

A REVIEW OF FAMILY OUTCOMES AND PERCEPTIONS

Appendix 1. Draft EMBASE search – ELSEVIER interface

Number	Query	Results
1	‘end of life*’: ab, ti AND [2013-2018]/py	11,576
2	‘palliative care*’: ab, ti AND [2013-2018]/py	15,844
3	‘dying*’: ab, ti AND [2013-2018]/py	10,736
4	‘terminal ill*’: ab, ti AND [2013-2018]/py	683
5	‘hospice*’: ab, ti AND [2013-2018]/py	6,082
6	#1 OR #2 OR #3 OR #4 OR #5	34,250
7	‘intensive care unit*’: ab, ti AND [2013-2018]/py	51,461
8	‘critical care*’: ab, ti AND [2013-2018]/py	13,916
9	‘icu*’: ab, ti AND [2013-2018]/py	45,697
10	‘coronary care unit*’: ab ti, AND [2013-2018]/py	1,043
11	#7 OR #8 OR #9 OR #10	86,549
12	(‘family*’: ab, ti OR ‘families*’: ab, ti) AND [2013-2018]/py	309,934
13	(‘caregiver*’: ab ti, OR ‘caregivers*’: ab ti) AND [2013-2018]/py	30,402
14	(‘relative*’: ab, ti OR ‘relatives*’: ab ti) AND [2013-2018]/py	428,830
15	‘surrogate*’: ab ti AND [2013-2018]/py	29,989
16	#12 OR #13 OR #14 OR #15	757,856
17	#6 AND #11 AND #16	1,126
18	#17 AND ‘article’/it AND ([adult]/lim OR [aged]/lim OR [middle ages]/lim OR [very elderly]/lim)	215

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Appendix 2. The matrix of Qualitative Results

#	Article	Objective	Method	Sample	Rigor	Result
1	Adams, Bailey Jr, Anderson, & Thygeson, 2013 ⁴⁶ United States	To describe the responses of family members through the lens of Adaptive Leadership in a prospective case study of a patient transitioning from curative to palliative care.	Qualitative descriptive case study	4 family members (1 patient) (contacted during the ICU stay)	(1) One in-depth interview (2) 3 observations of family conferences (3) ICU daily rounds (saturation not met)	* Nurse Adaptive Leadership behaviors can facilitate the transition from curative to palliative care by helping family members do the adaptive work of letting go. * Adaptive Leadership provides a framework for health care professionals to provide family centered shared decision-making in an ICU setting. * The adaptive challenges involve recognizing that the prognosis is poor, identifying the patient's goals and making decisions based on those goals.
2	Baumhover, 2015 ³⁵ United States	To generate a substantive theory on how family members of patients in adult critical care come to realize that their loved one is dying.	Glaserian grounded theory methodology retrospective study	14 family members (contacted 6 to 60 months after patients died in order to spare those who might have been actively grieving)	Semi-structured interviews (saturation met)	* Family members went through 6 phases in the process during end-of-life in the ICU: (1) patient's near-death awareness, (2) dying right in front of me, (3) turning points in the patient's condition, (4) no longer the person I once knew, (5) doing right by them, and (6) time to let go. * Nurses are in a pivotal position to educate families. * The early validation of the code status and advanced directive of the patient is priority, especially before the patient's health condition worsens.
3	Cook et al., 2015 ⁴⁷ Canada	To explore the bereaved families' experiences of 3 Wishes Project in the ICU	Mixed study – qualitative descriptive study	50 family members (40 patients) (Contacted each family member by telephone 1 to 6 months after the patient's death)	Semi-structured interview (29 face-to-face interviews; 11 telephone interviews) (saturation met)	* For families, the 3 wishes project (was generated by patients, family members and clinicians) created positive memories and individualized end of life care for their loved ones. * The central theme: personalizing dying in the ICU; 3 related domains: (1) dignifying the patient (2) giving the family a voice (3) fostering clinician compassion.

