctors consult the elder patient. In some cases, family members will also choose not to disclose the bad news to the patients [25]. Collusion, a scenario wherein the family wishes to hide the diagnosis from the patient, is common in Asian cultures. In a study conducted in Singapore by Low et al. [26] found that 96% of family members expressed reluctance in disclosing the prognosis to the patient. This situation is also prevalent in Hong Kong, in which its culture is heavily influenced by both Chinese and Western beliefs. In research conducted with Chinese patients, maintaining a strong connection with the family during palliative care has been reported to be one of the most important components of a “good death” for elderly patients [27]. This interdependent relationship between family caregivers and patients opposes the ideology of autonomy and self-determination that predominate in Western culture, and is to a certain extent, culturally understood and accepted by patients in the Chinese context.

Regardless of the effects of different cultural norms, recent reports have shown that healthcare professionals widely agree that EOL communication should involve both the patient and family members [28-29]. In one international survey of palliative care professionals, more than 80% of the participants agreed that more practical instructions during communication with patients’ family members would enhance EOL decision-making [29-30]. Recently, the English Parliamentary and Health Service Ombudsman [31] found that the main area of health professionals’ complaints about EOL care was communication failure with terminally ill patients and their family members. Without adequate family involvement, promoting the holistic care of patients during their EOL is difficult.

In response to such dissatisfaction with EOL communication, several guidelines have been established for practitioners with focus on individuals ’rights and autonomy in the medical context. Guidelines such as the COMFORT model (an acronym for Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative messages, and Team) and SPIKES protocol (an acronym for Setting, Perception, Invitation, Knowledge, Empathetic Response, Summary) provides a framework for clinicians to engage in palliative care discussion with patients [5, 32]. Meanwhile, existing recommendations mostly focus on the patient–clinician conversation rather than a family-oriented conversation. Many close family members are eager to thoroughly understand the dying process and the importance of understanding medical jargon, inclusivity, and full transparency [33] is lost in the existing recommendations.

Due to the aforementioned factors, the development of an EOL communication strategy that considers active family involvement is necessary. While previous systematic reviews on family decision-making and involvement [34], nurse to family support during withdrawal of life-sustaining treatment and imminent death [35-36], and EOL communication to patients and caregivers during the advanced stages of related illnesses [37] are present, an integrative review is lacking. As such, in this integrative review, the researchers aimed to contribute to the current literature by systematically reviewing research findings that highlights the roles of patients’ families in EOL decision making. The aim of the review was to answer the following question: What is the existing research evidence regarding the role of family in EOL communication, and what themes can be derived from their synthesis?

The summarised information sheds light on the role of family in EOL communication and decision-making and contributes to future research and policy making regarding EOL communication. Although culture and its related elements regarding EOL communication and care have been heavily foregrounded thus far, it is not saliently marked in the research question because it is a prominent theme elicited after, rather than prior, the systematic review search (see also [38]).

Methods

This integrative review aimed to provide integrated information on the role of family in EOL communication using the PRISMA guideline as reporting system (see Figure 1).

[**Figure 1** PRISMA flow diagram]

Search strategy

PsycINFO, Embase, MEDLINE and the Ovid nursing databases were searched in the initial screening process to identify relevant articles using the following keywords and synonyms of ‘end of life’, ‘communication’ and ‘family’. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevant studies, e.g. ‘end of life AND communication AND family’ (See Appendix 1 for the details on our search strategies). In addition, a manual search was made of relevant journals, and the bibliographies of relevant articles and reviews were also cross-checked for potential eligible studies. Studies that met the inclusion criteria were included for further review and duplicated articles were removed.

Inclusion and exclusion criteria

An initial search was carried out to identify relevant articles on EOL communication that were published between 1st January 1991 and 31st December 2021. Studies were included if they were peer-reviewed and concerned EOL communication and family. Studies were excluded for the following reasons: (a) having a focus on topics that were unrelated to EOL communication (e.g., religious studies of EOL care); (b) not being original research based on empirical findings (e.g., literature reviews, opinion pieces); (c) being non-English language articles; (d) being non-peer reviewed studies.

Our investigation encompasses a broad scope. The various aspects of EOL care includes EOL communication studies in general (i.e. not limited to diagnosis, prognosis etc.)[1] and focus on the involvement and roles of and between family, clinicians, and relatives. Peer-reviewed full-text journal articles such as original studies and reviews were included. The initially shortlisted articles were cross-checked by the three authors for final review and data extraction. Articles that were not peer-reviewed or written in English were excluded. Although we have a bilingual research team, EOL care articles that were written in Chinese were not included in the research due to insufficient peer-reviewed articles and the paucity of EOL communicative aspect-oriented research.

Data extraction

Three authors were involved throughout the entire title screening, data collection, and text review process. Before data extraction, the authors independently screened the titles and read the whole abstract of each paper to exclude irrelevant articles according to the inclusion criteria. The full papers were retrieved if their abstracts were considered potentially relevant. The full texts of the chosen articles were subjected to in-depth data extraction. The objectives, research design, participant characteristics and key findings were examined and recorded and appraised for quality by oncologists and palliative care practitioners to ensure that all relevant journals were included in the search. Any disagreements were resolved by discussion to reach a consensus amongst all the authors.

Patient and Public Involvement

No patient involved.

Results

Quality assessment

The Quality Assessment Tool for Quantitative Studies [39] was used to assess quantitative (*n* = 14) and mixed-method studies (*n* = 2). Each article was given ratings on a 3-level ordinal scale: "weak", "moderate", or "strong" in eight areas such as research design and selection of study population. Qualitative (*n* = 37) were evaluated with the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research [40], which is a 10-item checklist covering components such as congruity and reflexivity, scored as "yes", "no", "unclear", or "not applicable". The quality of the included studies was evaluated independently by the first and second authors. Any disagreements in ratings were discussed and resolved with the third author.

Weight of Evidence Measure

To ensure the quality of the included studies, the papers' "weight of evidence" was measured according to three criteria: the relevance of each paper to the current review; the appropriateness of the research; and the validity of the study; and the overall contribution of the research to this review. These variables are specified in Table 1 below.

Regarding the relevance aspect of the included studies, that is, to which the degree of the topic(s) examined align with our review questions, 86% of the 53 reviewed articles were considered as either high or medium level of relevance. Appropriateness is evaluated based on whether the research designs were appropriately employed. The authors judged that 28% and 38% were deemed to be highly appropriate and fairly appropriate, respectively. 83% of the included studies were considered to have a medium-to-high level validity, where the scorings were based on the preciseness and consistency of data analysis. These ratings therefore draw an overall conclusion that 30% of the included studies were able to make a strong contribution in answering the review questions whilst 43% made a fairly significant contribution.

Table 1. Weight of Evidence of the current review

	Relevance	**Appropriateness**	**Validity**	**Overall contribution**
High	46%	28%	38%	30%
Medium	40%	38%	45%	43%
Low	13%	33%	16%	26%

Included articles

The initial search identified 25,305 eligible studies, 25,318 of which were excluded after abstract screening. The search includes keywords and synonyms of 'end of life', 'communication' and 'family'. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevant studies, e.g. 'end of life AND communication AND family'.

The full-text screening of the remaining 109 studies were then subjected to in-depth review (see Figure 1). This led to the further exclusion of 56 articles because they: (a) focused on unrelated topics of family-oriented EOL communication; (b) lacked empirical evidence; (c) were written in other languages rather than English; or (d) were not peer reviewed. Finally, 53 studies were included in this review.

The Characteristics Of The Included Studies

The characteristics of the 53 studies that met the inclusion criteria are summarised in Table 2 (See Appendix 2 for a summary of each included study). The number of studies on the role of family in EOL communication increased significantly after 2010. Most of the studies were from the United States (24), closely followed by Hong Kong (7), Canada (4), the United Kingdom (3), China (2), South Korea (2), Netherlands (2), France (2) and other countries (7). Of the 53 included studies, 37 were qualitative studies, 14 were quantitative and 2 were mixed-method.

Table 2. Main ideas of the themes emerged from the reviewed studies

Theme	Main ideas	Studies
1. Conflicts in family decision-making in EOL communication	There existed a certain degree of discrepancies in decision-making between the patient and family caregivers; to optimise EOL communication among the relevant stakeholders, physicians should be able to gauge and respond to the patient's psychosocial needs and to also take the family's perspective into account when having EOL conversations.	[9, 20, 23, 29, 41-51]
2. The significance of timing of EOL communication	There is typically a delay in initiating EOL communication; it is often due to the avoidance of having open physician-patient discussion about the illness. Patients were generally worried about making EOL decisions once informed about the diagnosis, whilst physicians were concerned that the negative prognostic information would impact the patients and hence, leading to a late timing of EOL communication.	[22, 26, 52-60]

3. Difficulty in identification of a "key person" responsible for decisions regarding EOL care	Some patients were found to not wish to be involved in making their own palliative care decision out of the fear and uncertainty of their EOL stage, family members or even the physicians themselves might in turn have to be responsible for decision-making; this likely leads to an unclear division of responsibility regarding EOL decision-making.	[14, 61-66]
4. Different cultural perspectives on EOL communication	Individualism is of value in the West where most patients preferred having the autonomy to make EOL decision for themselves, whilst collectivism and filial piety are the main values typically found in Eastern society; patients tended to rely on their children or discussing within the family when making palliative care decisions.	[14, 25, 67-76]

Identified themes

Thematic analysis was conducted to capture any re-occurring topics in the included studies [see 77-78]. To do this, all the authors will first read through the transcripts carefully and give an initial free-coding to all segments relevant to the role of family in EOL communication. We then conducted several review rounds to compare, sort, and recode, as we look for connections among the coded segments and compared analyses from the other included papers. In this way, the authors identified and coded issues from each of the included studies, which were then synthesised into a set of broad reoccurring themes about the role of family in EOL communication [79]. Four themes were identified: 1) Conflict in family decision-making in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a "key person" responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Conflicts in family decision-making in EOL communication

Internationally, the involvement of family members in EOL communication has often been discussed in the context of provision of support, but very few studies have directly explored how important the role of family is and in what way the family must be involved.

Family caregivers traditionally play their own unique roles in providing emotional and financial support to contribute to a "good death"— a pain-free situation during the last phase of life and not on exhausting possible treatments to prolong life unnecessarily---for the dying patients [20,41]. In fact, the patients expect to receive family support more than the support from healthcare workers. Furthermore, the social support from family members serves as the fulfilment of their own familial obligations and is a foundation providing quality EOL care [42-44].

Many clinicians nowadays have come to realise that the patients' and families' views and beliefs have to be considered in the decision-making process [20, 29]. In circumstances where disagreement about the medical advice arises between the doctor and the family, establishing a care plan could become difficult, and this could cause the withholding or withdrawal of treatment implementation. Family members have also noticed that healthcare staff would avoid EOL conversations. However, it is important for healthcare staff to initiate EOL conversations so that patient's needs and their family's preferences are properly addressed [29]. It was also found that some doctors have to follow the family's wishes, even if it was against the professional judgement of what was appropriate for the patient [45-47]. For instance, against the doctors' recommendations, some family might still desire more unnecessary treatments just to sustain a dying patient's life when he or she could not make an EOL decision.

Disagreements about decisions on EOL treatments could also occur between terminally ill patients and their family members. There are contradictions between family members who wish to hold on to their loved ones for as long as possible and the patients who wish to let go and reject life-sustaining treatments [48-50]. Fan et al.[23] and Shin et al.[51] used standardised questionnaires to examine the preference and concordance among the patients with cancer, family members, and clinicians regarding EOL communication. This includes the disclosure of diagnosis and prognosis, family involvement in such processes, and EOL decision-making. Findings revealed that family members' preferences did not always align with that of the patients in some cultural contexts such as China and Korea [23; 51]. For example, Shin et al. [51] found that discussions between patients and their family regarding treatment preferences might not always end in agreement, since patients' family tended to opt for life-sustaining treatments when the patients desired otherwise. Fan et al. [23] suggested that mainland Chinese patients depended largely on their families and doctors tended to substitute patients' consents with that of their families. Additionally, there are discrepancies between clinicians' medical practice and the preferences of the patients and their family caregivers. For instance, rigid protocols and guidelines that inform the healthcare of the young patients created tension among family caregivers and clinicians as they did not take into account the patients' individual needs [9].

The significance of timing of EOL communication

Owing to the complexity of EOL communication, that is, the constitution of delivering exhaustive information from doctors, the complicated emotions derived from relevant stakeholders, and the dynamics of family involvement in the patient's health care, there typically appears a delay in conducting EOL communication [52-54]. Cherlin et al. [52] found that the communication between family caregivers and clinicians about the terminal illness and possible use of hospice care occurs late in the course of the illness. Some patients consistently wrestled with the thought of knowing that they were ill and trying to defer EOL decisions [55-57]. From the perspective of clinicians, there seems to be a tendency for clinicians to initiate the communication of negative prognostic information until they reach a perceived "threshold" of certainty in the accuracy of a prognosis [55]. This observation corroborates with those of Lind et al. [57], who discovered that the doctor's directive to "wait and see" may cause miscommunication between the doctor and family members. One possible reason for the delayed initiation of EOL conversations from doctors might be due to their lack of communication skills, in which many of them were unable to discuss EOL issues with the patients and the families in an effective and timely manner [58]. Yet, this directive to further delay diagnosis could potentially give the family a sense of false hope that the patient's situation can be improved. When miscommunication occurs, it would appear to be too late to conduct proper EOL communication, or for family members to provide input in the decision-making process about terminating treatment.

Another potential reason why EOL communication may not be implemented in a timely fashion is the presence of physician-family collusion, a situation where family members choose to hide the diagnosis and prognosis from the patients. Notwithstanding the fact that collusion goes against medical ethics and can potentially cause various complications in EOL treatment, admittedly, collusion is widely seen across Europe and Asia [26]. This is because of the fear of disappointing the patients by informing them of their deteriorating health condition, and more prevailing in Asian countries that the social norm of holding family members to be responsible for the main body of communication about EOL care.

The failure to have patients engage in timely EOL conversations can lead to aggressive life-sustaining treatments, under-utilisation of palliative care, and negative outcomes for both patients and their families. Patients' psychological conditions, including depression scores and quality of life metrics, will be compromised without good palliative care. Moreover, introducing palliative care relieves caregiver stress and improves caregiver depression scores [22, 56]. As a result of these side effects, clinical prediction models to provide estimated remaining survival time of the patient have started to gain popularity in medical practices to aid the EOL discussion pacing of clinicians.

Prompt palliative care referrals are also important. Frameworks for effective EOL communication could also encourage clinicians to identify an optimal time to refer the patient to palliative care. [59-60].

Difficulty in identification of a "key person" who is responsible for decisions regarding EOL care

Communication required to negotiate EOL care extends beyond the patients and the doctors. It also includes the patients' families, especially in the context of Asia, which family-oriented practices prevail [14]. Families may wish to take up the responsibility for the patient's EOL care. The involvement of multiple parties often leads to difficulty in identifying a main person to hold responsibility for making palliative care decisions.

Failure to identify a key person among family members in EOL care and conversations can cause confusion and misunderstanding, undermining decision making and contributing to a confused process which is already fraught with uncertainty [61-62]. Unclear responsibilities and responses can create contradictory expectations between the family members and the patient. Discrepancies have been observed between the last wishes of patients to follow the natural course comfortably and the desire of their family members to hold on to their loved ones for as long as possible [63-64]. Even when the decision-making responsibility is delegated to one family member, their decisions may be affected by contradicting opinions within the family [65]. To further complicate the matter, McDarby et al. [66] showed that elderly parents' EOL preferences may not be understood by their children. Consequently, misunderstanding and a lack of communication between the patients and their families emerge, resulting in confusion and disagreements in the EOL decision-making process.

Different cultural perspectives on EOL communication

Sociocultural factors play a significant role in EOL communication. In the West, individualism and autonomy are emphasised. EOL communication usually occurs between the doctor and the patient. Depending on the patient's wishes, family members may also be involved [25]. Although there are significant cultural differences between Chinese and Western regions, clinicians of Chinese contexts undertake the same EOL communication models adopted by clinicians from the West [25]. They would look for social cues such as the nonverbal communication behaviour including tone of voice, manner, and attitude, to determine the readiness of patients to engage in EOL conversations. However, the implications of these social cues may differ by cultures. Heavy reliance on social cues lead to miscommunication. In certain cultural contexts, understanding the non-verbal cues from patients are essential to perceiving their readiness with EOL communication, and to help (re)calibrate the conversation flow; thus, potentially making non-verbal communication even more crucial than the verbal content (see also [67-68]). These factors influence the agencies manifested across the multiple parties, which potentially contribute further to the EOL decision-making conflicts. Meanwhile, in Chinese contexts, EOL communication is largely affected by sociocultural factors. Decisions are made as a collective family rather than between the individual patient and doctor [69]. Studies have shown that some patients do not wish to be involved in the decision-making process of their treatments even if it concerns their own life. This belief is prevalent among Chinese patients. Due to the Chinese cultural beliefs, dying Chinese patients prefer to let their children make the EOL decisions. Bowman and Singer [14] reported that the role of family in the Chinese culture emphasises interdependency, obligation, and responsibility to others. Family members in a Chinese family are expected to be responsible for protecting the patient's health, safety, and general well-being. Chinese patients believe in their children's ability to make decisions on their behalf and sees no need for advance directives about treatment or communication on EOL needs, resulting to increased miscommunication and misunderstanding about the patient' s needs.

Similar findings were observed in Eastern countries, where Asian family members typically preferred to be involved in making EOL decisions together with, or sometimes, on behalf of the elderly patients

[25, 70-73]. In China and nations of proximity such as Korea, where Chinese culture poses significant impact, EOL decision-making tends to be a family-centred practice rather than an individual decision [72, 74-75]. Alternatively, Kato and Tamura [76] offered relational authority as another dynamic found within East Asian cultures, where family members will leave medical decisions to the clinicians. Kato and Tamura's [76] study also stresses that family members felt a great responsibility to care for their parents and that failure to continue the care, such as admitting their parents to a nursing home, led to feelings of guilt and abandonment among the family members. This is because the ideology behind it, which is constructed from traditional Confucianist and Buddhist beliefs, largely focuses on collectivism and familial responsibility. Filial piety is a key value to maintain social stability and familial harmony. Based on this premise, parents become the recipients of their adult children's care, and children of dying patients are highly trusted in making treatment plans and EOL decisions for their parents [70, 72, 74, 76]. In addition, in the East Asian context, immediate family members generally possess the power to decide whether to inform the patient of their current medical situations [25], creating a common phenomenon where the doctors would have consultations with the family caregivers prior to speaking with the patients.

