

Supplementary table 2 – Conceptualisation and occurrence of End-Of-Life communication

First author, year, country	Participants	Communication about End-Of-Life care, death and dying	Occurrence of communication in the sample
Bachner [24], 2009, Israel	N=236 primary caregivers of shortly deceased cancer patients	Caregivers' perceived level of open communication about the illness and approaching death with their terminally ill relatives in the last 3 months of the patient's life	The level of open communication between caregivers and patients about illness and death was found to be low, indicating substantial communication difficulties between them.
Boerner [25], 2013, USA	N=293 older adults (>55) with a life-threatening chronic illness: colorectal cancer, Type II diabetes or congestive heart failure	Different types of ACP including informal discussions about future health care plans and preferences with family members	Nearly half (48.1%) of study participants adopted a two-pronged approach to planning: having had discussions and having executed at least one of the two formal components of the AD (i.e., living will or DPAHC). 23.5% had discussions only, 28.3% had done no planning.
An [28], 2017, Canada	N=17 Patients with advanced cancer (prognosis: 12 - 18 months)	Communication about mortality-related concerns or death-related distress or fears	While it was important for participants to discuss death-related fears, they perceived numerous obstacles to doing so. Most participants stated that they primarily received instrumental support (e.g., help with household chores, daily activities) rather than emotional support from their caregivers and loved ones.
Badr [8], 2006, USA	N=25 Patients with advanced lung cancer (n=13), Spouses (n=12)	Relationship talk (e.g. quality of relationship, shared memories, planning for the future, problem solving) and discussing illness: e.g. discussing continued tobacco use, cancer-related symptoms, prognosis, and the emotional effects of lung cancer on the spouse	Many participants reported avoiding or having difficulty discussing the cancer itself (36%) or prognosis, fears of death, or funeral arrangements (68%) because of the emotional toll of the disease and a desire to protect one's partner
Booker [39], 2018, Canada	N=19 Patients undergoing haematopoietic stem cell	Engagement in ACP, including discussion of disease and treatment expectations with family caregivers	ACP discussions occurred sporadically and, at times, in less than ideal

	transplantation (n=6), family members (n=5) and clinicians (n=8)		circumstances, such as when a patient's condition deteriorated, often precluding meaningful discussion.
Caughlin [31], 2011, USA	N=35 Adult children from a parent deceased due to lung cancer	Families' communication and coping in response to a parent's diagnosis of, and eventual death from, lung cancer; exploring what issues are (not) discussed, reasons for avoidance of certain topics	Results showed that family members frequently avoid discussing both informational and emotional issues.
Cervantes [30], 2017, USA	N=20 Latinos with end-stage renal disease on hemodialysis	Talking about palliative care preferences of Latino patients with ESRD around symptom management and advance care planning (ACP) conversations	No further information
Generous [26], 2017, USA	N=107 Participants with a deceased relational partner (age range: 18-79)	Retrospectively wished for and avoided conversations during the end of life with a deceased relational partner (avoided topics in final conversations); focus on relational communication between loved ones at the End-of-Life	Results revealed the following wished for but avoided conversations: negative relationship characteristics; death and dying; postdeath arrangements; and personal information
Glass [37], 2008, USA	N=30 Older adults (>70), n=15 Adult children, n=15	Focus on informal family communication about end-of-life preparation and preferences (e.g. discussions about funeral or end-of-life care, living will, health care proxy)	Nine older adults reported discussing end-of-life preparation and preferences with their adult children; six had barely discussed the topic at all. Ten younger adults reported having talked with their parents about end-of-life preparation and preferences; five had not discussed it.
Fried [32], 2008, UA	N=64 caregivers of community dwelling patients who were age 60 years or older who died with advanced cancer, COPD, or heart failure	Communication about End-Of-Life care and medical decision-making, talking about disease and prognosis before the patient's death (e.g. how decisions were made, about patient-caregiver communication, concerns)	No further information on the level of communication (67 % of deceased patients had a living will, 60 % named a health care proxy)
Im [40], 2019, Canada	N=19	Talking about the understanding of illness, experiences of uncertainty and end-of-life	Most participants had not engaged in prior end-of-life discussions with family members or health-care providers. Even among