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4	Coombs, 2015 ³⁶ UK	To explore the needs of family members during and after treatment has been withdrawn in intensive care unit	Interpretive phenomenological qualitative study – thematic analysis	21 family members (17 interviews) (contacted in 6-12 months after the death)	In-depth semi-structured interview (saturation met)	* Three themes emerged: (1) alleviate further suffering of the dying person (2) re-establish identity of the dying person (3) re-connect relationships with the dying person. * Family members expressed on-going distress. * As such situations can leave negative memories about end-of-life care in the ICU, it is important that nurses address any such deficits using effective, structured and honest communication approaches.
5	Coomb, Tang, & Long-Sutehall, 2016 ⁵¹ UK	To explore the concept of vigilant attentiveness in family members of adult patients dying in intensive care.	Qualitative study – Secondary data analysis	11 family members (8 interviews) (Secondary data analysis from two studies: (1) the 18-month study 2008-2009 (2) the 12-month study in 2012)	Secondary data analysis (saturation not met)	1. The quality of information given to families and the understanding of families about death and dying impacts on health outcomes of bereaved family members. 2. The concept of ‘vigilant attentiveness’ can inform how doctors and nurses assess family understanding and comprehension of deterioration at end of life. 3. By asking pertinent questions about what families notice, and do not notice about their relative at end of life, health care professionals can refine their communication style, tailoring the information provided to family members in preparation for death.
6	Dionne-Odom, Willis, Bakitas, Crandall, & Grace, 2015 ³⁷ United States	To identify and describe the underlying psychological processes of surrogate decision making for adults at end-of-life in the ICU.	Qualitative case study	19 surrogate decision makers (contacted a minimum of 8 weeks after patient’s death to allow for bereavement)	In-depth semi structured ‘cognitive task analysis’ interviews (saturation met)	* Before outwardly expressing decisions to the health care team about the patient’s care, all surrogate decision makers reported making an internal judgment about the degree to which one or more medical treatments or the general condition of the patient was acceptable or unacceptable. * These internal decision judgments were impacted by three primary psychological dimensions: (1) gist impressions (2) distressing emotions (3) moral intuitions.

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						* Nurses can best help surrogate decision makers in their decision making by encouraging their physical presence at the bedside.
7	Donnelly & Psirides, 2015 ³⁸ New Zealand	To explore the experience of relatives of patients dying in ICU.	Grounded theory qualitative study	14 family members (10 patients) (contacted 2 weeks following the death)	In-depth face-to-face interview (saturation met)	* Families appreciate kindness and attention, with sensitive regular communication from nurses and doctors. * One to one nursing is ideal for families, but families wish more contact with ICU doctors. * Limited access to the patient according to ICU protocol is distressing for grieving relatives. * The QODD (quality of dying and death) used in ICU has limitations.
8	Gutierrez, 2013 ⁴⁸ United States	To explore critical care physician communication of negative prognoses to families and identify timing influences.	Ethnographic methodology	20 family members (58 patients) (contacted during the ICU stay)	12 to 18 hours per week were spent each week observing communication in the ICU) 5 interviews with physicians and 20 interviews with family members (saturation not met)	* Providers will better meet the needs of families who desire earlier prognostic information by separating prognostic communication from decision-making and communicating the possibility of a poor prognosis based on intuitive knowledge, while acknowledging the uncertainty inherent in prognostication. * Six prognostic categories: 1) death is imminent 2) death is inevitable 3) recovery is highly unlikely 4) death is probable 5) recovery is prolonged 6) recovery is unknown.
9	Higginson et al., 2016 ⁴⁹ UK	To explore patterns of the decision-making process during critical care, and sources of conflict and resolution.	Ethnographic study	19 family members (16 patients) (contacted during the ICU stay)	(1) Non-participant observation (2) Case studies (3) Semi-structured interviews (4) Direct observation (5) Review of medical records (saturation not met)	* Four trajectories with distinct patterns: (1) curative care from admission (2) oscillating curative and comfort care (3) shift to comfort care (4) comfort care from admission. * Conflict occurred most commonly in the trajectories with oscillating curative and comfort care. * A need to support early communication, especially around values and preferred care outcomes, from which other decision follows, including DNAR.

