Supplemental material

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BMJ Support Palliat Care

Supplementary table 1 – study characteristics and quality appraisal

First author, year, country	Research question	Data collection method	Participants	Quality (clarity of reporting/ robustness)
Quantitative questionnaire studies				
1) Bachner[24], 2009, Israel	To assess caregivers' perceived level of open communication about illness and death with their terminally ill relatives and to examine the contribution of caregivers' characteristics and situational variables	6 items to assess the level of open communication, structured interviews for caregivers' characteristics and situational variables	N=236 primary caregivers of shortly deceased cancer patients	12 of 13 (7/5)
2) Boerner[25], 2013, USA	To explore the association between family relationship dynamics and ACP (including informal discussions)	type(s) of ACP one engaged in; questionnaires to assess family functioning & relationship	N=293 older adults (>55) with a life-threatening chronic illness: colorectal cancer, Type II diabetes or congestive heart failure	12 of 13 (7/5)
Qualitative studies				
3) An[28], 2017, Canada	To examine (1) the experience of death-related distress; (2) the perceived challenges of communicating distress to family and loved ones; (3) the perceived influence of *Managing Cancer and Living Meaningfully* (CALM) therapy on communication	In-person semi-structured interviews	N=17 Patients with advanced cancer (prognosis: 12 - 18 months)	10 of 16 (7/3)
4) Badr[8], 2006, USA	To delineate what social constraints exist for couples facing lung cancer and to determine whether couples use relationship talk, which, with other communication strategies, may assist them in overcoming these constraints	Individual semi-structured interviews	N=25 Patients with advanced lung cancer (n=13), Spouses (n=12)	10 of 16 (7/3)
5) Booker[39], 2018,	To understand the barriers to and facilitators of ACP from the perspectives of patients, family members and clinicians in the	Individual semi-structured interviews	N=19	12 of 16 (7/5)

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	Canada	unique context of haematological malignancy (high risk of treatment related mortality)		Patients undergoing haematopoietic stem cell transplantation (n=6), family members (n=5) and clinicians (n=8)	
6)	Caughlin[31], 2011, USA	What do families discuss or avoid discussing regarding the lung cancer experience? What reasons do family members report having for avoiding certain topics? How do people manage communicative dilemmas pertaining to the avoidance of discussions about lung cancer?	In-depth, semi-structured interviews	N=35 Adult children from a parent deceased due to lung cancer	13 of 16 (8/5)
7)	Cervantes[30], 2017, USA	to explore the preferences of Latino patients receiving dialysis regarding symptom management and ACP	semistructured face-to-face interviews	N=20 Latinos with end-stage renal disease on hemodialysis	11 of 16 (7/4)
8)	Fried[32], 2008, USA	To examine the experiences of patients and caregivers, focusing on communication and decision-making about treatment at the end of life, as related by the caregiver, in order to improve our understanding of how they might best plan for end-of-life care.	In-depth, semi-structured interviews	N=64 caregivers of community dwelling patients who were age 60 years or older who died with advanced cancer, chronic obstructive pulmonary disease, or heart failure	11 of 16 (6/5)
9)	Generous[26], 2017, USA	To examine retrospectively wished for and avoided conversations during the EoL with a deceased relational partner and reasons why they did not engage in the conversations	Two open-ended questions as part of a larger national online survey	N=107 Participants with a deceased relational partner (age range: 18-79)	12 of 16 (7/5)
10)	Glass[37], 2008, USA	To examine informal family communication about EoL preparation and preferences	In-depth exploratory interviews	N=30 Older adults (>70), n=15, Adult children, n=15	10 of 16 (7/3)
11)	Im[40], 2019, Canada	To explore patients' and caregivers' understanding of illness, experiences of uncertainty, and perceptions of end-of-life discussions in advanced illness.	Semi-structured interviews	N=19	14 of 16 (8/6)

			Older adults with advanced heart failure (n=12) and family caregivers (n=7)	
12) Keeley[33], 2015, USA	To examine how participants recall the challenges they encountered during the final conversations they had with a family member who has since died	Online survey Open-ended questions	N=107 Participants with a deceased family member	11 of 16 (8/3)
13) Lum[38], 2019, USA	To describe Parkinson disease patient and care partner perspectives on ACP	Structured Interview guide	N=60 Patients with Parkinson disease (n=30) and care partners (n=30)	14 of 16 (7/7)
14) McGrath[29], 2004, Australia	To compare findings from hospice patients and hematology survivors on the topic of talking about dying to significant others within their network of family and friends.	Open-ended Interviews	N=14 Hospice participants with a terminal diagnosis	9 of 16 (7/2)
15) Salander[41], 2002, Sweden	To detect the various ways the patient spouse couples dealt with this severe situation and how they discussed it with each other.	Repeated thematically structured interviews	N=50 Patients with malignant gliomas grade III-IV (n=25) and their spouses (n=25)	11 of 16 (8/3)
16) Schubert[35], 2018, USA	To characterize post-ACP conversations (and reasons for missed conversations) regarding medical wishes between seriously ill patients and their family caregivers.	Semi-Structured interviews	N=188 Family caregivers of patients in an advanced stage of a life-limiting illness (cancer, cardiac, pulmonary, renal)	12 of 16 (6/6)
17) Stone[34], 2012, USA	What are the communication challenges associated with caregiving in the context of lung cancer? How do adult children who have provided care and lost a parent to lung cancer cope with the communication challenges they experience?	Interviews with open-ended and follow-up questions	N=35 Adult children and familial caregivers for a parent who had died from lung cancer	12 of 16 (8/4)
18) Towsley[42], 2015, USA	To describe the communication, content and process, related to EOL conversations among nursing home residents, family, and staff	Semi-Structured interviews	N=38	12 of 16 (7/5)

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			Nursing home residents (average ages of 88.4 years; n=16), family members (n=12) and staff (n=10)	
19) Zhang[15], 2003, USA	How do the patient and family avoid talking about their experiences during later stage cancer? What specific issues do patients with late-stage cancer and their families avoid discussing? What are the common thought processes associated with the avoidance of family communications in later stage cancer?	Interviews (individual or focus group)	N=77 Stage III or IV lung cancer patients (n=37), Caregivers (n=40)	12 of 16 (8/4)
20) Wittenberg-Lyles[36], 2012, USA	To investigate concerns shared by informal caregivers (friends or family members) who were designated or legally appointed as the family caregiver of a hospice patient to learn more about family communication patterns during hospice caregiving	secondary data analysis	N=56 Family caregivers of hospice patients	10 of 16 (7/3)