Discussion

This review identified the significance of family members in EOL communication and how their engagement in EOL discussions can improve the quality of patients' EOL and death. Moreover, this review found that there is a need for Chinese and East Asian specific EOL communication model to address cultural needs of elderly patients. An important trend identified in the included studies is the accumulating body of knowledge on the significance of family on care, support, as well as communication with the patients. Open discussions initiated by clinicians are key to decreasing psychological side effects in patients and family members such as anxiety, psychological stress, and pressure [80].

Referencing to the research question, existing research about familial roles in EOL communication can be categorised into four different themes. As discussed, family can be a prominent source of decision-making conflict in EOL communication. For instance, family caregivers may have to perform the role of the patient's 'doctor' in home-based care by assessing the patient's symptoms, administering drugs, and providing hands-on care. With little to no support from professional healthcare staff, home care becomes the very source of anxiety and stress for the carer [81]. Decision-making conflicts could also occur between the family and clinicians, and the family and the patient, particularly if resources for support from professionals were limited. It goes without saying that these conflicts do affect the provision of holistic and effective care for the patient [81]. Not only that, the lack of identifying a key person responsible for EOL-decision making results in decision-making conflict. These conflicts could result in significant delays of exercising EOL treatments.

Despite the associated challenges and issues of involving family in the decision-making process, families are an important source of support for patients who are undergoing EOL care. Family support could be manifested through providing the basic needs of the patient (i.e., helping to make the patient more comfortable, offering food and drinks, etc.), monitoring the patient's emotional status, and offering immediate support and assistance [42, 46]. Family participation in EOL matters is also found to be negatively correlated with the level of psychological distress in bereaved family caregivers, implying that the more the family members engage in the patient's EOL journey, the lesser extent they experienced psychological symptoms such as anxiety and depression since the patient's departure [80,81-83]. Chui and Chan's [84] research echoes this finding, demonstrating that longer EOL discussions could significantly reduce the incidence of post-traumatic stress disorder, anxiety, and depression of the families of patients who died in the ICU. On the other hand, Mitchell et al.'s [9] findings noted that there was insufficient time for family caregivers to consider the possibility of death, as avoiding the possibility served as a coping mechanism for the caregiver, and the life-threatening aspect of the patient's condition was only acknowledged after an episode was resolved. As for the impact on the patients, Byock's [85] clinical observation revealed that despite the typical suffering at the EOL, the quality of family input during EOL discussions, such as careful, relationship-appropriate, and goal-directed EOL communications, was important for the patient's emotional wellbeing and the overall experience towards the EOL stage. Thus, quality communication between the patients and their family members are vital in improving the quality of life of dying patients during their EOL stage [41, 43, 48].

Considering the value that familial support could have, healthcare workers must learn what is important to the patients and their families, and ensure that their preferences are adequately explored, adhered to, and respected even in cases where their preferences contradict the clinician's decision. From the clinician's point of view, EOL communication is most effective when family members participate and engage in the joint decision-making discussion [20, 86]. Fostering positivity in EOL communication as a clinician was also viewed to be important [29]. When family members and patients clearly understand one another's EOL preferences, decisions on treatments and palliative care could effectively address patients' needs [82].

There is also plenty of material to discuss with the significance of timing in EOL communication. With regards to physician-family discussions, clinicians should be equipped with the competency to explain its negative effects on the patient and family members in an empathetic and compassionate way, as well as encourage communication between family members and the patients so that family members could understand the patients' wishes and explain their diagnoses [26]. Clinicians should also be educated to take on a bridging role between family members and the patients, acting as a facilitator of communication and exploring any unspoken issues that either side are intentionally avoiding. As such, with continual training and education, healthcare professionals could develop effective communication skills for palliative care and collaborate with the patients' families to provide quality EOL care. Furthermore, healthcare providers should act as mediators and advisors to assist both parties in making appropriate treatment decisions and thus enable the patients to have a "good death" [14]. The barriers and uncertainties among the patients, family members and the clinicians should be moderated to build trust and facilitate open EOL communication [63, 87].

Moreover, healthcare providers may be capable of initiating EOL conversations at optimal timing with widespread adoption of prognostic tools. When EOL discussions are conducted at optimal timing, patients' comfort and dignity during EOL could be immensely improved [52]. The Palliative Care Chart developed by Bailey et al. [48] is a tool for clinicians to assists in generating effective EOL communication, aiming to facilitate continuity and co-ordination of care and sense of partnership between patients and their families. The chart serves as a checklist for clinicians. Together with the training on use of the tool, results showed that clinicians were able to resolve ongoing concerns occurred between the patients and family members during palliative discussions. Another means to educate health care professionals to provide better palliative care is the development of quality indicators as suggested by Raijmakers et al. [30]. Clinicians can be trained to monitor different aspects of the patient according to the quality indicators, for instance, limited need for pain control, providing palliative care accordingly, and improving the patients' quality of life towards the last stages of their lives. Educational interventions may be one way to raise the awareness and significance of patient participation in EOL planning. As suggested in this review, family participation in the process of EOL discussions should also be considered. Family participation in EOL communication were shown to have positive effects on the patients' quality of EOL treatment receptions [21, 60]. However, the degree of involvement varies between Eastern and Western countries given cultural differences, requiring a Chinese and Eastern specific communication model to address the cultural implications of different regions. Chinese patients and families commonly avoid EOL communication due to Buddhism and Confucianism beliefs, which accepts that talking about death brings death closer [14]. These beliefs also emphasise a balance of physical, emotional, and social harmony, which provides a culturally sound reason for them to evade such conversations regarding palliative care and EOL decisions [14, 60]. Also, in China specifically, filial piety plays an important role in the conduct of children. In cases of medical care, the burden of making treatment decisions and EOL choices are usually delegated to the children of elderly patients [14, 24, 56, 88]. Some elderly patients may even choose to exclude themselves from the EOL communication between clinicians and family caregivers and family members would become the first and main persons to contact during the discussion about their conditions and EOL decisions [11].

In western countries, contrarily, patients and elderly people are generally familiar with palliative care. The awareness of setting up wills and arranging palliative care enable them to be relatively prepared to engage in early EOL conversations [64]. Furthermore, autonomy and self-determination are prevailing concepts, and patient's self-exclusion during medical consultation is rarely observed. Given the prevalence of individualism most patients of the Western contexts wish to make EOL decisions for themselves [68, 89]. In occasional circumstances, patients prefer to withhold information on diagnosis and treatments to their family members, this would lead to a lack of communication [90] as well as insufficient understanding of the illness among family members and hence, compromised preparedness in dealing with their beloved's EOL issues [84].

Prior research also addressed potential solutions to improve the quality and communicative environment of EOL care. Effective EOL communication is essential in creating a fulfilling EOL experience for the patients and their family members, while advance preparation could help achieve successful EOL conversations. As the majority of patients trust that their healthcare providers are capable of providing quality treatment, diagnosis, and other information regarding their illness. Clinicians could build good rapport over time and establish trust with patients [56]. This promotes patient-centred care, which is vital for effective EOL communication in both Eastern and Western contexts as the patients 'needs are always top priority when the doctors are developing medical plans. To attain such patient-oriented practices, clinicians must address the elements of 1) sensitivity to the patients' needs, personal experiences and perspectives; 2) self-participation of the patients' own recovery journey; and 3) enhancement of doctor-patient relationships.

It is also critical to keep the patients informed about their diseases. In a previous study [61], half of the respondents reported that neither were they notified about the diagnosis and prognoses, nor did they fully understand the information provided by doctors. Clinicians should have regular meetings with the patients and family members to keep them up to date on the disease progress and prognoses. Advance notification of the nature of the meeting, as well as the provision of a quiet and calm atmosphere could help decrease the anxiety of family members. Issues regarding the manner of delivery are present as well; when delivering bad news, clinicians were typically found not to have a specific goal or did not consider ahead how would the news impact the receiver [68]. All these can become obstacles in conducting effective consultation as well as disclosing the unpleasant news to the patients. To balance both medical and interpersonal needs in such difficult EOL discussions, there are developed protocols to help clinicians to better approach the conversation. One example being COMFORT model, which is a step-by-step guide on breaking bad news in a humane manner and at the same time, providing comfort to the recipient [32, 90]. SPIKES protocol, which is a six-step framework, assists doctors with proper preparation in delivering bad news while ensuring the patients' comfort and understanding of the discussion[5, 91]. Whilst these protocols were developed and validated in the Western context; since sociocultural factors play a significant role in doctor-patient communication, they may not be applicable in non-Western nations due to the different traditional beliefs in the East [92]. More specifically, the Chinese philosophy of death being a taboo subject has wide influences across many Asian countries, resulting in hesitation of prognosis disclosure to dying patients. Having communication frameworks as a guideline for clinicians to navigate around EOL conversations is plausible; yet, a formulaic approach without cultural considerations of the patients could reduce patient satisfaction. Clinicians therefore need to adapt to families on a case-by-case basis while considering the nuances of patient perspective, context of the discussion, and content of the conversation so that they can adjust the communication accordingly [11].

Lastly, clinicians should attend to the family caregivers' expectations according to the cultural context. They need to understand and respect the expectations of the patient and their family regarding the treatment. Differences in preferences and the lack of communication between medical professionals and patients are known to create conflicts. Careful listening and understanding the patients' preferences enhance the quality of patients' dying process [23]. In addition, a one-size-fits-all approaches does not work in EOL communication due to the variety of factors [24]. It is essential to improvise discussions according to each patient and family needs. Moreover, keeping the general cultural guidelines in mind enables clinicians to connect with their patients more precisely in respect of different scenarios regardless of the cultural backgrounds of both parties. More research is warranted to investigate how clinicians could and should communicate with different patients, by looking for the best model to assess the need and preference in communication. Medical staff must be trained to be prepared for providing a smooth EOL communication experience to patients based on their cultural backgrounds and practice [24].

Strengths and limitations of the study

This review has synthesized the research findings from a range of diversified data sources in order to produce a comprehensive view towards the understanding of family role in EOL communication. To our best of knowledge, there is limited research on exploring the role of family in EOL communication, this review fills in the gap by highlighting the importance of culture and how it can affect the beliefs and roles of families in EOL decision-making. Better family oriented EOL communication suggests that family participation will likely lead to improved quality of life and death in patients, managing family expectations during prognosis disclosure and facilitating patients' fulfilment of familial roles while making EOL decision-making. While patients from the East depend on their family members to make EOL decisions, this paper urges for a family-oriented framework which helps patients to fulfil their social role in the family.

There are several limitations in this review. First, the literature search only includes four databases, with only 53 eligible included articles and many are quantitative studies, leading to a possible bias of the literature representation. Second, studies written in other languages were not included. Only those fully published in English were reviewed and included in this study, which may have skewed our findings and interpretations. The included articles were not be able to cover all aspects of family in EOL communication, which may have affected the generalisability of the findings. Third, in our analysis, we use the signposting of 'the East and the West' which is beneficial in distinguishing EOL communicative practices across different cultural contexts, we also acknowledge the generalizability of such labelling; there are many additional factors which contribute to the complexity of EOL communication. Readers are reminded to interpret the findings cautiously due to a number of studies included in this review are emerged from East Asian context.

Conclusion

This review identified the important and unique roles of family caregivers in EOL communication and the pressing need to develop an EOL communication framework designed for the Chinese and Eastern contexts. The reviewed studies indicated that family engagement in EOL discussions is beneficial for both patients and their family members. Knowledge about the patient's diagnosis and prognosis information factoring in EOL decisions will facilitate fruitful communication among healthcare providers, patients and family members. Clinicians should identify and remove barriers to enable sufficient understanding of the information desired by each party, tackle collusions tactfully, and bridge the gap between the parties if direct communication is difficult and distressing. The timing of EOL communication and communicative content are important, especially in circumstances where clinical deterioration is inevitable. Existing palliative care communication frameworks, such as the COMFORT model and SPIKES protocol could be modified according to the implications of this review to fit the family-oriented cultures in Chinese and Eastern contexts. With such guiding principles, clinicians will be able to engage and discuss EOL issues with patients confidently, thus performing a well-rounded EOL communication practice.

The current review identified four significant themes that presented the roles of family caregivers in EOL communication. Many of the articles in the review search in the results and discussion show the involvement of family members in EOL decision-making. Clinicians should acknowledge the significance of families' views during the decision-making process. It is paramount to respect and understand the decisions of the patient and the family, while also acting as a bridge to mediate between them and facilitate open discussions. Clinicians can also use prediction models or prognostic tools to predict the patients' survival time to ensure a timely EOL conversation to prepare for the end of their life.

Previous studies showed that programs introducing advance care planning and acculturation could successfully encourage patients to participate in EOL communication with their palliative care team and family caregivers [24, 56]. However, while previous palliative care tools have shown to improve doctor-patient interaction, a lot of them do not focus on further factors that contextualise and complicate EOL communication, such as sociocultural factors, patient-centred care, and patient autonomy. Palliative care tools can be designed to be inclusive of family involvement in EOL communication, reflecting both the role of family members and patients' individual role with respect to their families. Regarding clinicians and practitioners' EOL communication praxis, our recommendations are twofold. The first is to be continually aware of the cultural implications. The second is for clinicians to be trained so that they can help the patient negotiate personal and familial obligations while undergoing EOL treatments.

Availability of data and materials

All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate

Not applicable. All the work was developed using published data.

Consent to participate

Not applicable.

Competing interest

None.

Funding
Not applicable.

Authors' contributions

JKHP contributed to the conception and design of the study. KMC, LF and CHJC revised the study protocol. JKHP, KMC, LF and CHJC contributed to the acquisition and analysis of data. JKHP evaluated the risk of bias of the included studies. JKHP and KMC interpreted the data. JKHP, LF and KMC drafted the manuscript. All the authors critically revised the manuscript and gave the final approval of the version to be published.

Acknowledgement
Not applicable.

References

1. Buckman R. Communication in palliative care: a practical guide. Death, Dying and Bereavement. 2nd edn. *Sage, London.* 2000 Dec 8:146-73.
2. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA internal medicine.* 2014 Dec 1;174(12):1994-2003.
3. Clayton JM, Hancock KM, Butow PN, Tattersall MH, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia.* 2007 Jun 18;186(12):S77.
4. Odgers J, Fitzpatrick D, Penney W, Shee AW. No one said he was dying: families' experiences of end-of-life care in an acute setting. *Australian Journal of Advanced Nursing*. 2018 Mar;35(3):21-31.
5. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *The oncologist.* 2000 Aug;5(4):302-11.
6. Simpson N, Knott CI. Stress and burnout in intensive care medicine: an Australian perspective. *Med J Aust.* 2017 Feb 20;206(3):107-8.
7. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: associations with end-of-life conversations. *Archives of internal medicine.* 2009 Mar 9;169(5):480-8.
8. Maubach N, Batten M, Jones S, Chen J, Scholz B, Davis A, Bromley J, Burke B, Tan R, Hurwitz M, Rodgers H. End-of-life care in an Australian acute hospital: a retrospective observational study. *Internal medicine journal.* 2019 Nov;49(11):1400-5.
9. Mitchell S, Slowther AM, Coad J, Dale J. Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation. Archives of Disease in Childhood. 2020 Nov 16; 106:570-576.
10. Ng GW, Pun JK, So EH, Chiu WW, Leung AS, Stone YH, Lam CL, Lai SP, Leung RP, Luk HW, Leung AK. Speak-up culture in an intensive care unit in Hong Kong: a cross-sectional survey exploring the communication openness perceptions of Chinese doctors and nurses. *BMJ open.* 2017 Aug 1;7(8):e015721.
11. Pun JK, Cheung KM, Chow JC, Chan WL. Chinese perspective on end-of-life communication: a systematic review. *BMJ Supportive & Palliative Care.* 2020 Jul 9.