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						* Decisional conflicts were associated with fluctuation and uncertainty. Consistent communication, understanding of individual preferences, and being flexible decreased levels of fluctuation and uncertainty.
10	Hutchinson & Van Wissen, 2017 ³⁹ New Zealand	To gain insight into family members' experiences when an adult intensive care unit patient is taken home to die.	Qualitative descriptive study (Sandelowski methodology)	Four family members (2 patients) (contacted during the ICU stay)	Open-ended Interviews (saturation not met)	* Two main themes: (1) "Value": the importance of going home for the family (2) "process": the family's experience of the process of going home. * Going home to die from the intensive care unit is a positive but challenging experience for the family and requires collaboration. * Nurse-led initiative to offer the option of going home to die.
11	Kisorio & Langley, 2016 ⁴⁰ South Africa	To elicit family members' experiences of end-of-life care in adult intensive care units.	A descriptive exploratory qualitative study - Using Tesch's steps of analysis	17 family members Purposeful sampling (contacted right after the death)	Semi-structured interviews Data collection and analysis took place simultaneously (saturation met)	* Five major themes emerged: (1) most of the time we are in darkness (2) emotional support (3) involvement (4) family presence (5) spiritual support. * Families who had dying relatives in the ICU did not receive adequate care. * Negative experiences expressed by the families outweighed their positive experiences, as most families were not happy with the care observed or personally received while their relatives were in the ICU. * To enhance family satisfaction with care and maintain regular, honest and direct communication from consistent health care providers. * Under supervision, families should be allowed to take part in direct patient care if they wish to as this could bring about peace of mind even after death. * Having a relative present at the end-of-life of a loved one can be distressing, hence there is a need to provide continuous emotional support to the families during the dying process of their relative in the ICU.

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12	Ling, Nortvedt, Lore, & Hevrøy, 2013 ⁴¹ Norway	To explore how relatives of terminally ill, alert and competent intensive care patients perceived their involvement in the end-of-life decision-making process.	Qualitative study – using a thematic narrative analysis and hermeneutic approach	11 family members (6 deceased patients); 6 interviews (contacted within one year of the death)	Semi-structured interview (saturation met)	* Three themes emerged: (1) Transparency in communication (2) Participation in the end-of-life decision-making process (3) Responsibility in the decision making. * Informed shared decision making should be utilized and optimized in intensive care, where nurses and physicians work with both the patient and his or her family and regard the family as partners in the process.
13	Noome, Dijkstra, van Leeuwen, & Vloet, 2016 ⁴² Netherlands	To examine the experience(s) of family with nursing end-of-life care in the intensive care unit after a decision to end life-sustaining treatment, and to describe what nursing care was most appreciated and what was lacking.	Phenomenological approach – inductive thematic analysis	26 family members (contacted > 3 weeks after death)	Semi-structured interview (saturation not met)	* Four themes emerged: (1) Communication between intensive care nurses, critically ill patients and family (2) Nursing care for critically ill patients (3) Nursing care for families of critically ill patients (4) Pre-conditions (such as single room, open visiting hour, chaplain). * Families appreciated that intensive care nurses were available at any time and willing to answer questions. * Care was lacking because families had a sense of responsibility for obtaining information, had problems to understand their role in the decision-making process, and were not invited by nurses to participate in the care. * Topics needing more attention are information and support for the family. ICU nurses can adapt their care to the needs of the family.
14	Nunez et al., 2015 ⁴³ United States	To describe acutely-bereaved surrogates' experiences surrounding the decision to limit life support in the ICU	Qualitative content analysis study	N = 23 (patients) N = 23 (surrogates) Interview with surrogates approximately 4 weeks after a patient's death in one of 6 ICUs at 4 hospitals	In-depth, single-session semi-structured interview (saturation met)	* Surrogates preferred an active decision-making role or preferred to share responsibility with the physicians. * No surrogates preferred a passive role. * Surrogates reported that key stressors are: 1) uncertainty and 2) witness or empathic suffering. * Participating in decision making helped surrogates to 1) regain control,