	Older adults with advanced heart failure (n=12) and family caregivers (n=7)	discussions (e.g. wishes before dying, end-of-life care preferences)	participants who shared their awareness of death as an inherent part of their future, they had not engaged in end-of-life discussions. Patients and caregivers wanted to wait until further decline to engage in end-of-life discussions.
Keeley [32], 2015, USA	N=107 Participants with a deceased family member	Final conversations, relationship talk, challenges encountered during final conversations	Participants had to confirm having had at least one final conversation with a deceased family member for inclusion. They report the challenges of communication at the End-of-Life.
Lum [43], 2019, USA	N=60 Patients with Parkinson disease (n=30) and care partners (n=30)	Talking about ACP, future medical care planning	No further information
McGrath [29], 2004, Australia	N=14 Hospice participants with a terminal diagnosis	Talking about dying and/or the experience with terminal illness	All the participants clearly indicated that the topic of death and dying is personal, frightening, and difficult to talk about for most people. Talking about dying is particularly problematic in intimate relationships with family and friends for a myriad of reasons.
Salander [41], 2002, Sweden	N=50 Patients with malignant gliomas grade III-IV (n=25) and their spouses (n=25)	Examination of the following themes: dealing with the severe situation and discussing it, experiences of medical care, knowledge and ideas about the disease, relationship to partner and family (including how they discussed the patient's disease), interests, and future plans.	Four different social processes were detected: 1) the patient does not seem to be aware, the spouse is aware but pretends not to be (16%); 2) both are aware, but the patient does not want to share; they drift apart (20%); 3) both are aware, they do/do not talk openly about the gravity of the situation; nevertheless, there is a joint platform (56%); and 4) neither patient nor spouse seems to be aware; they carry on living as before (8%).
Schubart [35], 2018, USA	N=188 Family caregivers of patients in an advanced stage of a life-limiting illness (cancer, cardiac, pulmonary, renal)	Conversations about patients' goals and preferences for end-of-life treatment in the weeks after an ACP event	69,7% of the dyads had 2–3 conversations lasting 3–5 minutes each in the weeks immediately following ACP. These conversations most commonly addressed general patient wishes about quality of life and specific medical treatments.
Stone [34], 2012, USA	N=35	Family communication in the context of advanced lung cancer and communication challenges	No further information

	Adult children and familial caregivers for a parent who had died from lung cancer	associated with caregiving in the context of lung cancer, coping with communication challenges	
Towsley [42], 2015, USA	N=38 Nursing home residents (average ages of 88.4 years; n=16), family members (n=12) and staff (n=10)	Conversations about end-of-life preferences (e.g. values, location of death, comfort and support, medical care)	The overarching theme—missed conversations—describes End-of-Life-related communication. Residents, families, and staff rarely talked about End-of-Life care preferences, nor did they pass along information about preferences or initiate conversations about End-of-Life care with each other.
Wittenberg-Lyles [36], 2012, USA	N=56 Family caregivers of hospice patients	Mortality communication, or talk between terminally ill patients and families about impending death and the dying process	No further information
Zhang [15], 2003, USA	N=77 Stage III or IV lung cancer patients (n=37), Caregivers (n=40)	Avoidance of family communication about cancer; how are families communicating about cancer, treatment and making treatment decisions together as a family, experiences during later stage cancer, avoided topics, thought processes associated with avoidance of family communication	65% of the families experienced a variety of communication problems. 27% reported that the patient hardly talked about cancer with any family members. In three of these families, patients kept family members completely in the dark. The remaining 10 families (38%) reported some communication breakdown between family members. In six of these families, a deliberate effort was made to avoid in-depth conversations about cancer with each other. In two other families, patients avoided talking to spouses because of the spouse's depressed or anxious mental state. These communication problems, taken as a whole, could be categorized as a phenomenon of silence