12. Hawryluck L. Communication with patients and families. *Ian Anderson Continuing Education Program in End-of-Life Care.* 2000.
13. Food and Health Bureau. End-of-life Care: Legislative Proposals on Advanced Directives and Dying in Place – Consultation Document. 2019 Sep https://www.fhb.gov.hk/download/press_and_publications/consultation/190900_eolcare/e_EOL_care_legisiative_proposals.pdf.
14. Bowman KW, Singer PA. Chinese seniors' perspectives on end-of-life decisions. *Social science & medicine.* 2001 Aug 1;53(4):455-64.
15. Wang X, Huang Y, Radha Krishna L, Puvanendran R. Role of the Nasogastric Tube and Lingzhi (Ganoderma lucidum) in Palliative Care. *Journal of Pain and Symptom Management*. 2016 Apr;51(4):794-9.
16. Peng NH, Liu HL, Chen CH, Bachman J. Cultural practices and end-of-life decision making in the neonatal intensive care unit in Taiwan. *Journal of Transcultural Nursing*. 2012 Jul;23(3):320-6.
17. Miljeteig I, Johansson KA, Sayeed SA, Norheim OF. End-of-life decisions as bedside rationing. An ethical analysis of life support restrictions in an Indian neonatal unit. *Journal of Medical Ethics*. 2010 Aug;36(8):473-8.
18. Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *General hospital psychiatry.* 2010 Jul 1;32(4):433-42.
19. Leung DY, Chan HY, Yau SZ, Chiu PK, Tang FW, Kwan JS. A video-supported nurse-led advance care planning on end-of-life decision-making among frail older patients: Protocol for a randomized controlled trial. *Journal of advanced nursing.* 2019 Jun;75(6):1360-9.
20. Ohs JE, Trees AR, Gibson C. Holding on and letting go: Making sense of end-of-life care decisions in families. *Southern Communication Journal.* 2015 Oct 20;80(5):353-64.
21. Keeley MP. Family communication at the end of life. Behavioral Sciences, 7, 45.
22. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C, Canoui P, Le Gall JR, Schlemmer B. Half the families of intensive care unit patients experience inadequate communication with clinicians. *Critical care medicine.* 2000 Aug 1;28(8):3044-9.
23. Fan Z, Chen L, Meng L, Jiang H, Zhao Q, Zhang L, Fang CK. Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff. *Supportive Care in Cancer.* 2019 Feb 1;27(2):583-9.
24. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The gerontologist.* 2005 Oct 1;45(5):634-41.
25. Wang Q. Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US. 2010.
26. Low JA, Kiow SL, Main N, Luan KK, Sun PW, Lim M. Reducing collusion between family members and clinicians of patients referred to the palliative care team. *The Permanente Journal.* 2009;13(4):11.
27. Lo RS, Woo J, Zhoc KC, Li CY, Yeo W, Johnson P, Mak Y. Cross-cultural validation of the McGill Quality of Life questionnaire in Hong Kong Chinese. *Palliative medicine.* 2001 Jul;15(5):387-97.
28. Almack K, Cox K, Moghaddam N, Pollock K, Seymour J. After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC palliative care.* 2012 Dec;11(1):1-0.
29. Kastbom L, Karlsson M, Falk M, Milberg A. Elephant in the room - Family members' perspectives on advance care planning. *Scandinavian journal of primary health care*. 2020 Nov 11;38(4):421-429.
30. Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, Popa-Velea O, Romotzky V, Schuler S, Ellershaw J, Ostgathe, on behalf of OPCARE9 C. Quality

indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. *Journal of palliative medicine.* 2012 Mar 1;15(3):308-16.

31. The English Parliamentary and Health Service Ombudsman. *The Ombudsman's Annual Report and Accounts 2015-16* (Rep.). 2016 Nov 3. Retrieved https://www.ombudsman.org.uk/sites/default/files/PHSO_Annual_Report_2015-16.pdf.
32. Wittenberg E, Goldsmith JV, Ragan SL, Parnell TA. Communication in palliative nursing: The COMFORT Model. *Oxford University Press.* 2019 Dec 24.
33. Paré K, Grudziak J, Lavin K, Sten MB, Huegerich A, Umble K, Twer E, Reid T. Family perceptions of palliative care and communication in the surgical intensive care unit. *Journal of Patient Experience*. 2021 July 14;8.
34. Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative medicine*. 2019 Sep;33(8):926-41.
35. Coombs MA, Parker R, Ranse K, Endacott R, Bloomer MJ. An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care. *Journal of advanced nursing*. 2017 Jan;73(1):39-55.
36. Lowey, SE. Communication between the Nurse and Family Caregiver in End-of-Life Care: A Review of the Literature. *Journal of hospice and palliative nursing*. 2008 Jan;10(1):35-45.
37. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*. 2007 Jul;34(1):81-93.
38. Pun JKH, Chan EA, Wang S, Slade D. Health professional-patient communication practices in East Asia: An integrative review of an emerging field of research and practice in Hong Kong, South Korea, Japan, Taiwan, and Mainland China. *Patient education and counselling*. 2018 Jul;101(7):1193-1206.
39. Thomas H, Ciliska D, Dobbins M. Quality assessment tool for quantitative studies. Toronto: Effective Public Health Practice Project McMaster University. 2003.
40. Joanna Briggs Institute. JBI critical appraisal checklist for qualitative research. Retrieved from http://joannabriggs.org/assets/docs/criticalappraisal-tools/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017. pdf. 2017.
41. Githaiga JN, Swartz L. Socio-cultural contexts of end-of-life conversations and decisions: bereaved family cancer caregivers' retrospective co-constructions. *BMC palliative care.* 2017 Dec;16(1):1-8.
42. Lee MK, Yun YH. Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study. *Cancer nursing.* 2018 May 1;41(3):E1-0.
43. Royak-Schaler R, Gadalla SM, Lemkau JP, Ross DD. Family perspectives on communication with healthcare providers during end-of-life cancer care. In Oncology nursing forum 2006 Jul 1 (Vol. 33, No. 4, p. 753). Oncology Nursing Society.
44. Towsley GL, Hirschman KB, Madden C. Conversations about end of life: perspectives of nursing home residents, family, and staff. *Journal of Palliative Medicine.* 2015 May 1;18(5):421-8. doi:10.1089/jpm.2014.0316
45. Shaunfield SL. "IT'SA VERY TRICKY COMMUNICATION SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN. *Theses and Dissertations--Communication* 2015;43. https://uknowledge.uky.edu/comm_etds/43.
46. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.

47. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
48. Bailey S, Sellick SM, Setliff AE, Linkewich B, Kelley ML, Poling M. Communication at life's end [A patient held palliative care chart facilitates communication]. *The Canadian Nurse.* 1999 May 1;95(5):41.
49. Kramer BJ, Kavanaugh M, Trentham-Dietz A, Walsh M, Yonker JA. Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer. *The Gerontologist.* 2010 Apr 1;50(2):215-25.
50. Kotecho M, Adamek ME. Gender differences in quality of life of urban elders in Ethiopia. *Innovation in Aging.* 2017 Jul;1(Suppl 1):879.
51. Shin DW, Cho J, Kim SY, Chung IJ, Kim SS, Yang HK, Ahn E, Park BR, Seo H, Park JH. Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. *Psycho-Oncology.* 2015 Feb;24(2):212-9.
52. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between clinicians and family caregivers about care at the end of life: when do discussions occur and what is said?. *Journal of palliative medicine.* 2005 Dec 1;8(6):1176-85.
53. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.
54. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
55. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation: benefit or harm?. *Jama.* 1995 Sep 13;274(10):826-9.
56. Huang HL, Chiu TY, Lee LT, Yao CA, Chen CY, Hu WY. Family experience with difficult decisions in end-of-life care. *Psycho-Oncology.* 2012 Jul;21(7):785-91. Doi: 10.1002/pon.3107
57. Lind R, Lorem GF, Nortvedt P, Hevrøy O. Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. *Intensive care medicine.* 2011 Jul;37(7):1143-50.
58. El-Jawahri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, Kamdar M, Jacobsen J, Chittenden EH, Rinaldi SP, Gallagher ER. Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial. *The oncologist.* 2017 Dec;22(12):1528. Doi: 10.1634/theoncologist.2017-0227
59. Hui D, Kim SH, Roquemore J, Dev R, Chisholm G, Bruera E. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer.* 2014 Jun 1;120(11):1743-9.
60. Rhoads S, Amass T. Communication at the End-of-Life in the Intensive Care Unit: A Review of Evidence-Based Best Practices. *Rhode Island Medical Journal.* 2019 Dec 1;102(10).
61. Biola H, Sloane PD, Williams CS, Daaleman TP, Williams SW, Zimmerman S. Physician communication with family caregivers of long-term care residents at the end of life. *Journal of the American Geriatrics Society.* 2007 Jun;55(6):846-56.
62. Chan WC. Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?. *Journal of palliative medicine.* 2011 Sep 1;14(9):997-1003.
63. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. Patient and Family Related Barriers of Integrating End-of-Life Communication into Advanced Illness Management. *Journal of Pain and Symptom Management.* 2018 Dec 1;56(6):e58-9.

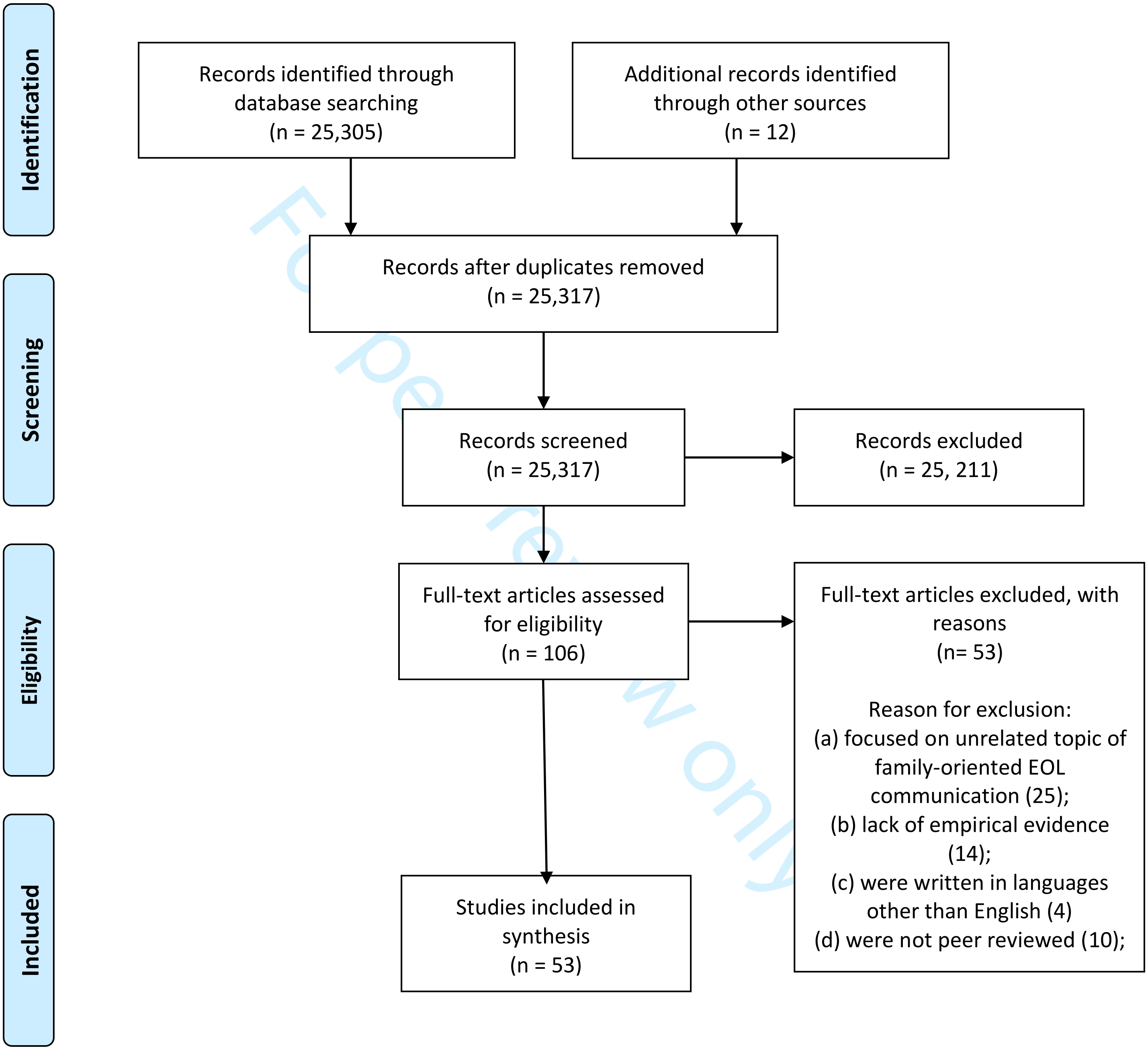
64. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. "Whatever happens, happens" challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study. *BMC palliative care.* 2019 Dec;18(1):1-9.
65. Trees AR, Ohs JE, Murray MC. Family communication about end-of-life decisions and the enactment of the decision-maker role. *Behavioral Sciences.* 2017 Jun;7(2):36.
66. McDarby M, Picchiello M, Kozlov EK, Ju C, Worthalter D, Carpenter B. ADULT CHILDREN'S UNDERSTANDING OF PARENTS'CARE AND LIVING PREFERENCES AT END OF LIFE. *Innovation in Aging.* 2019 Nov;3(Supplement_1):S668-9. doi:10.1093/geroni/igz038.2473
67. McElroy JA, Proulx CM, Johnson L, et al. Breaking bad news of a breast cancer diagnosis over the telephone: an emerging trend. *Supportive care in cancer* 2019 Mar; 27(3): 943-950.
68. Schonfeld TL, Stevens EA, Lampman MA, et al. Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities. *American journal of hospice and palliative medicine* 2012 Jun; 29(4): 260-267.
69. Ayers NE, Vydelingum V, Arber A. An ethnography of managing emotions when talking about life-threatening illness. *International nursing review.* 2017 Dec;64(4):486-93.
70. Chan WC, Epstein I, Reese D, Chan CL. Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the "support paradox". *Social Work in Health Care.* 2009 Jul 8;48(5):519-32.
71. Ho AH, Chan CL, Leung PP, Chochinov HM, Neimeyer RA, Pang SM, Tse DM. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age and ageing.* 2013 Jul 1;42(4):455-61.
72. Tse CY, Chong A, Fok SY. Breaking bad news: a Chinese perspective. *Palliative medicine.* 2003 Jun;17(4):339-43. Doi: 10.1191/0269216303pm751oa
73. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
74. Ko E, Roh S, Higgins D. Do older Korean immigrants engage in end-of-life communication?. *Educational Gerontology.* 2013 Aug 1;39(8):613-22.
75. Zheng RS, Guo QH, Dong FQ, Owens RG. Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study. *International journal of nursing studies.* 2015 Jan 1;52(1):288-96.
76. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
77. Bryman A. Social research methods. Oxford university press; 2016.
78. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC medical research methodology. 2008 Dec;8(1):1-0.
79. Peters MD. Managing and coding references for systematic reviews and scoping reviews in EndNote. Medical Reference Services Quarterly. 2017 Jan 2;36(1):19-31.
80. Abbey JG. Communication about end-of-life topics between terminally ill cancer patients and their family members. 2008.
81. Salifu Y, Almack K, Caswell G. 'My wife is my doctor at home': A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative medicine.* 2021 Jan;35(1):97-108.
82. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of the American Geriatrics Society.* 1997 Nov;45(11):1339-44.
83. Scott AM. Family conversations about end-of-life health decisions. University of Illinois at Urbana-Champaign; 2010.

84. Chui WY, Chan SW. Stress and coping of Hong Kong Chinese family members during a critical illness. *Journal of clinical nursing.* 2007 Feb;16(2):372-81.
85. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clinics in geriatric medicine.* 1996 May 1;12(2):237-52.
86. Ohs JE, Trees AR, Kurian N. Problematic integration and family communication about decisions at the end of life. *Journal of Family Communication.* 2017 Oct 2;17(4):356-71.
87. Van den Heuvel LA, Hoving C, Schols JM, Spruit MA, Wouters EF, Janssen DJ. Barriers and facilitators to end-of-life communication in advanced chronic organ failure. *International journal of palliative nursing.* 2016 May 2;22(5):222-9.
88. Peterson LJ, Hyer K, Meng H, Dobbs D, Gamaldo A, O'Neil K. Factors associated with whether older adults discuss their EOL care preferences with family members. *Innovation in Aging.* 2018 Nov;2(suppl_1):843. doi:10.1093/geroni/igy023.3141
89. Colletti L, Gruppen L, Barclay M, Stern D. Teaching students to break bad news. *The American journal of surgery.* 2001 Jul 1;182(1):20-3.
90. Villagran M, Goldsmith J, Wittenberg-Lyles E, Baldwin P. Creating COMFORT: A communication-based model for breaking bad news. *Communication Education.* 2010 Jul 1;59(3):220-34.
91. Schapira L. Delivering bad news to patients and their families. *Tumors of the Chest* 2006 (pp. 597-605). Springer, Berlin, Heidelberg.
92. Labaf A, Jahanshir A, Shahvaraninasab A. Difficulties in using Western guidelines for breaking bad news in the emergency department: the necessity of indigenizing guidelines for non-Western countries. *Journal of Medical Ethics & History of Medicine.* 2014 Jan 1;7(1).

---

[1] To avoid conflating EOL and palliative care, we mainly include studies that are primary focus on EOL topic but we note that some EOL studies may contain topic such as palliative care.

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix 1. Search strategy details

Search logic are also used to assist the search through using Boolean operators such as AND, the search logic allows different combinations to access the most relevant studies, e.g. ‘end of life’ AND ‘communication’ AND ‘family’. All searches were limited to publication dates 1991 to 2021, English language only. The following is a summary of the search strategy in each of the included databases.

1. PsycINFO

Primary keywords and search string using “advanced search” tool; limited to abstracts:

Primary keywords and search string:

abstract((family) OR (parent*) OR (caregiver*)) AND abstract((communicat*) OR (communication skill*)) AND abstract((“end of life”) OR (end-of-life) OR (EOL) OR (terminal) OR (terminally ill)) AND pd(19910101-20211231))

2. Embase

Search string:

((‘family’/exp) OR (parent*) OR (caregiver*)) AND ((communicat*) OR (communication skill*)) AND ((end of life) OR (end-of-life) OR (EOL) OR ((terminal) OR (terminally ill))

3. MEDLINE

Search string:

((“family”) OR (“parent*” OR “parent+”) OR (“caregiver*” OR “caregiver+”)) AND ((“communicat*” OR “communication+”) OR (“communication skill*”)) AND ((“end of life”) OR (“end-of-life”) OR ((“terminal”) OR (“terminally ill”))

4. Ovid nursing database

Primary keywords and search string:

((family) OR (parent*) OR (caregiver*)) AND abstract((communicat*) OR (communication skill*)) AND ((“end of life”) OR (end-of-life) OR (EOL) OR (terminal) OR (terminally ill))

Appendix 2 Summary of each included study.