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						2) counteract feelings of helplessness, and 3) end their empathic suffering.
15	Pattison, Carr, Turnock, & Dolan, 2013 ⁴⁴ UK	To explore the meaning of end-of-life care for critically ill cancer patients through family experiences	Heideggerian Phenomenological qualitative study – using Van Manen’s phenomenological analysis framework	6 patients’ spouses and 12 non-spouse family members (contacted 3 months after the death)	Face-to-face interview (saturation not met)	* Three main themes included: (1) dual prognostication (was characterized by cancer and critical illness issues and the ongoing need to face mortality in the context of a diagnosis of cancer and critical illness) (2) the meaning of decision-making (3) care practices at end of life. * Core tenets of good practice in end of life care included comfort, less visible technology, privacy and dignity. * Nurses had an important role in determining and enacting end of life care.
16	Wiegand, 2016 ⁴⁵ United States	To understand the experience of families when a family member had an unexpected life-threatening illness or injury and who died after life-sustaining therapy was withdrawn	Hermeneutic phenomenological study – inductive approach and thematic analysis by Van Manen	22 family members (1-2 years after the patient’s death)	13 telephone interview 9 face-to-face interview (saturation met)	* Six categories evolved: (1) Preparing for the dying process (2) The dying environment (3) Perceptions of patient comfort (4) The death vigil (5) Essential aspects of care (6) Together as a family. * The death vigil was very difficult for families. * It was important to families that they have consistent nurses especially at the time of death. * It was especially helpful that there were no restrictions placed on visitation.
17	White et al., 2016 ⁵⁰ United States	To determine the prevalence of and factors related to physician-surrogate discordance about prognosis in intensive care units (ICUs)	Mixed methodology	N = 174 (patients) N = 229 (surrogates) (contact family on a patient’s fifth day of receiving mechanical ventilation)	Semi-structured interview (saturation not met)	* Three factors of discordance are that 1) surrogates need to maintain hope to benefit the patient, 2) a belief that the patient had unique strengths unknown to the physician and 3) the religious belief.

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Appendix 3. The Matrix of Quantitative Results

#	Study	Purpose / Intervention	Methodology / Theory	Sample / Setting	Measurement	Outcomes
1	Braus et al., 2016 ⁵²	To evaluate the effects of the end-of-life intervention on family outcomes <u>Intervention:</u> A palliative care clinician interacting with the ICU physicians on daily rounds for high-risk patients	Prospective, descriptive study with a post survey <u>Theory:</u> Not reported	<u>Patients:</u> N = 103 (intervention); 100 (control) <u>Family:</u> N = 58 (intervention); 62 (control) <u>Setting:</u> MICU/ Single center/ United States	<ul style="list-style-type: none"> Family Satisfaction in the ICU (FS-ICU) The overall quality of death and dying (QODD-1) The Post-Traumatic Stress Disorder (PTSD) Checklist-Civilian (PCL-C) The Patient Health Questionnaire depression scale (PHQ-8) 	<ul style="list-style-type: none"> Integrating a palliative care clinician into the ICU daily rounds could provide: <ol style="list-style-type: none"> Increased amount of and earlier family meetings. A Shorter hospital stay. Less PTSD and depression. No differences on family satisfaction.
2	Cook et al., 2015 ⁴⁷	To evaluate 3 Wishes Project on families' perception <u>Intervention:</u> 3 Wishes project	Mixed method <u>Theory:</u> Not reported	<u>Patients:</u> N = 40 <u>Families:</u> N = 29 <u>Settings:</u> medical-surgical ICU/ Single center/ Canada	<ul style="list-style-type: none"> Quality of end-of-life Care -10 instrument 	<ul style="list-style-type: none"> End-of-life care was rated high by Quality on end-of-life Care-10 scores (completed by 26 out of 29 families).
3	Cox et al., 2018 ⁵³	To develop and pilot an app platform for families of ICU patients that enhances the delivery of needs-targeted palliative care <u>Intervention:</u> app platform to help clinicians identify potential families for palliative care referral and allow families to report their needs	Two-phases pilot study <u>Theory:</u> Concept framework from Cox et al. (2016)	<u>Patients:</u> N = 39 (14 in intervention; 25 in control group) <u>Families:</u> N = 67 (18 in intervention; 49 in control group) <u>Settings:</u> medical, surgical, cardiac, neurological ICUs/ Single center/ United States	<ul style="list-style-type: none"> Client Satisfaction Questionnaire (CSQ) Systems Usability Scale (SUS) needs of social nature, existential concerns, symptoms, and therapeutic interaction (NEST) Patient-centeredness of care scale (PCCS) Perceived stress scale (PSS) 	<ul style="list-style-type: none"> Family members report high PC planner acceptability (CSQ), usability (SUS). Decreased scores of NEST, increased scores of PCCS and decreased scores of PSS. Compared to control group, intervention patients received earlier palliative care consultation, shorter hospital length of stay, and more hospice care.
4	Curtis et al., 2016 ³²	To determine if an ICU communication facilitator reduces family distress and intensity of end-of-life care <u>Intervention:</u> ICU communication facilitator	RCT <u>Theory:</u> Not reported	<u>Patients:</u> 168 (82 in intervention group; 85 in control group) <u>Families:</u> N = 268	<ul style="list-style-type: none"> Patient Health Questionnaire (PHQ-9) Generalized Anxiety Disorder (GAD-7) PTSD Checklist Civilian Version (PCL) 	<ul style="list-style-type: none"> The intervention was associated with decreased depressive symptoms at 6 months, but no differences at 3 months or in anxiety or PTSD. The intervention decreased ICU costs among all patients,

