

## 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.

<b>Theme</b>	<b>Author(s)</b>	<b>Article</b>	<b>Objective(s)</b>	<b>Research design</b>	<b>Sample</b>
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 trial	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