Theme	Author(s)	Article	Objective(s)	Research design	Sample
1	Abbey, 2008 [41]	Communication about end-of-life topics between terminally ill cancer patients and their family members	To explore EOL communication by addressing patient-family communications	Quantitative - Questionnaire	369 patients
1	Bailey et al., 1999 [55]	Communication at life's end [A patient held palliative care chart facilitates communication]	To promote effective communication, the continuity and co-ordination of care, and sense of partnership for patients and their families through developing a care chart relating to palliative communication	Qualitative - Interviews	40 families and health care providers
1	Byock, 1996 [42]	The nature of suffering and the nature of opportunity at the end of life	To explore the personal experience of suffering in life-limiting illness and to understand the nature of opportunity at the end of life.	Qualitative - Clinical observation	N/A
1	Chui & Chan, 2007 [43]	Stress and coping of Hong Kong Chinese family members during a critical illness	To assess how families cope with stress during a family members' admission to ICU and the relationships between stress and coping	Qualitative - Structured interview	133 participants
1	Fan et al., 2019 [23]	Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff	To study the preferences of cancer patients and their families in way of being informed of their conditions and explore the factors in the underlying preferences	Quantitative - Questionnaire	216 cancer patients 242 family caregivers 176 clinical staff members

1	Githaiga & Swartz, 2017 [44]	Socio-cultural contexts of end-of-life conversations and decisions: bereaved family caregivers' retrospective co-constructions	To examine the content and context of EOL conversations and decisions based on family caregivers of cancer patients in resource-limited areas.	Qualitative - Focus group interview	13 participants
1	Hanson et al., 1997 [45]	What is wrong with end-of-life care? Opinions of bereaved family members	To explore family perceptions of EOL care and communication	Qualitative - Interview	461 family members
1	Kastbom et al., 2020 [29]	Elephant in the room - Family members' perspectives on advance care planning	To explore family members' experiences of advance care planning and EOL communication	Qualitative - Interview	18 family members of deceased nursing home patients
1	Kotecho & Adamek, 2017 [57]	Gender differences in quality of life of urban elders in Ethiopia	To explore how death of a resident affects Certified Nursing Assistants in terms of impacts and support they received.	Qualitative - Semi-structured interviews	140 participants
1	Kramer et al., 2010 [56]	Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer	To examine the correlates and predictors of family conflict at the end of life	Quantitative - Surveys	155 participants
1	Lee & Yun, 2018 [46]	Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study	To determine whether family caregiver functioning predicts EOL Quality of life received by terminally ill patients with cancer	Quantitative - Questionnaire	264 family caregivers of terminally ill patients
1	Mitchell et al., 2020 [9]	Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening	To understand experiences of healthcare services concerning children with life-limiting conditions and their family members	Qualitative - Interview	31 family members including 10 children

		conditions and their families: a longitudinal qualitative investigation			
1	Ohs et al., 2015 [20]	Holding on and letting go: Making sense of end-of-life care decisions in families	To understand how family members make EOL care decisions and their discursive contradictions that appears during the process	Qualitative - Interview	15 family caregivers of cancer patients
1	Ohs et al., 2017 [47]	Problematic integration and family communication about decisions at the end of life	To examine how families make decisions on behalf of their dying family members at the end of life and how they manage the stressful situation	Qualitative - Interview	22 family members who engaged in EOL conversations
1	Royak-Schaler et al., 2006 [48]	Family perspectives on communication with healthcare providers during end-of-life cancer care	To assess healthcare provider communication on EOL with patients and their family members	Mixed method - Focus group discussions and questionnaires	24 family members of deceased patients
1	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
1	Shaunfield, 2016 [51]	“IT’S A VERY TRICKY COMMUNICATION SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY	To explore the communication stressors experienced by family caregivers to examine why communication tasks are perceived as difficult	Qualitative - Interviews	40 caregivers

		CAREGIVER COMMUNICATION BURDEN			
1	Shin et al., 2015 [49]	Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices	To assess cancer patient preferences, family caregiver preferences, and family caregiver predictions of patient preferences regarding the disclosure of terminal status, family involvement in the disclosure process, and EOL choices	Quantitative - Cross-sectional survey	990 patients
1	Towsley et al., 2015 [22]	Conversations about End of Life: Perspectives of Nursing Home Residents, Family, and Staff	To describe the communication, content and process related to EOL conversations among nursing home residents, family and staff	Qualitative - Semi-structured interview	16 residents 12 family members 10 staff members
1	Wong & Chan, 2006 [53]	The qualitative experience of Chinese parents with children diagnosed of cancer	To describe the coping experience of Chinese parents with children diagnosed as having cancer during the treatment stage	Qualitative - Interview	9 parents with children diagnosed with cancer
1	Zhang & Siminoff, 2003 [54]	Silence and Cancer: Why Do Families and Patients Fail To Communicate?	To examine how patients with cancer and their family members make treatment decisions together, and to explore the avoidance of communication and issues families face	Qualitative - Interview	64 participants
2	Azoulay et al., 2000 [22]	Half the families of intensive care unit patients experience inadequate communication with physicians	To explore the needs of family members of patients with terminal illness in order to improve communication and ease their burden	Quantitative - Prospective study	102 ICU patients

2	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
2	Carrese & Rhodes, 1995 [60]	Western bioethics on the Navajo Reservation: Benefit or harm?	To explore the influence of Western biomedical and ethical principles on Navajo values, and how it affects the quality of health care	Qualitative - Interview	34 Navajo people
2	Cherlin et al., 2005 [61]	Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said?	To examine family caregivers' communication with physicians on illness, life expectancy, hospice, EOL discussion timing and their understanding on these issues.	Qualitative - Survey and interviews	218 family caregivers
2	El-Jawahri et al., 2017 [62]	Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial	To explore the influence of early integrated palliative care on patients and evaluate caregivers' stress and quality of life	Quantitative - Clinical trail	350 patients
2	Gamble et al., 1991 [63]	Knowledge, attitudes, and behavior of elderly persons regarding living wills	To explore elderly's knowledge, attitude and behavior regarding living wills	Quantitative - Questionnaire	75 elders
2	Gonella et al., 2020 [87]	A qualitative study of family carers views on how end-of-life communication	To explore how EOL communication may contribute to palliative care in nursing homes.	Qualitative - Interview	32 bereaved family carers from 13 different nursing homes

		contributes to palliative-oriented care in nursing home			
2	Gutierrez, 2013 [64]	Prognostic categories and timing of negative prognostic communication from critical care physicians to family members at end- of-life in an intensive care unit	To explore how physicians communicate negative prognoses to families and the influence of timing	Qualitative - Observations and interviews	7 critical care attending physicians 3 critical care fellows 20 family members of patients
2	Huang et al., 2012 [65]	Family experience with difficult decisions in end-of-life care	To determine the frequency and difficulty of decision making in EOL care and its related factors	Quantitative - Questionnaires	302 family caregivers
2	Hui et al., 2014 [58]	Impact of timing and setting of palliative care referral on quality of end- of-life care in cancer patients	To examine the association between timing and setting of palliative care referral and the quality of EOL care	Quantitative – Retrospective cohort study	366 adult patients who died of advanced cancer
2	Lind et al., 2011 [66]	Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions	To examine patients' family members experience of EOL decision making and the process of making the decisions	Qualitative - Interviews	27 family members
2	Low et al., 2009 [26]	Reducing collusion between family members and clinicians of patients referred to the palliative care team	To explore the rate of collusion among family members and clinicians. And to reduce the rate of collusion through the project	Qualitative - Clinical practice improvement project (defining the problem, establish strategies for intervention)	655 patients
2	Ohs et al., 2017 [47]	Problematic integration and family communication	To examine how families make decisions on behalf of their dying family members at	Qualitative - Interview	22 family members who engaged in EOL conversations

		about decisions at the end of life	the end of life and how they manage the stressful situation		
2	Rhoads & Amass, 2013 [59]	Communication at the End-of- Life in the Intensive Care Unit: A Review of Evidence- Based Best Practices	To explore the current data and recommendations on the care of patients in ICU at the end of life	Qualitative	N/A
2	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
3	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
3	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors
3	Chan, 2011 [68]	Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?	To explore the relationships among the patient's awareness of the prognosis, the family's awareness of the prognosis, the patient's anxiety, and difficulty in communicating with family members	Qualitative - Clinical records of deceased cancer patients in a palliative care unit of a public hospital	935 Patients
3	Im et al., 2018 [69]	Patient and Family Related Barriers of Integrating End-	To explore the barriers EOL communication from the	Qualitative - Semi-structured interviews	19 patients with advanced heart failures and their

		of-Life Communication into Advanced Illness Management	perspective of the patients and their family members		family caregivers
3	Im et al., 2019 [70]	"Whatever happens, happens" challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study	To explore the challenges of EOL communication among older adults and their family care-givers, as well as to understand the illness and goals of care among patients in advanced heart failure.	Qualitative - Semi-structured interviews	22 participants
3	McDarby et al., 2019 [71]	Adult Children's Understanding of Parents' Care and Living Preferences at End of Life	To examine how contact between patients and adult children relate to EOL conversations	Quantitative - Questionnaires	66 adult children 36 older adult patients
3	Trees et al., 2017 [72]	Family communication about end-of-life decisions and the enactment of the decision- maker role	To explore how families enacts their roles as decision makers for their family members who are at the end of their lives	Qualitative - Interview	22 participants
3	Van den Heuvel et al., 2016 [73]	Barriers and facilitators to end-of-life communication in advanced chronic organ failure	To identify the challenges, facilitators and agreement to EOL communication among family members and patients	Qualitative - Interview	158 patients and family caregiver
4	Ayers et al., 2017 [74]	An ethnography of managing emotions when talking about life-threatening illness	To explore how dying patients, palliative care staff and family caregivers communicate about life-threatening illness in Ethiopia	Qualitative - Observations and ethnographic interviews	4 patients. 6 family caregivers and 5 palliative care staff
4	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors

4	Chan et al., 2009 [75]	Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the “support paradox”	To explore the relationship of family- related factors and psychosocial outcomes among HK Chinese cancer patients in palliative care.	Qualitative - Clinical records and interviews	935 patients
4	Fielding & Hung, 1996 [76]	Preferences for information and involvement in decisions during cancer care among a Hong Kong Chinese population	To assess differences that between Western and Asia cancer patients’ preferences for information on diagnosis, prognosis and treatment options and involvement in treatment decision making	Quantitative - Telephone survey	1136 cancer patients
4	Ho et al., 2013 [79]	Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong	To examine the concept of ‘living and dying with dignity’ in Chinese context; and how the dignity model influenced older terminal patients in Hong Kong	Qualitative - Interview	16 patients
4	Kato & Tamura, 2020 [88]	Family Members’ Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members’ Narratives	To explain the meaning of continuous EOL discussion for family members	Qualitative - Semi-structured interviews	13 family members of residents from 3 nursing homes in Kyoto
4	Ko et al., 2013 [77]	Do Older Korean Immigrants Engage in End-	To understand patients’ communication with	Quantitative - Questionnaire	195 older Korean immigrants

		of-Life Communication ?	family and their healthcare providers on EOL care among older Korean immigrants		
4	Peterson et al., 2018 [78]	Factors associated with whether older adults discuss their EOL care preferences with family members	To examine the factors associated with EOL care wishes discussions with family, especially race and ethnicity	Quantitative - Survey	364 participants
4	Tse et al., 2003 [80]	Breaking bad news: a Chinese perspective	To address this difference in attitudes, the ethical principles for and against disclosure are analysed, considering the views in Chinese philosophy, sociological studies and traditional Chinese medicine	Qualitative	N/A
4	Wang, 2010 [25]	Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US	To examine the relationship between doctor and patient in the Chinese context and the differences with the US	Mixed method -Survey and interview	Survey: 1097 Chinese and 1280 Americans Interview: 26 Chinese
4	Zheng et al., 2015 [81]	Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study	To elucidate Chinese oncology nurses' experience of caring for dying cancer patients	Qualitative - Interview	28 nurses

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	N/A
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	4-6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	4-6
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	4-6
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	4-6
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	4-6
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	4-6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	4-6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	4-6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	4-6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	4-6
Certainty	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	4-6

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	6-10
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	6-10
Study characteristics	17	Cite each included study and present its characteristics.	6-10
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	6-10
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	6-10
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	6-10
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	6-10
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	6-10
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	6-10
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	6-10
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	6-10
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	10-12
	23b	Discuss any limitations of the evidence included in the review.	10-12
	23c	Discuss any limitations of the review processes used.	10-12
	23d	Discuss implications of the results for practice, policy, and future research.	10-12
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

PRISMA 2020 Checklist

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

The Role of Patients’ Family Members in End-Of-Life Communication: An Integrative Review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-067304.R3
Article Type:	Original research
Date Submitted by the Author:	09-Dec-2022
Complete List of Authors:	Pun, Jack; City University of Hong Kong, Department of English Chow, James C. H.; Queen Elizabeth Hospital, Department of Clinical Oncology FOK, Leslie; Queen Elizabeth Hospital, Department of Clinical Oncology CHEUNG, Ka Man; Queen Elizabeth Hospital, Department of Clinical Oncology
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health services research, Patient-centred medicine
Keywords:	PALLIATIVE CARE, ONCOLOGY, MEDICAL EDUCATION & TRAINING

TITLE PAGE

Title: The Role of Patients' Family Members in End-Of-Life Communication: An Integrative Review

Authors: Jack PUN[a], Chung Hang James CHOW[b], Leslie FOK[b], Ka Man CHEUNG[b]

Affiliations:
a-Department of English, City University of Hong Kong, Hong Kong SAR, China
b-Department of Clinical Oncology, Queen Elizabeth Hospital, Hong Kong SAR, China

Postal addresses:
a-Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong SAR, China.
b-Department of Clinical Oncology, Queen Elizabeth Hospital, 30 Gascoigne road, Kowloon, Hong Kong SAR, China.

Emails:
Jack PUN: jackpun@me.com
Leslie FOK: fl684@ha.org.hk
James Chung Hang CHOW: cch932@ha.org.hk
Ka Man CHEUNG-ckm792@ha.org.hk

Corresponding author:
Jack PUN
Email: jackpun@me.com
Postal address: Department of English, City University of Hong Kong, 83, Tat Chee Avenue, Kowloon, Hong Kong.

ABSTRACT

Objectives: To synthesise empirical findings on the role of family in end-of-life (EOL) communication and to identify the communicative practices that are essential for EOL decision-making in family-oriented cultures.

Setting: The end-of-life (EOL) communication settings.

Participants: This integrative review followed the PRISMA reporting guideline. Relevant studies published between 1st January 1991 and 31st December 2021 were retrieved from four databases, including the PsycINFO, Embase, MEDLINE, and Ovid nursing databases, using keywords with meanings of "end-of-life", "communication" and "family". Data were then extracted and coded into themes for analysis. The search strategy yielded 53 eligible studies; all 53 included studies underwent quality assessment. Quantitative Studies were evaluated using the Quality Assessment Tool, and Joanna Briggs Institute Critical Appraisal Checklist was used for Qualitative Research.

Primary and secondary outcome measures: Research evidence on EOL communication with a focus on family.

Results: Four themes emerged from these studies: 1) Conflicts in family decision-making in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a "key person" who is responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Conclusions: The current review pointed towards the importance of family in EOL communication and illustrated that family participation likely leads to improved quality of life and death in patients. Future research should develop a family-oriented communication framework which is designed for the Chinese and Eastern contexts that targets on managing family expectations during prognosis disclosure and facilitating patients' fulfilment of familial roles while making EOL decision-making. Clinicians should also be aware of the significance of the role of family in EOL care and manage family members' expectations according to cultural contexts.

Keywords:
End of life; Family; Palliative care; Communication; Family-oriented cultures, East Asian Cultures.

Strengths and limitations of this study

- This review offers a timely synthesis of research evidence of the role of family in end-of-life communication.
- The search strategy was developed in collaboration with frontline clinicians, academics, and librarians to offer a diversified view towards a holistic understanding of the topic, study methodologies and study settings.
- This review includes different research designs and methods including quantitative, qualitative and mixed-methods studies within the topic of family role in end-of-life communication.
- As an integrative review, the themes emerged from the included studies can inform future research on developing a family-oriented communication framework that targets on managing family expectations when making EOL decision-making
- Findings have to be interpreted cautiously due to a number of studies included in this review are emerged from Chinese context.

Introduction

End-of-life (EOL)[1] communication has a crucial influence on medical decision-making and the quality of care at the final stage of a patient journey. It informs patients and their families on the current medical conditions; explores unanswered concerns and health needs; provides emotional support and practical advice; reveals what lies ahead; and allows care providers to understand how they can improve the care for the patients during their final days. EOL communication during palliative care removes the stigma around death and help the patients set out their final wishes to the family [1]. In general, effective communication regarding prognoses and optimal treatment has multidimensional benefits, for instance, promoting the quality of EOL care and decreasing the stress of the carers [2]. In contrast, poorly conducted medical conversations may lead to negative treatment outcomes such as aggressive life-sustaining treatments [3-4], unsatisfactory hospital experiences [5], poor well-being [6], and unnecessary healthcare costs [2, 7]. Thorough EOL communication among clinicians, patients and carers help to alleviate anxiety and enable patients to be cared for in desired ways [2, 8].

However, empirical evidence shows that the EOL communication practice is not always performed effectively [9-10]. Many patients and carers are reported to be poorly informed about their patients' situations and that the patients were often unaware of their own risks of imminent deaths [11]. Similarly, clinicians' unawareness of patients' wishes may hinder the provision of the most appropriate healthcare options for patients. Healthcare professionals also find it challenging to directly discuss deaths with patients and caregivers, as patients and caregivers are often being ill informed and tend to be over-optimistic on the prognoses [12]. There are different expectations for palliative care in Chinese and Western cultures. Most Chinese patients rely on doctors to make the final decision regarding EOL treatments [13-14], the wishes of close family members are also considered. Research results show that in the broader Asian context, family members and religious beliefs heavily influences patients decisions on EOL and palliative care [15-17].

Nowadays, many developed regions such as the United States, Europe, and Australia adopt the shared decision-making approach to family–clinician EOL communication [18]. However, patients who are admitted to general wards or intensive care units (ICUs) which are aggressively managed have no prior opportunities for effective discussions with their families or clinicians about their desires and goals [19]. There is a lack of clear communication framework that sets the standard for essential information that family caregivers should receive, which will likely include patients' current medical condition and prognosis estimates, additional options of treatment and support measures available and their risks and benefits, and the preferences of patients and family to guides clinicians to reach realistic care goals [20-21]. When family members receive insufficient information, difficulties may arise during EOL communication. This occurs especially in the ICU settings, where urgent decisions about whether to pursue aggressive life-sustaining treatments for patients are required. In a study by Azoulay et al.[22], 54% of the family members of ICU patients did not have a clear understanding of the patients ' diagnoses, prognoses and treatments, and the physician–family meetings lasted for no more than 10 minutes. As a result, family members have poor understandings of the situations they were facing, which led to suboptimal decision making. In addition to time constraints, the lack of communication skills is also an important factor. Clinicians tended to discuss EOL life-sustaining treatments in a scripted, depersonalised and procedure-focused manner. Clinicians also tended not to initiate EOL conversation directly and in a timely manner [18].