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				<u>Settings:</u> ICUs/ Multi center/ United States		<ul style="list-style-type: none"> particularly among decedents. Among decedents, the intervention reduced ICU and hospital length of stay. The intervention was not associated with ICU mortality.
5	Ersek, Thorpe, Kim, Thomasson, & Smith, 2015 ⁶⁴	To compare family evaluation of end-of-life care in communication living centers (CLC) with ICUs <u>Variables:</u> Location of end-of-life care	Retrospective chart review and survey <u>Theory:</u> Not reported	<u>Patients:</u> N = 33,497 deceased veterans (7,384 in CLC; 7,244 in ICU) <u>Family:</u> N = 21,867 <u>Setting:</u> ICUs/ Multicenter/ United States	<ul style="list-style-type: none"> The global Bereaved Family Survey (BFS) 	<ul style="list-style-type: none"> Quality of end-of-life care was better in community living centers than ICUs.
6	Ersek et al., 2017 ⁶³	To compare families' evaluations of end-of-life care for patients with non-small cell lung cancer between aggressive care and palliative care <u>Variables:</u> 1) aggressive care 2) hospice/palliative care	Retrospective observational study <u>Theory:</u> Not reported	<u>Patients:</u> N = 847 <u>Family:</u> N = 847 <u>Setting:</u> ICUs/ Multicenter/ United States	<ul style="list-style-type: none"> The Bereaved Family Survey Performance Measure (BFS-PM) 	<ul style="list-style-type: none"> Mean BFS-PM (bereaved family survey performance measure) scores were found lower for veterans who experienced aggressive care compared with those who did not. Among aggressive care, chemotherapy was associated with lower BFS-PM.
7	Gallagher & Krawczyk, 2013 ⁸¹	To assess family satisfaction with end-of-life care, focusing on the last 48 hours of life across diverse locations of care <u>Variables:</u> Locations of end-of-life care (palliative care unit, ICU, small acute care, residential care, large acute care and hospice)	Retrospective observational study <u>Theory:</u> Not reported	<u>Patients:</u> N = 100 <u>Family:</u> N = 90 <u>Setting:</u> ICU/ Single center/ Canada	<ul style="list-style-type: none"> The After-Death Bereaved Family Member Interview (ADBFMI) 	<ul style="list-style-type: none"> Compared to palliative care unit residents, ICU residents had more unmet needs for emotional support.
8	Gerritsen et al., 2013 ⁶⁰	To elucidate how family members experience the	Prospective study	<u>Patients:</u> N = 100 <u>Family:</u> N = 100	<ul style="list-style-type: none"> Quality of Dying and Death (QODD) 	<ul style="list-style-type: none"> Families were satisfied with overall QODD and felt

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		dying process of their loved ones in ICUs	<u>Theory</u> : Not reported	<u>Setting</u> : ICU/Multicenter/Netherlands		supported by the ICU caregivers. <ul style="list-style-type: none"> 38% of families believed that they participated in making the decision. Pain control and the quality of the discussion were scored lower by families.
		<u>Intervention</u> : No specific intervention				
9	Gerritsen et al., 2018 ⁶⁶	To examine the euroQODD's usability and its assessments of end-of-life care between Denmark and the Netherlands family members	Prospective study	<u>Patients</u> : N = 178 <u>Families</u> : N = 217	• Quality of Dying and Death (QODD)	• Overall rating of care and pain control was higher in Denmark than Netherlands.
		<u>Variables</u> : Locations of end-of-life care	<u>Theory</u> : Not reported	<u>Setting</u> : ICU/Multination/Multicenter/Netherlands & Denmark		
10	Gerritsen et al., 2017 ⁶⁷	To evaluate families' end-of-life experience as measured by the QODD between the United States and the Netherlands	Prospective study	United States <u>Patients</u> : N = 346 <u>Families</u> : N = 346 Netherlands <u>Patients</u> : N = 100 <u>Families</u> : N = 100	• Quality of Dying and Death (QODD)	• Overall QODD score was the same in both countries. • U.S. families rated the quality of two items higher than did the Netherlands families: 1) time spent with loved ones 2) time spent alone.
		<u>Variables</u> : Locations of end-of-life care	<u>Theory</u> : Not reported	<u>Setting</u> : ICU/Multination/Multicenter/United States & Netherlands		
11	Hartog et al., 2015 ¹³	To assess end-of-life care and communication from families' psychological symptoms	Prospective observational study	<u>Patients</u> : N = 145 <u>Families</u> : N = 84	• Impact of Event Scales (IES) • Hospital Anxiety and Depression Scale (HADS)	• Families reported high satisfaction with decision-making and care. • 87% thought their degree of involvement had been just right. • 51%, 48% and 33% of families had symptoms of PTSD, anxiety or depression. • Families' satisfaction with medical care and communication predicted less anxiety.
		<u>Intervention</u> : No specific intervention	<u>Theory</u> : Not reported	<u>Setting</u> : 2 mixed-surgical, 1 neurological and 1 medical ICUs/single center/Germany		

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12	Hinderer, Friedmann, & Fins, 2015 ⁶⁸	To explore proxy decisions related to mechanical ventilator withdrawal in scenarios characterizing 3 distinct disease trajectories (cancer, stroke, and heart failure) <u>Variables:</u> End-of-life decision making among diseases (cancer, stroke and heart failure)	Retrospective secondary analysis <u>Theory:</u> 1) theory of surrogate decision making 2) the contractual-covenantal hypothesis	<u>Patients:</u> N = 59 <u>Families:</u> N = 51 <u>Setting:</u> ICU/ Single center/ United States	<ul style="list-style-type: none"> Developed a questionnaire for the study (Cronbach $\alpha = 0.925$) 	<ul style="list-style-type: none"> Patient and proxy agreement ranged from 48% to 94%. Agreement was the lowest in heart failure when the directive indicated “do nothing” or “did not indicate any preference”. Changing directives from “do nothing” to “more hopeful” in heart failure (uncertain prognosis) had the highest agreement among modified scenarios. Despite wide variability in agreement, patients reported a high level of trust in their proxies’ decisions.
13	Jinsoo et al., 2016 ⁵⁴	To assess the effects of multidisciplinary meetings with family members of patients in the ICU <u>Intervention:</u> multidisciplinary meeting with families	Pilot prospective descriptive study <u>Theory:</u> Not reported	<u>Patients:</u> N = 8 <u>Families:</u> N = 8 <u>Settings:</u> Medical ICU/ Single center/ South Korea	<ul style="list-style-type: none"> Outcomes of the family meetings 	<ul style="list-style-type: none"> With an exception of 1 family meeting, which failed to make a decision, 7 family meetings were successfully conducted: 1 case of withdrawal of life-sustaining treatment (LST), 1 case of withholding of LST, 1 case of refusal of any LST, 2 cases of do-not-resuscitate, 1 case of full active treatment, and 1 case of supportive care.
14	Johnson et al., 2014 ⁵⁵	To evaluate the activities conducted by spiritual care providers to support families and whether those activities are associated with family satisfaction with ICU care <u>Intervention:</u> spiritual care	Prospective cohort study <u>Theory:</u> Not reported	<u>Patients:</u> N = 494 <u>Families:</u> N = 275 <u>Settings:</u> ICUs/ Single center/ United States	<ul style="list-style-type: none"> Family Satisfaction in the ICU (FS-ICU) 	<ul style="list-style-type: none"> Discussions about the patient’s wishes for end-of-life care and a greater number of spiritual care activities performed were both associated with increased overall family satisfaction with ICU care. Discussions about a patient’s end-of-life wishes, preparation for a family conference, and total number of activities performed were associated with improved