Amongst the factors affecting EOL communication as well as the engagement of patients and their family caregivers, the factor most discussed is cultural differences between the Eastern and Western countries. Chinese culture values collectivism, wherein patients prefer to make joint decisions with their family members or sometimes even rely completely on them [14]. Rooted in Confucian morality, filial piety is a very important moral tenet in Chinese culture that has been advocated and practiced for thousands of years. People of the Chinese culture are required to provide care to their parents in return for the care they received from their parents in their childhood years. Therefore, many Chinese elderly patients believe that their children may naturally understand their preferences and are able to make decisions for them in their final days [14, 23-24]. For example, family members of elderly patients would request the doctors to discuss with them first, before the doctors consult the elder patient. In some cases, family members will also choose not to disclose the bad news to the

---

patients [25]. Collusion, a scenario wherein the family wishes to hide the diagnosis from the patient, is common in Asian cultures. In a study conducted in Singapore by Low et al. [26] found that 96% of family members expressed reluctance in disclosing the prognosis to the patient. This situation is also prevalent in Hong Kong, in which its culture is heavily influenced by both Chinese and Western beliefs. In research conducted with Chinese patients, maintaining a strong connection with the family during palliative care has been reported to be one of the most important components of a "good death" for elderly patients [27]. This interdependent relationship between family caregivers and patients opposes the ideology of autonomy and self-determination that predominate in Western culture, and is to a certain extent, culturally understood and accepted by patients in the Chinese context.

Regardless of the effects of different cultural norms, recent reports have shown that healthcare professionals widely agree that EOL communication should involve both the patient and family members [28-29]. In one international survey of palliative care professionals, more than 80% of the participants agreed that more practical instructions during communication with patients' family members would enhance EOL decision-making [29-30]. Recently, the English Parliamentary and Health Service Ombudsman [31] found that the main area of health professionals' complaints about EOL care was communication failure with terminally ill patients and their family members. Without adequate family involvement, promoting the holistic care of patients during their EOL is difficult.

In response to such dissatisfaction with EOL communication, several guidelines have been established for practitioners with focus on individuals 'rights and autonomy in the medical context. Guidelines such as the COMFORT model (an acronym for Communication, Orientation, Mindfulness, Family, Ongoing, Reiterative messages, and Team) and SPIKES protocol (an acronym for Setting, Perception, Invitation, Knowledge, Empathetic Response, Summary) provides a framework for clinicians to engage in palliative care discussion with patients [5, 32]. Meanwhile, existing recommendations mostly focus on the patient–clinician conversation rather than a family-oriented conversation. Many close family members are eager to thoroughly understand the dying process and the importance of understanding medical jargon, inclusivity, and full transparency [33] is lost in the existing recommendations.

Due to the aforementioned factors, the development of an EOL communication strategy that considers active family involvement is necessary. While previous systematic reviews on family decision-making and involvement [34], nurse to family support during withdrawal of life-sustaining treatment and imminent death [35-36], and EOL communication to patients and caregivers during the advanced stages of related illnesses [37] are present, an integrative review is lacking. As such, in this integrative review, the researchers aimed to contribute to the current literature by systematically reviewing research findings that highlights the roles of patients' families in EOL decision making. The aim of the review was to answer the following question: What is the existing research evidence regarding the role of family in EOL communication, and what themes can be derived from their synthesis?

The summarised information sheds light on the role of family in EOL communication and decision-making and contributes to future research and policy making regarding EOL communication. Although culture and its related elements regarding EOL communication and care have been heavily foregrounded thus far, it is not saliently marked in the research question because it is a prominent theme elicited after, rather than prior, the systematic review search (see also [38]).

Methods

This integrative review aimed to provide integrated information on the role of family in EOL communication using the PRISMA guideline as reporting system (see Figure 1). The review included relevant studies published between 1st January 1991 and 31st December 2021. The purpose behind the proposed date is the majority of related studies and articles regarding familial roles in EOL communication were published since the specified date.

[**Figure 1** PRISMA flow diagram]

Search strategy

PsycINFO, Embase, MEDLINE and the Ovid nursing databases were searched in the initial screening process to identify relevant articles using the following keywords and synonyms, such as ‘end of life’, ‘communication’ and ‘family’. The search restriction on the publication date was from 1991 to 2021. Search logic is also used to assist the search by using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevant studies (See Appendix 1 for the details on our search strategies). Specifically, the search strings of the four employed databases are presented as follows (See table 1):

Table 1. Search Strings

- **PsycINFO**: abstract((family) OR (parent*) OR (caregiver*)) AND abstract((communicat*) OR (communication skill*)) AND abstract((“end of life”) OR (end-of-life) OR (EOL) OR (terminal) OR (terminally ill)) AND pd(19910101-20211231))
- **Embase**: ((‘family’/exp) OR (parent*) OR (caregiver*)) AND ((communicat*) OR (communication skill*)) AND ((end of life) OR (end-of-life) OR (EOL) OR ((terminal) OR (terminally ill))
- **MEDLINE**: ((“family”) OR (“parent*” OR “parent+”) OR (“caregiver*” OR “caregiver+”)) AND ((“communicat*” OR “communication+”) OR (“communication skill*”)) AND ((“end of life”) OR (“end-of-life”) OR ((“terminal”) OR (“terminally ill”))
- **Ovid nursing database**: ((family) OR (parent*) OR (caregiver*)) AND abstract((communicat*) OR (communication skill*)) AND ((“end of life”) OR (end-of-life) OR (EOL) OR (terminal) OR (terminally ill))

In addition, a manual search was made of relevant journals, and the bibliographies of relevant articles and reviews were also cross-checked for potential eligible studies. Studies that met the inclusion criteria were included for further review and duplicated articles were removed.

Inclusion and exclusion criteria

An initial search was carried out to identify relevant articles on EOL communication that were published between 1st January 1991 and 31st December 2021. Studies were included if they were peer-reviewed and concerned EOL communication and family. Studies were excluded for the following reasons: (a) having a focus on topics that were unrelated to EOL communication (e.g., religious studies of EOL care); (b) not being original research based on empirical findings (e.g., literature reviews, opinion pieces); (c) being non-English language articles; (d) being non-peer reviewed studies.

Our investigation encompasses a broad scope. The various aspects of EOL care includes EOL communication studies in general (i.e. not limited to diagnosis, prognosis etc.)[1] and focus on the involvement and roles of and between family, clinicians, and relatives. Peer-reviewed full-text journal articles such as original studies and reviews were included. Furthermore, those relating to the Chinese context were especially retrieved and included as a subset of articles considering the effects of Confucianism-influenced family culture in the Chinese context on EOL. The initially shortlisted articles were cross-checked by the three authors for final review and data extraction. Articles that were not peer-reviewed or written in English were excluded. Although we have a bilingual research team, EOL care articles that were written in Chinese were not included in the research due to insufficient peer-reviewed articles and the paucity of EOL communicative aspect-oriented research.

Data extraction

Three authors were involved throughout the entire title screening, data collection, and text review process. Before data extraction, the authors independently screened the titles and read the whole abstract of each paper to exclude irrelevant articles according to the inclusion criteria. The full papers were retrieved if their abstracts were considered potentially relevant. The full texts of the chosen articles were subjected to in-depth data extraction. The objectives, research design, participant characteristics and key findings were examined and recorded and appraised for quality by oncologists and palliative care practitioners to ensure that all relevant journals were included in the search. Any disagreements were resolved by discussion to reach a consensus amongst all the authors.

Patient and Public Involvement

No patient involved.

Results

Quality assessment

The Quality Assessment Tool for Quantitative Studies [39] was used to assess quantitative (*n* = 14) and mixed-method studies (*n* = 2). Each article was given ratings on a 3-level ordinal scale: "weak", "moderate", or "strong" in eight areas such as research design and selection of study population. Qualitative (*n* = 37) and mixed-method studies (*n* = 2) were evaluated with the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Qualitative Research [40], which is a 10-item checklist covering components such as congruity and reflexivity, scored as "yes", "no", "unclear", or "not applicable". The quality of the included studies was evaluated independently by the first and second authors. Any disagreements in ratings were discussed and resolved with the third author.

Weight of Evidence Measure

To ensure the quality of the included studies, the papers' "weight of evidence" was measured according to three criteria: the relevance of each paper to the current review; the appropriateness of the research; and the validity of the study; and the overall contribution of the research to this review. These variables are specified in Table 2 below.

Regarding the relevance aspect of the included studies, that is, to which the degree of the topic(s) examined align with our review questions, 86% of the 53 reviewed articles were considered as either high or medium level of relevance. Appropriateness is evaluated based on whether the research designs were appropriately employed. The authors judged that 28% and 38% were deemed to be highly appropriate and fairly appropriate, respectively. 83% of the included studies were considered to have a medium-to-high level validity, where the scorings were based on the preciseness and consistency of data analysis. These ratings therefore draw an overall conclusion that 30% of the included studies were able to make a strong contribution in answering the review questions whilst 43% made a fairly significant contribution.

Table 2. Weight of Evidence of the current review

	Relevance	**Appropriateness**	**Validity**	**Overall contribution**
High	46%	28%	38%	30%
Medium	40%	38%	45%	43%
Low	13%	33%	16%	26%

Included articles

The initial search identified 25,305 eligible studies, 25,318 of which were excluded after abstract screening. The search includes keywords and synonyms of 'end of life', 'communication' and 'family'. Search logic are also used to assist the search through using Boolean operators such as OR, AND, NOT, the search logic allows different combinations to access the most relevant studies, e.g. 'end of life AND communication AND family'. The full-text screening of the remaining 109 studies were then subjected to in-depth review (see Figure 1). This led to the further exclusion of 56 articles because they: (a) focused on unrelated topics of family-oriented EOL communication; (b) lacked empirical evidence; (c) were written in other languages rather than English; or (d) were not peer reviewed. Finally, 53 studies were included in this review.

The Characteristics Of The Included Studies

The characteristics of the 53 studies that met the inclusion criteria are summarised in Table 3 (See Appendix 2 for a summary of each included study). The number of studies on the role of family in EOL communication increased significantly after 2010. Most of the studies were from the United States (24), closely followed by Hong Kong (7), Canada (4), the United Kingdom (3), China (2), South Korea (2), Netherlands (2), France (2) and other countries (7). Of the 53 included studies, 37 were qualitative studies, 14 were quantitative and 2 were mixed-method.

Table 3. Main ideas of the themes emerged from the reviewed studies

Theme	Main ideas	Studies
1. Conflicts in family decision-making in EOL communication	There existed a certain degree of discrepancies in decision-making between the patient and family caregivers; to optimise EOL communication among the relevant stakeholders, physicians should be able to gauge and respond to the patient's psychosocial needs and to also take the family's perspective into account when having EOL conversations.	[9, 20, 23, 29, 41-51]
2. The significance of timing of EOL communication	There is typically a delay in initiating EOL communication; it is often due to the avoidance of having open physician-patient discussion about the illness. Patients were generally worried about making EOL decisions once informed about the diagnosis, whilst physicians were concerned that the negative prognostic information would impact the patients and hence, leading to a late timing of EOL communication.	[22, 26, 52-60]
3. Difficulty in identification of a "key person" responsible for decisions regarding EOL care	Some patients were found to not wish to be involved in making their own palliative care decision out of the fear and uncertainty of their EOL stage, family members or even the physicians themselves might in turn have to be responsible for decision-making; this likely leads to an unclear division of responsibility regarding EOL decision-making.	[14, 61-66]
4. Different cultural perspectives on EOL communication	Individualism is of value in the West where most patients preferred having the autonomy to make EOL decision for themselves, whilst collectivism and filial piety are the main values typically found in Eastern society; patients tended to rely on their children or discussing within the family when making palliative care decisions.	[14, 25, 67-76]

Identified themes

Thematic analysis was conducted to capture any re-occurring topics in the included studies [see 77-78]. The coding process is inductive without referring to any existing coding framework. To do this, all the authors will first read through the transcripts carefully and give an initial free-coding to all segments relevant to the role of family in EOL communication. We then conducted several review rounds to compare, sort, and recode, as we look for connections among the coded segments and compared analyses from the other included papers. In this way, the authors identified and coded issues from each of the included studies, which were then synthesised into a set of broad reoccurring themes about the role of family in EOL communication [79]. Four themes were identified: 1) Conflict in family decision-making in EOL communication; 2) The significance of timing of EOL communication; 3) Difficulty in identification of a "key person" responsible for decisions regarding EOL care; and 4) Different cultural perspectives on EOL communication.

Conflicts in family decision-making in EOL communication

Internationally, the involvement of family members in EOL communication has often been discussed in the context of provision of support, but very few studies have directly explored how important the role of family is and in what way the family must be involved.

Family caregivers traditionally play their own unique roles in providing emotional and financial support to contribute to a "good death"— a pain-free situation during the last phase of life and not on exhausting possible treatments to prolong life unnecessarily--- for the dying patients [20,41]. In fact, the patients expect to receive family support more than the support from healthcare workers. Furthermore, the social support from family members serves as the fulfilment of their own familial obligations and is a foundation providing quality EOL care [42-44].

Many clinicians nowadays have come to realise that the patients' and families' views and beliefs have to be considered in the decision-making process [20, 29]. In circumstances where disagreement about the medical advice arises between the doctor and the family, establishing a care plan could become difficult, and this could cause the withholding or withdrawal of treatment implementation. Family members have also noticed that healthcare staff would avoid EOL conversations. However, it is important for healthcare staff to initiate EOL conversations so that patient's needs and their family's preferences are properly addressed [29]. It was also found that some doctors have to follow the family's wishes, even if it was against the professional judgement of what was appropriate for the patient [45-47]. For instance, against the doctors' recommendations, some family might still desire more unnecessary treatments just to sustain a dying patient's life when he or she could not make an EOL decision.

Disagreements about decisions on EOL treatments could also occur between terminally ill patients and their family members. There are contradictions between family members who wish to hold on to their loved ones for as long as possible and the patients who wish to let go and reject life-sustaining treatments [48-50]. Fan et al.[23] and Shin et al.[51] used standardised questionnaires to examine the preference and concordance among the patients with cancer, family members, and clinicians regarding EOL communication. This includes the disclosure of diagnosis and prognosis, family involvement in such processes, and EOL decision-making. Findings revealed that family members' preferences did not always align with that of the patients in some cultural contexts such as China and Korea [23; 51]. For example, Shin et al. [51] found that discussions between patients and their family regarding treatment preferences might not always end in agreement, since patients' family tended to opt for life-sustaining treatments when the patients desired otherwise. Fan et al. [23] suggested that mainland Chinese patients depended largely on their families and doctors tended to substitute patients' consents with that of their families. Additionally, there are discrepancies between clinicians' medical practice and the preferences of the patients and their family caregivers. For instance, rigid protocols and guidelines that inform the healthcare of the young patients created tension among family caregivers and clinicians as they did not take into account the patients' individual needs [9].

The significance of timing of EOL communication

Owing to the complexity of EOL communication, that is, the constitution of delivering exhaustive information from doctors, the complicated emotions derived from relevant stakeholders, and the dynamics of family involvement in the patient's health care, there typically appears a delay in conducting EOL communication [52-54]. Cherlin et al. [52] found that the communication between family caregivers and clinicians about the terminal illness and possible use of hospice care occurs late in the course of the illness. Some patients consistently wrestled with the thought of knowing that they were ill and trying to defer EOL decisions [55-57]. From the perspective of clinicians, there seems to be a tendency for clinicians to initiate the communication of negative prognostic information until they reach a perceived "threshold" of certainty in the accuracy of a prognosis [55]. This observation corroborates with those of Lind et al. [57], who discovered that the doctor's directive to "wait and see" may cause miscommunication between the doctor and family members. One possible reason for the delayed initiation of EOL conversations from doctors might be due to their lack of incompetent communication skills, in which many of them were unable to discuss EOL issues with the patients and the families in an effective and timely manner [58]. Yet, this directive to further delay diagnosis could potentially give the family a sense of false hope that the patient's situation can be improved. When miscommunication occurs, it would appear to be too late to conduct proper EOL communication, or for family members to provide input in the decision-making process about terminating treatment.

Another potential reason why EOL communication may not be implemented in a timely fashion is the presence of physician-family collusion, a situation where family members choose to hide the diagnosis and prognosis from the patients; and it is not uncommon in the palliative care context. Notwithstanding the fact that collusion goes against medical ethics and can potentially cause various complications in EOL treatment, admittedly, collusion is widely seen across Europe and Asia [26]. This is because of the fear of disappointing the patients by informing them of their deteriorating health condition, and more prevailing in Asian countries that the social norm of holding family members to be responsible for the main body of communication about EOL care.

The failure to have patients engage in timely EOL conversations can lead to aggressive life-sustaining treatments, under-utilisation of palliative care, and negative outcomes for both patients and their families. Patients' psychological conditions, including depression scores and quality of life metrics, will be compromised without good palliative care. Moreover, introducing palliative care relieves caregiver stress and improves caregiver depression scores [22, 56]. As a result of these side effects, clinical prediction models to provide estimated remaining survival time of the patient have started to gain popularity in medical practices to aid the EOL discussion pacing of clinicians.

Proper and Prompt palliative care referrals are also important. Frameworks for effective EOL communication could also encourage clinicians to identify an optimal time to refer the patient to palliative care. [59-60].

Difficulty in identification of a "key person" who is responsible for decisions regarding EOL care

Communication required to negotiate EOL care extends beyond the patients and the doctors. It also includes the patients' families, especially in the context of Asia, which family-oriented practices prevail [14]. Families may wish to take up the responsibility for the patient's EOL care. The involvement of multiple parties often leads to difficulty in identifying a main person to hold responsibility for making palliative care decisions.