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family satisfaction with decision-making in the ICU.						
15	Kentish-Barnes et al., 2015 ⁶¹	To determine the prevalence and risk factors of complicated grief during the first year following the death of an adult relative in the ICU <u>Intervention</u> : No specific intervention	Prospective observational study <u>Theory</u> : Not reported	<u>Patients</u> : N = 475 <u>Families</u> : N = 282 <u>Settings</u> : ICUs/ Multi center/ France	<ul style="list-style-type: none"> Hospital Anxiety and Depression Scale (HADS) Revised Impact of Event Scale (IES-R) 	<ul style="list-style-type: none"> Complicated grief symptoms were identified in 147 family members. Independent determinants of complicated grief symptoms were 1) refusal of treatment by the patient 2) patient died while intubated 3) relatives presented at the time of death 4) relatives did not say goodbye to the patient 5) poor communication between physicians and relatives.
16	Khandelwal, Engelberg, Benkeser, Coe, & Curtis, 2014 ⁷⁹	To investigate the association of ICU costs with family-assessed quality of dying and family satisfaction <u>Intervention</u> : No specific intervention	Observational study <u>Theory</u> : Not reported	<u>Patients</u> : N = 607 <u>Families</u> : N = 307 <u>Settings</u> : ICUs/ Multi center/ United States	<ul style="list-style-type: none"> Quality of Death and Dying (QODD-1) Family Satisfaction in the ICU (FS-ICU) 	<ul style="list-style-type: none"> For underinsured patients, higher daily ICU costs were significantly associated with higher FS-ICU and QODD.
17	Kinoshita & Miyashita, 2013 ⁸⁰	To investigate the evaluation of end-of-life from bereaved family of cancer patients who had died in ICUs in Japan <u>Intervention</u> : No specific intervention	Cross-sectional study <u>Theory</u> : Not reported	<u>Patients</u> : N/A <u>Families</u> : N = 390 <u>Settings</u> : ICUs/ Multi center/ Japan	<ul style="list-style-type: none"> Care Evaluation Scale (CES), short version Good Death Inventory (GDI) 	<ul style="list-style-type: none"> Bereaved family of cancer patients evaluated lower than the non-cancer patients for 1) the doctor dealt promptly with discomforting symptoms of the patients 2) the nurses had adequate knowledge and skills 3) admission was possible when necessary without waiting 4) consideration was given to the health of the family 5) physical and psychological comfort.
18	Kross et al., 2014 ⁶⁹	To examine whether ICU attending specialty was associated with the quality of end-of-life care <u>Variables</u> : ICU attending specialty	Retrospective observational study <u>Theory</u> : Not reported	<u>Patients</u> : N = 3124 <u>Families</u> : N = 1184 <u>Settings</u> : MICU, Medical-surgical ICU, Neuro-ICU,	<ul style="list-style-type: none"> Quality of Dying and Death (QODD) Family Satisfaction in the ICU (FS-ICU) 	<ul style="list-style-type: none"> Patients with neurological or neurosurgical attending physicians had higher family rating of quality of dying than patients with attending physicians specializing in medicine.