Failure to identify a key person among family members in EOL care and conversations can cause confusion and misunderstanding, undermining decision making and contributing to a confused process which is already fraught with uncertainty [61-62]. Unclear responsibilities and responses can create contradictory expectations between the family members and the patient. Discrepancies have been observed between the last wishes of patients to follow the natural course comfortably and the desire of their family members to hold on to their loved ones for as long as possible [63-64]. Even when the decision-making responsibility is delegated to one family member, their decisions may be affected by contradicting opinions within the family [65]. To further complicate the matter, McDarby et al. [66] showed that elderly parents' EOL preferences may not be understood by their children. Consequently, misunderstanding and a lack of communication between the patients and their families emerge, resulting in confusion and disagreements in the EOL decision-making process.

Different cultural perspectives on EOL communication

Sociocultural factors play a significant role in EOL communication. In the West, individualism and autonomy are emphasised. EOL communication usually occurs between the doctor and the patient. Depending on the patient's wishes, family members may also be involved [25]. Although there are significant cultural differences between Chinese and Western regions, clinicians of Chinese contexts undertake the same EOL communication models adopted by clinicians from the West [25]. They would look for social cues such as the nonverbal communication behaviour including tone of voice, manner, and attitude, to determine the readiness of patients to engage in EOL conversations. However, the implications of these social cues may differ by cultures. Heavy reliance on social cues lead to miscommunication. In certain cultural contexts, understanding the non-verbal cues from patients are essential to perceiving their readiness with EOL communication, and to help (re)calibrate the conversation flow; thus, potentially making non-verbal communication even more crucial than the verbal content (see also [67-68]) . These factors influence the agencies manifested across the multiple parties, which potentially contribute further to the EOL decision-making conflicts. Meanwhile, in Chinese contexts, EOL communication is largely affected by sociocultural factors. Decisions are made as a collective family rather than between the individual patient and doctor [69]. Studies have shown that some patients do not wish to be involved in the decision-making process of their treatments even if it concerns their own life. This belief is prevalent among Chinese patients. Due to the Chinese cultural beliefs, dying Chinese patients prefer to let their children make the EOL decisions. Bowman and Singer [14] reported that the role of family in the Chinese culture emphasises interdependency, obligation, and responsibility to others. Family members in a Chinese family are expected to be responsible for protecting the patient's health, safety, and general well-being. Chinese patients believe in their children's ability to make decisions on their behalf and sees no need for advance directives about treatment or communication on EOL needs, resulting to increased miscommunication and misunderstanding about the patient' s needs.

Similar findings were observed in Eastern countries, where Asian family members typically preferred to be involved in making EOL decisions together with, or sometimes, on behalf of the elderly patients [25, 70-73]. In China and nations of proximity such as Korea, where Chinese culture poses significant impact, EOL decision-making tends to be a family-centred practice rather than an individual decision [72, 74-75]. Alternatively, Kato and Tamura [76] offered relational authority as another dynamic found within East Asian cultures, where family members will leave medical decisions to the clinicians. Kato and Tamura's [76] study also stresses that family members felt a great responsibility to care for their parents and that failure to continue the care, such as admitting their parents to a nursing home, led to feelings of guilt and abandonment among the family members. This is because the ideology behind it, which is constructed from traditional Confucianist and Buddhist beliefs, largely focuses on collectivism and familial responsibility. Filial piety is a key value to maintain social stability and familial harmony. Based on this premise, parents become the recipients of their adult children's care, and children of dying patients are highly trusted in making treatment plans and EOL decisions for their parents [70, 72, 74, 76]. In addition, in the East Asian context, immediate family members generally possess the power to decide whether to inform the patient of their current medical situations [25], creating a common phenomenon where the doctors would have consultations with the family caregivers prior to speaking with the patients.

Discussion

This review identified the significance of family members in EOL communication and how their engagement in EOL discussions can improve the quality of patients' EOL and death. Moreover, this review found that there is a need for Chinese and East Asian specific EOL communication model to address cultural needs of elderly patients. An important trend identified in the included studies is the accumulating body of knowledge on the significance of family on care, support, as well as communication with the patients. Open discussions initiated by clinicians are key to decreasing psychological side effects in patients and family members such as anxiety, psychological stress, and pressure [80].

Referencing to the research question, existing research about familial roles in EOL communication can be categorised into four different themes. As discussed, family can be a prominent source of decision-making conflict in EOL communication. For instance, family caregivers may have to perform the role of the patient's 'doctor' in home-based care by assessing the patient's symptoms, administering drugs, and providing hands-on care. With little to no support from professional healthcare staff, home care becomes the very source of anxiety and stress for the carer [81]. Decision-making conflicts could also occur between the family and clinicians, and the family and the patient, particularly if resources for support from professionals were limited. It goes without saying that these conflicts do affect the provision of holistic and effective care for the patient [81]. Not only that, the lack of identifying a key person responsible for EOL-decision making results in decision-making conflict. These conflicts could result in significant delays of exercising EOL treatments.

Despite the associated challenges and issues of involving family in the decision-making process, families are an important source of support for patients who are undergoing EOL care. Family support could be manifested through providing the basic needs of the patient (i.e., helping to make the patient more comfortable, offering food and drinks, etc.), monitoring the patient's emotional status, and offering immediate support and assistance [42, 46]. Family participation in EOL matters is also found to be negatively correlated with the level of psychological distress in bereaved family caregivers, implying that the more the family members engage in the patient's EOL journey, the lesser extent they experienced psychological symptoms such as anxiety and depression since the patient's departure [80,81-83]. Chui and Chan's [84] research echoes this finding, demonstrating that longer EOL discussions could significantly reduce the incidence of post-traumatic stress disorder, anxiety, and depression of the families of patients who died in the ICU. On the other hand, Mitchell et al.'s [9] findings noted that there was insufficient time for family caregivers to consider the possibility of death, as avoiding the possibility served as a coping mechanism for the caregiver, and the life-threatening aspect of the patient's condition was only acknowledged after an episode was resolved. As for the impact on the patients, Byock's [85] clinical observation revealed that despite the typical suffering at the EOL, the quality of family input during EOL discussions, such as careful, relationship-appropriate, and goal-directed EOL communications, was important for the patient's emotional wellbeing and the overall experience towards the EOL stage. Thus, quality communication between the patients and their family members are vital in improving the quality of life of dying patients during their EOL stage [41, 43, 48].

Considering the value that familial support could have, healthcare workers must learn what is important to the patients and their families, and ensure that their preferences are adequately explored, adhered to, and respected even in cases where their preferences contradict the clinician's decision. From the clinician's point of view, EOL communication is most effective when family members participate and engage in the joint decision-making discussion [20, 86]. Fostering positivity in EOL communication as a clinician was also viewed to be important [29]. When family members and patients clearly understand one another's EOL preferences, decisions on treatments and palliative care could effectively address patients' needs [82].

There is also plenty of material to discuss with the significance of timing in EOL communication. With regards to physician-family discussions, clinicians should be equipped with the competency to explain its negative effects on the patient and family members in an empathetic and compassionate way, as well as encourage communication between family members and the patients so that family members could understand the patients' wishes and explain their diagnoses [26]. Clinicians should also be educated to take on a bridging role between family members and the patients, acting as a facilitator of communication and exploring any unspoken issues that either side are intentionally avoiding. As such, with continual training and education, healthcare professionals could develop effective communication skills for palliative care and collaborate with the patients' families to provide quality EOL care. Furthermore, healthcare providers should act as mediators and advisors to assist both parties in making appropriate treatment decisions and thus enable the patients to have a "good death" [14]. The barriers and uncertainties among the patients, family members and the clinicians should be moderated to build trust and facilitate open EOL communication [63, 87].

Moreover, healthcare providers may be capable of initiating EOL conversations at optimal timing with widespread adoption of prognostic tools. When EOL discussions are conducted at optimal timing, patients' comfort and dignity during EOL could be immensely improved [52]. The Palliative Care Chart developed by Bailey et al. [48] is a tool for clinicians to assists in generating effective EOL communication, aiming to facilitate continuity and co-ordination of care and sense of partnership between patients and their families. The chart serves as a checklist for clinicians. Together with the training on use of the tool, results showed that clinicians were able to resolve ongoing concerns occurred between the patients and family members during palliative discussions. Another means to educate health care professionals to provide better palliative care is the development of quality indicators as suggested by Raijmakers et al. [30]. Clinicians can be trained to monitor different aspects of the patient according to the quality indicators, for instance, limited need for pain control, providing palliative care accordingly, and improving the patients' quality of life towards the last stages of their lives. Educational interventions may be one way to raise the awareness and significance of patient participation in EOL planning. As suggested in this review, family participation in the process of EOL discussions should also be considered. Family participation in EOL communication were shown to have positive effects on the patients' quality of EOL treatment receptions [21, 60]. However, the degree of involvement varies between Eastern and Western countries given cultural differences, requiring a Chinese and Eastern specific communication model to address the cultural implications of different regions. Chinese patients and families commonly avoid EOL communication due to Buddhism and Confucianism beliefs, which accepts that talking about death brings death closer [14]. These beliefs also emphasise a balance of physical, emotional, and social harmony, which provides a culturally sound reason for them to evade such conversations regarding palliative care and EOL decisions [14, 60]. Also, in China specifically, filial piety plays an important role in the conduct of children. In cases of medical care, the burden of making treatment decisions and EOL choices are usually delegated to the children of elderly patients [14, 24, 56, 88]. Some elderly patients may even choose to exclude themselves from the EOL communication between clinicians and family caregivers and family members would become the first and main persons to contact during the discussion about their conditions and EOL decisions [11].

In Western countries, contrarily, patients and elderly people are generally familiar with palliative care. The awareness of setting up wills and arranging palliative care enable them to be relatively prepared to engage in early EOL conversations [64]. Furthermore, autonomy and self-determination are prevailing concepts, and patient's self-exclusion during medical consultation is rarely observed. Given the prevalence of individualism most patients of the Western contexts wish to make EOL decisions for themselves [68, 89]. In occasional circumstances, patients prefer to withhold information on diagnosis and treatments to their family members, this would lead to a lack of communication [90] as well as insufficient understanding of the illness among family members and hence, compromised preparedness in dealing with their beloved's EOL issues [84].

Prior research also addressed potential solutions to improve the quality and communicative environment of EOL care. Effective EOL communication is essential in creating a fulfilling EOL experience for the patients and their family members, while advance preparation could help achieve successful EOL conversations. As the majority of patients trust that their healthcare providers are capable of providing quality treatment, diagnosis, and other information regarding their illness. Clinicians could build good rapport over time and establish trust with patients [56]. This promotes patient-centred care, which is vital for effective EOL communication in both Eastern and Western contexts as the patients 'needs are always top priority when the doctors are developing medical plans. To attain such patient-oriented practices, clinicians must address the elements of 1) sensitivity to the patients' needs, personal experiences and perspectives; 2) self-participation of the patients' own recovery journey; and 3) enhancement of doctor-patient relationships.

It is also critical to keep the patients informed about their diseases. In a previous study [61], half of the respondents reported that neither were they notified about the diagnosis and prognoses, nor did they fully understand the information provided by doctors. Clinicians should have regular meetings with the patients and family members to keep them up to date on the disease progress and prognoses. Advance notification of the nature of the meeting, as well as the provision of a quiet and calm atmosphere could help decrease the anxiety of family members. Issues regarding the manner of delivery are present as well; when delivering bad news, clinicians were typically found not to have a specific goal or did not consider ahead how would the news impact the receiver [68]. All these can become obstacles in conducting effective consultation as well as disclosing the unpleasant news to the patients. To balance both medical and interpersonal needs in such difficult EOL discussions, there are developed protocols to help clinicians to better approach the conversation. One example being 'COMFORT model, which is a step-by-step guide on breaking bad news in a humane manner and at the same time, providing comfort to the recipient [32, 90]. 'SPIKES' protocol, which is a six-step framework, assists doctors with proper preparation in delivering bad news while ensuring the patients' comfort and understanding of the discussion[5, 91]. Whilst these protocols were developed and validated in the Western context; since sociocultural factors play a significant role in doctor-patient communication, they may not be applicable in non-Western nations due to the different traditional beliefs in the East [92]. More specifically, the Chinese philosophy of death being a taboo subject has wide influences across many Asian countries, resulting in hesitation of prognosis disclosure to dying patients. Having communication frameworks as a guideline for clinicians to navigate around EOL conversations is plausible; yet, a formulaic approach without cultural considerations of the patients could reduce patient satisfaction. Clinicians therefore need to adapt to families on a case-by-case basis while considering the nuances of patient perspective, context of the discussion, and content of the conversation so that they can adjust the communication accordingly [11].

Lastly, clinicians should attend to the family caregivers' expectations according to the cultural context. They need to understand and respect the expectations of the patient and their family regarding the treatment. Differences in preferences and the lack of communication between medical professionals and patients are known to create conflicts. Careful listening and understanding the patients' preferences enhance the quality of patients' dying process [23]. In addition, a one-size-fits-all approaches does not work in EOL communication due to the variety of factors [24]. It is essential to improvise discussions according to each patient and family needs. Moreover, keeping the general cultural guidelines in mind enables clinicians to connect with their patients more precisely in respect of different scenarios regardless of the cultural backgrounds of both parties. More research is warranted to investigate how clinicians could and should communicate with different patients, by looking for the best model to assess the need and preference in communication. Medical staff must be trained to be prepared for providing a smooth EOL communication experience to patients based on their cultural backgrounds and practice [24].

Strengths and limitations of the study

This review has synthesized the research findings from a range of diversified data sources in order to produce a comprehensive view towards the understanding of family role in EOL communication. To our best of knowledge, there is limited research on exploring the role of family in EOL communication, this review fills in the gap by highlighting the importance of culture and how it can affect the beliefs and roles of families in EOL decision-making. Better family oriented EOL communication suggests that family participation will likely lead to improved quality of life and death in patients, managing family expectations during prognosis disclosure and facilitating patients' fulfilment of familial roles while making EOL decision-making. While patients from the East depend on their family members to make EOL decisions, this paper urges for a family-oriented framework which helps patients to fulfil their social role in the family.

There are several limitations in this review. First, the literature search only includes four databases, with only 53 eligible included articles and many are quantitative studies, leading to a possible bias of the literature representation. Second, studies written in other languages were not included. Only those fully published in English were reviewed and included in this study, which may have skewed our findings and interpretations. The included articles were not be able to cover all aspects of family in EOL communication, which may have affected the generalisability of the findings. Third, in our analysis, we use the signposting of 'the East and the West' which is beneficial in distinguishing EOL communicative practices across different cultural contexts, we also acknowledge the generalizability of such labelling; there are many additional factors which contribute to the complexity of EOL communication. Readers are reminded to interpret the findings cautiously due to a number of studies included in this review are emerged from Chinese context.

Conclusion

This review identified the important and unique roles of family caregivers in EOL communication and the pressing need to develop an EOL communication framework designed for the Chinese and Eastern contexts. The reviewed studies indicated that family engagement in EOL discussions is beneficial for both patients and their family members. Knowledge about the patient's diagnosis and prognosis information factoring in EOL decisions will facilitate fruitful communication among healthcare providers, patients and family members. Clinicians should identify and remove barriers to enable sufficient understanding of the information desired by each party, tackle collusions tactfully, and bridge the gap between the parties if direct communication is difficult and distressing. The timing of EOL communication and communicative content are important, especially in circumstances where clinical deterioration is inevitable. Existing palliative care communication frameworks, such as the COMFORT model and SPIKES protocol could be modified according to the implications of this review to fit the family-oriented cultures in Chinese and Eastern contexts. With such guiding principles, clinicians will be able to engage and discuss EOL issues with patients confidently, thus performing a well-rounded EOL communication practice.

The current review identified four significant themes that presented the roles of family caregivers in EOL communication. Many of the articles in the review search in the results and discussion show the involvement of family members in EOL decision-making. Clinicians should acknowledge the significance of families' views during the decision-making process. It is paramount to respect and understand the decisions of the patient and the family, while also acting as a bridge to mediate between them and facilitate open discussions. Clinicians can also use prediction models or prognostic tools to predict the patients' survival time to ensure a timely EOL conversation to prepare for the end of their life.

Previous studies showed that programs introducing advance care planning and acculturation could successfully encourage patients to participate in EOL communication with their palliative care team and family caregivers [24, 56]. However, while previous palliative care tools have shown to improve doctor-patient interaction, a lot of them do not focus on further factors that contextualise and complicate EOL communication, such as sociocultural factors, patient-centred care, and patient autonomy. Palliative care tools can be designed to be inclusive of family involvement in EOL communication, reflecting both the role of family members and patients' individual role with respect to their families. Regarding clinicians and practitioners' EOL communication praxis, our recommendations are twofold. The first is to be continually aware of the cultural implications. The second is for clinicians to be trained so that they can help the patient negotiate personal and familial obligations while undergoing EOL treatments.

Availability of data and materials
All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate
Not applicable. All the work was developed using published data.

Consent to participate
Not applicable.

Competing interest
None.

Funding
Not applicable.

Authors' contributions
JKHP contributed to the conception and design of the study. KMC, LF and CHJC revised the study protocol. JKHP, KMC, LF and CHJC contributed to the acquisition and analysis of data. JKHP evaluated the risk of bias of the included studies. JKHP and KMC interpreted the data. JKHP, LF and KMC drafted the manuscript. All the authors critically revised the manuscript and gave the final approval of the version to be published.

Acknowledgement
Not applicable.

References

1. Buckman R. Communication in palliative care: a practical guide. Death, Dying and Bereavement. 2nd edn. *Sage, London.* 2000 Dec 8:146-73.
2. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA internal medicine.* 2014 Dec 1;174(12):1994-2003.
3. Clayton JM, Hancock KM, Butow PN, Tattersall MH, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *The Medical Journal of Australia.* 2007 Jun 18;186(12):S77.
4. Odgers J, Fitzpatrick D, Penney W, Shee AW. No one said he was dying: families' experiences of end-of-life care in an acute setting. *Australian Journal of Advanced Nursing*. 2018 Mar;35(3):21-31.
5. Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *The oncologist.* 2000 Aug;5(4):302-11.
6. Simpson N, Knott CI. Stress and burnout in intensive care medicine: an Australian perspective. *Med J Aust.* 2017 Feb 20;206(3):107-8.
7. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Health care costs in the last week of life: associations with end-of-life conversations. *Archives of internal medicine.* 2009 Mar 9;169(5):480-8.
8. Maubach N, Batten M, Jones S, Chen J, Scholz B, Davis A, Bromley J, Burke B, Tan R, Hurwitz M, Rodgers H. End-of-life care in an Australian acute hospital: a retrospective observational study. *Internal medicine journal.* 2019 Nov;49(11):1400-5.
9. Mitchell S, Slowther AM, Coad J, Dale J. Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening conditions and their families: a longitudinal qualitative investigation. Archives of Disease in Childhood. 2020 Nov 16; 106:570-576.
10. Ng GW, Pun JK, So EH, Chiu WW, Leung AS, Stone YH, Lam CL, Lai SP, Leung RP, Luk HW, Leung AK. Speak-up culture in an intensive care unit in Hong Kong: a cross-sectional survey exploring the communication openness perceptions of Chinese doctors and nurses. *BMJ open.* 2017 Aug 1;7(8):e015721.
11. Pun JK, Cheung KM, Chow JC, Chan WL. Chinese perspective on end-of-life communication: a systematic review. *BMJ Supportive & Palliative Care.* 2020 Jul 9.
12. Hawryluck L. Communication with patients and families. *Ian Anderson Continuing Education Program in End-of-Life Care.* 2000.
13. Food and Health Bureau. End-of-life Care: Legislative Proposals on Advanced Directives and Dying in Place – Consultation Document. 2019 Sep https://www.fhb.gov.hk/download/press_and_publications/consultation/190900_eolcare/e_EOL_care_legisiative_proposals.pdf.
14. Bowman KW, Singer PA. Chinese seniors' perspectives on end-of-life decisions. *Social science & medicine.* 2001 Aug 1;53(4):455-64.
15. Wang X, Huang Y, Radha Krishna L, Puvanendran R. Role of the Nasogastric Tube and Lingzhi (Ganoderma lucidum) in Palliative Care. *Journal of Pain and Symptom Management*. 2016 Apr;51(4):794-9.
16. Peng NH, Liu HL, Chen CH, Bachman J. Cultural practices and end-of-life decision making in the neonatal intensive care unit in Taiwan. *Journal of Transcultural Nursing*. 2012 Jul;23(3):320-6.
17. Miljeteig I, Johansson KA, Sayeed SA, Norheim OF. End-of-life decisions as bedside rationing. An ethical analysis of life support restrictions in an Indian neonatal unit. *Journal of Medical Ethics*. 2010 Aug;36(8):473-8.
18. Levin TT, Moreno B, Silvester W, Kissane DW. End-of-life communication in the intensive care unit. *General hospital psychiatry.* 2010 Jul 1;32(4):433-42.
19. Leung DY, Chan HY, Yau SZ, Chiu PK, Tang FW, Kwan JS. A video-supported nurse-led advance care planning on end-of-life decision-making among frail older patients: Protocol for a randomized controlled trial. *Journal of advanced nursing.* 2019 Jun;75(6):1360-9.
20. Ohs JE, Trees AR, Gibson C. Holding on and letting go: Making sense of end-of-life care decisions in families. *Southern Communication Journal.* 2015 Oct 20;80(5):353-64.
21. Keeley MP. Family communication at the end of life. Behavioral Sciences, 7, 45.
22. Azoulay E, Chevret S, Leleu G, Pochard F, Barboteu M, Adrie C, Canoui P, Le Gall JR, Schlemmer B. Half the families of intensive care unit patients experience inadequate communication with clinicians. *Critical care medicine.* 2000 Aug 1;28(8):3044-9.

23. Fan Z, Chen L, Meng L, Jiang H, Zhao Q, Zhang L, Fang CK. Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff. *Supportive Care in Cancer.* 2019 Feb 1;27(2):583-9.
24. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *The gerontologist.* 2005 Oct 1;45(5):634-41.
25. Wang Q. Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US. 2010.
26. Low JA, Kiow SL, Main N, Luan KK, Sun PW, Lim M. Reducing collusion between family members and clinicians of patients referred to the palliative care team. *The Permanente Journal.* 2009;13(4):11.
27. Lo RS, Woo J, Zhoc KC, Li CY, Yeo W, Johnson P, Mak Y. Cross-cultural validation of the McGill Quality of Life questionnaire in Hong Kong Chinese. *Palliative medicine.* 2001 Jul;15(5):387-97.
28. Almack K, Cox K, Moghaddam N, Pollock K, Seymour J. After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC palliative care.* 2012 Dec;11(1):1-0.
29. Kastbom L, Karlsson M, Falk M, Milberg A. Elephant in the room - Family members' perspectives on advance care planning. *Scandinavian journal of primary health care*. 2020 Nov 11;38(4):421-429.
30. Raijmakers N, Galushko M, Domeisen F, Beccaro M, Lundh Hagelin C, Lindqvist O, Popa-Velea O, Romotzky V, Schuler S, Ellershaw J, Ostgathe, on behalf of OPCARE9 C. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. *Journal of palliative medicine.* 2012 Mar 1;15(3):308-16.
31. The English Parliamentary and Health Service Ombudsman. *The Ombudsman's Annual Report and Accounts 2015-16* (Rep.). 2016 Nov 3. Retrieved https://www.ombudsman.org.uk/sites/default/files/PHSO_Annual_Report_2015-16.pdf.
32. Wittenberg E, Goldsmith JV, Ragan SL, Parnell TA. Communication in palliative nursing: The COMFORT Model. *Oxford University Press.* 2019 Dec 24.
33. Paré K, Grudziak J, Lavin K, Sten MB, Huegerich A, Umble K, Twer E, Reid T. Family perceptions of palliative care and communication in the surgical intensive care unit. *Journal of Patient Experience*. 2021 July 14;8.
34. Anderson RJ, Bloch S, Armstrong M, Stone PC, Low JT. Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence. *Palliative medicine*. 2019 Sep;33(8):926-41.
35. Coombs MA, Parker R, Ranse K, Endacott R, Bloomer MJ. An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care. *Journal of advanced nursing*. 2017 Jan;73(1):39-55.
36. Lowey, SE. Communication between the Nurse and Family Caregiver in End-of-Life Care: A Review of the Literature. *Journal of hospice and palliative nursing*. 2008 Jan;10(1):35-45.
37. Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R, Tattersall MH. A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*. 2007 Jul;34(1):81-93.
38. Pun JKH, Chan EA, Wang S, Slade D. Health professional-patient communication practices in East Asia: An integrative review of an emerging field of research and practice in Hong Kong, South Korea, Japan, Taiwan, and Mainland China. *Patient education and counselling*. 2018 Jul;101(7):1193-1206.
39. Thomas H, Ciliska D, Dobbins M. Quality assessment tool for quantitative studies. Toronto: Effective Public Health Practice Project McMaster University. 2003.
40. Joanna Briggs Institute. JBI critical appraisal checklist for qualitative research. Retrieved from http://joannabriggs.org/assets/docs/criticalappraisal-tools/JBI_Critical_Appraisal-Checklist_for_Qualitative_Research2017. pdf. 2017.
41. Githaiga JN, Swartz L. Socio-cultural contexts of end-of-life conversations and decisions: bereaved family cancer caregivers' retrospective co-constructions. *BMC palliative care.* 2017 Dec;16(1):1-8.
42. Lee MK, Yun YH. Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study. *Cancer nursing.* 2018 May 1;41(3):E1-0.
43. Royak-Schaler R, Gadalla SM, Lemkau JP, Ross DD. Family perspectives on communication with healthcare providers during end-of-life cancer care. In Oncology nursing forum 2006 Jul 1 (Vol. 33, No. 4, p. 753). Oncology Nursing Society.

44. Towsley GL, Hirschman KB, Madden C. Conversations about end of life: perspectives of nursing home residents, family, and staff. *Journal of Palliative Medicine.* 2015 May 1;18(5):421-8. doi:10.1089/jpm.2014.0316
45. Shaunfield SL. "IT'SA VERY TRICKY COMMUNICATION SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY CAREGIVER COMMUNICATION BURDEN. *Theses and Dissertations--Communication* 2015;43. https://uknowledge.uky.edu/comm_etds/43.
46. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.
47. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
48. Bailey S, Sellick SM, Setliff AE, Linkewich B, Kelley ML, Poling M. Communication at life's end [A patient held palliative care chart facilitates communication]. *The Canadian Nurse.* 1999 May 1;95(5):41.
49. Kramer BJ, Kavanaugh M, Trentham-Dietz A, Walsh M, Yonker JA. Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer. *The Gerontologist.* 2010 Apr 1;50(2):215-25.
50. Kotecho M, Adamek ME. Gender differences in quality of life of urban elders in Ethiopia. *Innovation in Aging.* 2017 Jul;1(Suppl 1):879.
51. Shin DW, Cho J, Kim SY, Chung IJ, Kim SS, Yang HK, Ahn E, Park BR, Seo H, Park JH. Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices. *Psycho-Oncology.* 2015 Feb;24(2):212-9.
52. Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between clinicians and family caregivers about care at the end of life: when do discussions occur and what is said?. *Journal of palliative medicine.* 2005 Dec 1;8(6):1176-85.
53. Wong MY, Chan SW. The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing.* 2006 Jun;15(6):710-7.
54. Zhang AY, Siminoff LA. Silence and cancer: why do families and patients fail to communicate?. *Health communication.* 2003 Oct 1;15(4):415-29. Doi: 10.1207/s15327027hc1504_03
55. Carrese JA, Rhodes LA. Western bioethics on the Navajo reservation: benefit or harm?. *Jama.* 1995 Sep 13;274(10):826-9.
56. Huang HL, Chiu TY, Lee LT, Yao CA, Chen CY, Hu WY. Family experience with difficult decisions in end-of-life care. *Psycho-Oncology.* 2012 Jul;21(7):785-91. Doi: 10.1002/pon.3107
57. Lind R, Lorem GF, Nortvedt P, Hevrøy O. Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. *Intensive care medicine.* 2011 Jul;37(7):1143-50.
58. El-Jawahri A, Greer JA, Pirl WF, Park ER, Jackson VA, Back AL, Kamdar M, Jacobsen J, Chittenden EH, Rinaldi SP, Gallagher ER. Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial. *The oncologist.* 2017 Dec;22(12):1528. Doi: 10.1634/theoncologist.2017-0227
59. Hui D, Kim SH, Roquemore J, Dev R, Chisholm G, Bruera E. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. *Cancer.* 2014 Jun 1;120(11):1743-9.
60. Rhoads S, Amass T. Communication at the End-of-Life in the Intensive Care Unit: A Review of Evidence-Based Best Practices. *Rhode Island Medical Journal.* 2019 Dec 1;102(10).
61. Biola H, Sloane PD, Williams CS, Daaleman TP, Williams SW, Zimmerman S. Physician communication with family caregivers of long-term care residents at the end of life. *Journal of the American Geriatrics Society.* 2007 Jun;55(6):846-56.
62. Chan WC. Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?. *Journal of palliative medicine.* 2011 Sep 1;14(9):997-1003.
63. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. Patient and Family Related Barriers of Integrating End-of-Life Communication into Advanced Illness Management. *Journal of Pain and Symptom Management.* 2018 Dec 1;56(6):e58-9.
64. Im J, Mak S, Upshur R, Steinberg L, Kuluski K. "Whatever happens, happens" challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study. *BMC palliative care.* 2019 Dec;18(1):1-9.

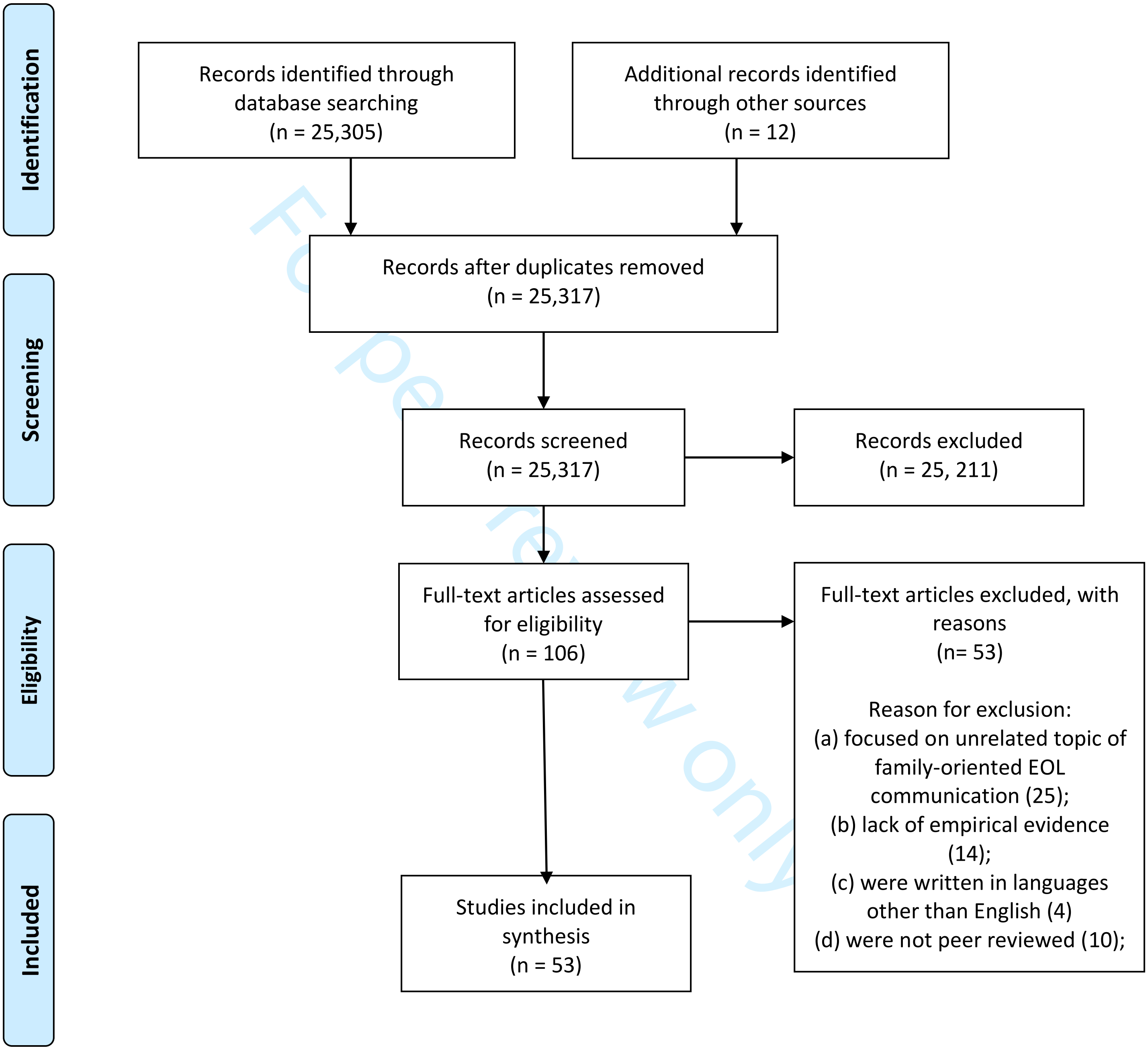
65. Trees AR, Ohs JE, Murray MC. Family communication about end-of-life decisions and the enactment of the decision-maker role. *Behavioral Sciences.* 2017 Jun;7(2):36.
66. McDarby M, Picchiello M, Kozlov EK, Ju C, Worthalter D, Carpenter B. ADULT CHILDREN'S UNDERSTANDING OF PARENTS'CARE AND LIVING PREFERENCES AT END OF LIFE. *Innovation in Aging.* 2019 Nov;3(Supplement_1):S668-9. doi:10.1093/geroni/igz038.2473
67. McElroy JA, Proulx CM, Johnson L, et al. Breaking bad news of a breast cancer diagnosis over the telephone: an emerging trend. *Supportive care in cancer* 2019 Mar; 27(3): 943-950.
68. Schonfeld TL, Stevens EA, Lampman MA, et al. Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities. *American journal of hospice and palliative medicine* 2012 Jun; 29(4): 260-267.
69. Ayers NE, Vydelingum V, Arber A. An ethnography of managing emotions when talking about life-threatening illness. *International nursing review.* 2017 Dec;64(4):486-93.
70. Chan WC, Epstein I, Reese D, Chan CL. Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the "support paradox". *Social Work in Health Care.* 2009 Jul 8;48(5):519-32.
71. Ho AH, Chan CL, Leung PP, Chochinov HM, Neimeyer RA, Pang SM, Tse DM. Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong. *Age and ageing.* 2013 Jul 1;42(4):455-61.
72. Tse CY, Chong A, Fok SY. Breaking bad news: a Chinese perspective. *Palliative medicine.* 2003 Jun;17(4):339-43. Doi: 10.1191/0269216303pm751oa
73. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
74. Ko E, Roh S, Higgins D. Do older Korean immigrants engage in end-of-life communication?. *Educational Gerontology.* 2013 Aug 1;39(8):613-22.
75. Zheng RS, Guo QH, Dong FQ, Owens RG. Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study. *International journal of nursing studies.* 2015 Jan 1;52(1):288-96.
76. Kato H, Tamura K. Family Members' Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members' Narratives. *Journal of Hospice & Palliative Nursing.* 2020 Oct; 22(5):401-406.
77. Bryman A. Social research methods. Oxford university press; 2016.
78. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC medical research methodology. 2008 Dec;8(1):1-0.
79. Peters MD. Managing and coding references for systematic reviews and scoping reviews in EndNote. Medical Reference Services Quarterly. 2017 Jan 2;36(1):19-31.
80. Abbey JG. Communication about end-of-life topics between terminally ill cancer patients and their family members. 2008.
81. Salifu Y, Almack K, Caswell G. 'My wife is my doctor at home': A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliative medicine*. 2021 Jan;35(1):97-108.
82. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? Opinions of bereaved family members. *Journal of the American Geriatrics Society.* 1997 Nov;45(11):1339-44.
83. Scott AM. Family conversations about end-of-life health decisions. University of Illinois at Urbana-Champaign; 2010.
84. Chui WY, Chan SW. Stress and coping of Hong Kong Chinese family members during a critical illness. *Journal of clinical nursing.* 2007 Feb;16(2):372-81.
85. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clinics in geriatric medicine.* 1996 May 1;12(2):237-52.
86. Ohs JE, Trees AR, Kurian N. Problematic integration and family communication about decisions at the end of life. *Journal of Family Communication.* 2017 Oct 2;17(4):356-71.
87. Van den Heuvel LA, Hoving C, Schols JM, Spruit MA, Wouters EF, Janssen DJ. Barriers and facilitators to end-of-life communication in advanced chronic organ failure. *International journal of palliative nursing.* 2016 May 2;22(5):222-9.

88. Peterson LJ, Hyer K, Meng H, Dobbs D, Gamaldo A, O'Neil K. Factors associated with whether older adults discuss their EOL care preferences with family members. *Innovation in Aging.* 2018 Nov;2(suppl_1):843. doi:10.1093/geroni/igy023.3141
89. Colletti L, Gruppen L, Barclay M, Stern D. Teaching students to break bad news. *The American journal of surgery.* 2001 Jul 1;182(1):20-3.
90. Villagran M, Goldsmith J, Wittenberg-Lyles E, Baldwin P. Creating COMFORT: A communication-based model for breaking bad news. *Communication Education.* 2010 Jul 1;59(3):220-34.
91. Schapira L. Delivering bad news to patients and their families. *Tumors of the Chest* 2006 (pp. 597-605). Springer, Berlin, Heidelberg.
92. Labaf A, Jahanshir A, Shahvaraninasab A. Difficulties in using Western guidelines for breaking bad news in the emergency department: the necessity of indigenizing guidelines for non-Western countries. *Journal of Medical Ethics & History of Medicine.* 2014 Jan 1;7(1).

---

[1] To avoid conflating EOL and palliative care, we mainly include studies that are primary focus on EOL topic but we note that some EOL studies may contain topic such as palliative care.

PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Appendix 1. Search strategy details

Search logic are also used to assist the search through using Boolean operators such as AND, the search logic allows different combinations to access the most relevant studies, e.g. ‘end of life’ AND ‘communication’ AND ‘family’. All searches were limited to publication dates 1991 to 2021, English language only. The following is a summary of the search strategy in each of the included databases.

1. PsycINFO

Primary keywords and search string using “advanced search” tool; limited to abstracts:

Primary keywords and search string:

abstract((family) OR (parent*) OR (caregiver*)) AND abstract((communicat*) OR (communication skill*)) AND abstract((“end of life”) OR (end-of-life) OR (EOL) OR (terminal) OR (terminally ill)) AND pd(19910101-20211231))

2. Embase

Search string:

((‘family’/exp) OR (parent*) OR (caregiver*)) AND ((communicat*) OR (communication skill*)) AND ((end of life) OR (end-of-life) OR (EOL) OR ((terminal) OR (terminally ill))

3. MEDLINE

Search string:

((“family”) OR (“parent*” OR “parent+”) OR (“caregiver*” OR “caregiver+”)) AND ((“communicat*” OR “communication+”) OR (“communication skill*”)) AND ((“end of life”) OR (“end-of-life”) OR ((“terminal”) OR (“terminally ill”))

4. Ovid nursing database

Primary keywords and search string:

((family) OR (parent*) OR (caregiver*)) AND abstract((communicat*) OR (communication skill*)) AND ((“end of life”) OR (end-of-life) OR (EOL) OR (terminal) OR (terminally ill))

Appendix 2 Summary of each included study.

Theme	Author(s)	Article	Objective(s)	Research design	Sample
1	Abbey, 2008 [41]	Communication about end-of-life topics between terminally ill cancer patients and their family members	To explore EOL communication by addressing patient-family communications	Quantitative - Questionnaire	369 patients
1	Bailey et al., 1999 [55]	Communication at life's end [A patient held palliative care chart facilitates communication]	To promote effective communication, the continuity and co-ordination of care, and sense of partnership for patients and their families through developing a care chart relating to palliative communication	Qualitative - Interviews	40 families and health care providers
1	Byock, 1996 [42]	The nature of suffering and the nature of opportunity at the end of life	To explore the personal experience of suffering in life-limiting illness and to understand the nature of opportunity at the end of life.	Qualitative - Clinical observation	N/A
1	Chui & Chan, 2007 [43]	Stress and coping of Hong Kong Chinese family members during a critical illness	To assess how families cope with stress during a family members' admission to ICU and the relationships between stress and coping	Qualitative - Structured interview	133 participants
1	Fan et al., 2019 [23]	Preference of cancer patients and family members regarding delivery of bad news and differences in clinical practice among medical staff	To study the preferences of cancer patients and their families in way of being informed of their conditions and explore the factors in the underlying preferences	Quantitative - Questionnaire	216 cancer patients 242 family caregivers 176 clinical staff members

1	Githaiga & Swartz, 2017 [44]	Socio-cultural contexts of end-of-life conversations and decisions: bereaved family caregivers' retrospective co-constructions	To examine the content and context of EOL conversations and decisions based on family caregivers of cancer patients in resource-limited areas.	Qualitative - Focus group interview	13 participants
1	Hanson et al., 1997 [45]	What is wrong with end-of-life care? Opinions of bereaved family members	To explore family perceptions of EOL care and communication	Qualitative - Interview	461 family members
1	Kastbom et al., 2020 [29]	Elephant in the room - Family members' perspectives on advance care planning	To explore family members' experiences of advance care planning and EOL communication	Qualitative - Interview	18 family members of deceased nursing home patients
1	Kotecho & Adamek, 2017 [57]	Gender differences in quality of life of urban elders in Ethiopia	To explore how death of a resident affects Certified Nursing Assistants in terms of impacts and support they received.	Qualitative - Semi-structured interviews	140 participants
1	Kramer et al., 2010 [56]	Predictors of family conflict at the end of life: The experience of spouses and adult children of persons with lung cancer	To examine the correlates and predictors of family conflict at the end of life	Quantitative - Surveys	155 participants
1	Lee & Yun, 2018 [46]	Family functioning predicts end-of-life care quality in patients with cancer: multicenter prospective cohort study	To determine whether family caregiver functioning predicts EOL Quality of life received by terminally ill patients with cancer	Quantitative - Questionnaire	264 family caregivers of terminally ill patients
1	Mitchell et al., 2020 [9]	Experiences of healthcare, including palliative care, of children with life-limiting and life-threatening	To understand experiences of healthcare services concerning children with life-limiting conditions and their family members	Qualitative - Interview	31 family members including 10 children

		conditions and their families: a longitudinal qualitative investigation			
1	Ohs et al., 2015 [20]	Holding on and letting go: Making sense of end-of-life care decisions in families	To understand how family members make EOL care decisions and their discursive contradictions that appears during the process	Qualitative - Interview	15 family caregivers of cancer patients
1	Ohs et al., 2017 [47]	Problematic integration and family communication about decisions at the end of life	To examine how families make decisions on behalf of their dying family members at the end of life and how they manage the stressful situation	Qualitative - Interview	22 family members who engaged in EOL conversations
1	Royak-Schaler et al., 2006 [48]	Family perspectives on communication with healthcare providers during end-of-life cancer care	To assess healthcare provider communication on EOL with patients and their family members	Mixed method - Focus group discussions and questionnaires	24 family members of deceased patients
1	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
1	Shaunfield, 2016 [51]	"IT'S A VERY TRICKY COMMUNICATION SITUATION": A COMPREHENSIVE INVESTIGATION OF END-OF-LIFE FAMILY	To explore the communication stressors experienced by family caregivers to examine why communication tasks are perceived as difficult	Qualitative - Interviews	40 caregivers

		CAREGIVER COMMUNICATION BURDEN			
1	Shin et al., 2015 [49]	Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices	To assess cancer patient preferences, family caregiver preferences, and family caregiver predictions of patient preferences regarding the disclosure of terminal status, family involvement in the disclosure process, and EOL choices	Quantitative - Cross-sectional survey	990 patients
1	Towsley et al., 2015 [22]	Conversations about End of Life: Perspectives of Nursing Home Residents, Family, and Staff	To describe the communication, content and process related to EOL conversations among nursing home residents, family and staff	Qualitative - Semi-structured interview	16 residents 12 family members 10 staff members
1	Wong & Chan, 2006 [53]	The qualitative experience of Chinese parents with children diagnosed of cancer	To describe the coping experience of Chinese parents with children diagnosed as having cancer during the treatment stage	Qualitative - Interview	9 parents with children diagnosed with cancer
1	Zhang & Siminoff, 2003 [54]	Silence and Cancer: Why Do Families and Patients Fail To Communicate?	To examine how patients with cancer and their family members make treatment decisions together, and to explore the avoidance of communication and issues families face	Qualitative - Interview	64 participants
2	Azoulay et al., 2000 [22]	Half the families of intensive care unit patients experience inadequate communication with physicians	To explore the needs of family members of patients with terminal illness in order to improve communication and ease their burden	Quantitative - Prospective study	102 ICU patients

2	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
2	Carrese & Rhodes, 1995 [60]	Western bioethics on the Navajo Reservation: Benefit or harm?	To explore the influence of Western biomedical and ethical principles on Navajo values, and how it affects the quality of health care	Qualitative - Interview	34 Navajo people
2	Cherlin et al., 2005 [61]	Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said?	To examine family caregivers' communication with physicians on illness, life expectancy, hospice, EOL discussion timing and their understanding on these issues.	Qualitative - Survey and interviews	218 family caregivers
2	El-Jawahri et al., 2017 [62]	Effects of early integrated palliative care on caregivers of patients with lung and gastrointestinal cancer: a randomized clinical trial	To explore the influence of early integrated palliative care on patients and evaluate caregivers' stress and quality of life	Quantitative - Clinical trail	350 patients
2	Gamble et al., 1991 [63]	Knowledge, attitudes, and behavior of elderly persons regarding living wills	To explore elderly's knowledge, attitude and behavior regarding living wills	Quantitative - Questionnaire	75 elders
2	Gonella et al., 2020 [87]	A qualitative study of family carers views on how end-of-life communication	To explore how EOL communication may contribute to palliative care in nursing homes.	Qualitative - Interview	32 bereaved family carers from 13 different nursing homes

		contributes to palliative-oriented care in nursing home			
2	Gutierrez, 2013 [64]	Prognostic categories and timing of negative prognostic communication from critical care physicians to family members at end- of-life in an intensive care unit	To explore how physicians communicate negative prognoses to families and the influence of timing	Qualitative - Observations and interviews	7 critical care attending physicians 3 critical care fellows 20 family members of patients
2	Huang et al., 2012 [65]	Family experience with difficult decisions in end-of-life care	To determine the frequency and difficulty of decision making in EOL care and its related factors	Quantitative - Questionnaires	302 family caregivers
2	Hui et al., 2014 [58]	Impact of timing and setting of palliative care referral on quality of end- of-life care in cancer patients	To examine the association between timing and setting of palliative care referral and the quality of EOL care	Quantitative – Retrospective cohort study	366 adult patients who died of advanced cancer
2	Lind et al., 2011 [66]	Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions	To examine patients' family members experience of EOL decision making and the process of making the decisions	Qualitative - Interviews	27 family members
2	Low et al., 2009 [26]	Reducing collusion between family members and clinicians of patients referred to the palliative care team	To explore the rate of collusion among family members and clinicians. And to reduce the rate of collusion through the project	Qualitative - Clinical practice improvement project (defining the problem, establish strategies for intervention)	655 patients
2	Ohs et al., 2017 [47]	Problematic integration and family communication	To examine how families make decisions on behalf of their dying family members at	Qualitative - Interview	22 family members who engaged in EOL conversations

		about decisions at the end of life	the end of life and how they manage the stressful situation		
2	Rhoads & Amass, 2013 [59]	Communication at the End-of- Life in the Intensive Care Unit: A Review of Evidence- Based Best Practices	To explore the current data and recommendations on the care of patients in ICU at the end of life	Qualitative	N/A
2	Scott, 2011 [50]	Family conversations about end-of-life health decisions	To demonstrate quality family communication on end-of-life matters is critical to delivering effective advance care through a multiple goals theoretic al perspective	Quantitative - Questionnaires and conversational tasks	121 older parent-adult children
3	Biola et al., 2007 [67]	Physician communication with family caregivers of long-term care residents at the end of life	To explore family perceptions of communication among physicians and family caregivers, as well as the associations of characteristics	Qualitative - Interview	1 family caregiver for each 440 patients
3	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors
3	Chan, 2011 [68]	Being aware of the prognosis: how does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong Chinese context?	To explore the relationships among the patient's awareness of the prognosis, the family's awareness of the prognosis, the patient's anxiety, and difficulty in communicating with family members	Qualitative - Clinical records of deceased cancer patients in a palliative care unit of a public hospital	935 Patients
3	Im et al., 2018 [69]	Patient and Family Related Barriers of Integrating End-	To explore the barriers EOL communication from the	Qualitative - Semi-structured interviews	19 patients with advanced heart failures and their

		of-Life Communication into Advanced Illness Management	perspective of the patients and their family members		family caregivers
3	Im et al., 2019 [70]	"Whatever happens, happens" challenges of end-of-life communication from the perspective of older adults and family caregivers: a Qualitative study	To explore the challenges of EOL communication among older adults and their family care-givers, as well as to understand the illness and goals of care among patients in advanced heart failure.	Qualitative - Semi-structured interviews	22 participants
3	McDarby et al., 2019 [71]	Adult Children's Understanding of Parents' Care and Living Preferences at End of Life	To examine how contact between patients and adult children relate to EOL conversations	Quantitative - Questionnaires	66 adult children 36 older adult patients
3	Trees et al., 2017 [72]	Family communication about end-of-life decisions and the enactment of the decision- maker role	To explore how families enacts their roles as decision makers for their family members who are at the end of their lives	Qualitative - Interview	22 participants
3	Van den Heuvel et al., 2016 [73]	Barriers and facilitators to end-of-life communication in advanced chronic organ failure	To identify the challenges, facilitators and agreement to EOL communication among family members and patients	Qualitative - Interview	158 patients and family caregiver
4	Ayers et al., 2017 [74]	An ethnography of managing emotions when talking about life-threatening illness	To explore how dying patients, palliative care staff and family caregivers communicate about life-threatening illness in Ethiopia	Qualitative - Observations and ethnographic interviews	4 patients. 6 family caregivers and 5 palliative care staff
4	Bowman & Singer, 2001 [14]	Chinese seniors' perspectives on end-of-life decisions	To examine Chinese attitude towards EOL communication	Qualitative - Interview	40 Chinese seniors

4	Chan et al., 2009 [75]	Family predictors of psychosocial outcomes among Hong Kong Chinese cancer patients in palliative care: Living and dying with the “support paradox”	To explore the relationship of family- related factors and psychosocial outcomes among HK Chinese cancer patients in palliative care.	Qualitative - Clinical records and interviews	935 patients
4	Fielding & Hung, 1996 [76]	Preferences for information and involvement in decisions during cancer care among a Hong Kong Chinese population	To assess differences that between Western and Asia cancer patients’ preferences for information on diagnosis, prognosis and treatment options and involvement in treatment decision making	Quantitative - Telephone survey	1136 cancer patients
4	Ho et al., 2013 [79]	Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong	To examine the concept of ‘living and dying with dignity’ in Chinese context; and how the dignity model influenced older terminal patients in Hong Kong	Qualitative - Interview	16 patients
4	Kato & Tamura, 2020 [88]	Family Members’ Experience of Discussions on End-of-Life Care in Nursing Homes in Japan A Qualitative Descriptive Study of Family Members’ Narratives	To explain the meaning of continuous EOL discussion for family members	Qualitative - Semi-structured interviews	13 family members of residents from 3 nursing homes in Kyoto
4	Ko et al., 2013 [77]	Do Older Korean Immigrants Engage in End-	To understand patients’ communication with	Quantitative - Questionnaire	195 older Korean immigrants

		of-Life Communication ?	family and their healthcare providers on EOL care among older Korean immigrants		
4	Peterson et al., 2018 [78]	Factors associated with whether older adults discuss their EOL care preferences with family members	To examine the factors associated with EOL care wishes discussions with family, especially race and ethnicity	Quantitative - Survey	364 participants
4	Tse et al., 2003 [80]	Breaking bad news: a Chinese perspective	To address this difference in attitudes, the ethical principles for and against disclosure are analysed, considering the views in Chinese philosophy, sociological studies and traditional Chinese medicine	Qualitative	N/A
4	Wang, 2010 [25]	Doctor-patient communication and patient satisfaction: A cross-cultural comparative study between China and the US	To examine the relationship between doctor and patient in the Chinese context and the differences with the US	Mixed method -Survey and interview	Survey: 1097 Chinese and 1280 Americans Interview: 26 Chinese
4	Zheng et al., 2015 [81]	Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study	To elucidate Chinese oncology nurses' experience of caring for dying cancer patients	Qualitative - Interview	28 nurses

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	N/A
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	4-6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	4-6
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	4-6
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	4-6
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	4-6
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	4-6
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	4-6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	4-6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	4-6
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	4-6
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	4-6
Certainty	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	4-6

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	6-10
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	6-10
Study characteristics	17	Cite each included study and present its characteristics.	6-10
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	6-10
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	6-10
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	6-10
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	6-10
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	6-10
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	6-10
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	6-10
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	6-10
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	10-12
	23b	Discuss any limitations of the evidence included in the review.	10-12
	23c	Discuss any limitations of the review processes used.	10-12
	23d	Discuss implications of the results for practice, policy, and future research.	10-12
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	N/A
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	N/A
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

PRISMA 2020 Checklist

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/