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				cardiac ICU, Trauma ICU, Burn ICU, Neurosurgical ICU/ Multi center/ United States		
19	Lee, Long, Curtis, & Engelberg, 2016 ⁷⁰	To understand the association of minority race/ethnicity and education with family ratings of the quality of dying and death <u>Variables:</u> Family's race/ethnicity and education	Retrospective observational study <u>Theory:</u> Not reported	<u>Patients:</u> N = 2850 <u>Families:</u> N = 1290 <u>Settings:</u> ICUs/ Multi center/ United States	<ul style="list-style-type: none"> Overall Quality of Dying and Death (QODD – 1) 	<ul style="list-style-type: none"> Patients' and family minority race/ethnicity were both associated with lower ratings of the quality of dying. Presence of a living will and dying in the setting of full support mediated the relationship between patient race and family ratings. Patient race exerted an indirect, rather than direct effect on the quality of dying. Neither patient nor family education was associated with the quality of dying.
20	Long et al., 2014 ⁷¹	To understand the impact of ICU admission source on family perceptions of end-of-life care <u>Variables:</u> ICU admission source	Retrospective cohort study <u>Theory:</u> Not reported	<u>Patients:</u> N = 1500 <u>Families:</u> N = 581 <u>Settings:</u> ICUs/ Multi center/ United States	<ul style="list-style-type: none"> Single-item Quality of Dying and Death (QODD-1) Family Satisfaction in the ICU (FS-ICU) 	<ul style="list-style-type: none"> ICU admission from the hospital ward was associated with lower family ratings of the quality of dying and satisfaction. Patients from hospital wards were less likely to have a family conference or discussion of prognosis in the first 72 hours after ICU admission but were more likely to receive spiritual care and have life support withdrawn.
21	Miller, Morris, Files, Gower, & Young, 2016 ⁷²	To test that family members facing end-of-life decisions will have more decisional conflict and decisional regret than those facing non-end-of-life decisions	Prospective study <u>Theory:</u> Not reported	<u>Patients:</u> N = 53 <u>Families:</u> N = 42 <u>Settings:</u> MICU/ Single center/ United States	<ul style="list-style-type: none"> Decision Conflict Scale (DCS) 	<ul style="list-style-type: none"> The average of DCS score for families facing end-of-life decisions was 25.5 compared with 18.7 for all other decisions. Those facing end-of-life decisions scored higher on the uncertainty subscale with a mean score of 43.4.

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		<u>Variables:</u> Types of decision making				
22	Mun, 2015 ⁵⁶	To incorporate basic palliative care principles into the routine ICU care <u>Intervention:</u> ICU nurse used a 6-item checklist to screen high risk patients and then initiated palliative care principles, such as informational videos on Goals-of-Care, social worker consultation for advanced directives, ICU family meetings and a multidisciplinary palliative care family meeting.	Pre- and Post-intervention study <u>Theory:</u> The Iowa model of evidence-based practice	<u>Patients:</u> N = 194 <u>Families:</u> N = 60 <u>Settings:</u> ICU/Single center/United States	<ul style="list-style-type: none"> Family Satisfaction in the ICU (FS-ICU) 	<ul style="list-style-type: none"> The intervention decreased the days of hospital stay and the days of using ventilator. An increase in the early identification of code status and goals-of-care. An increase in early ICU family meetings. An increase in the number of palliative care consultations. The result from the family's surveys were generally positive.
23	Probst, Gustin, Goodman, Lorenz, & Wells-Di Gregorio, 2016 ⁷³	To explore differences in rates and levels of complicated grief, PTSD and depression between families of patients who died in an ICU and a non-ICU <u>Variables:</u> Location of end-of-life care	Observational cohort study <u>Theory:</u> Not reported	<u>Patients:</u> N = 121 <u>Families:</u> N = 111 <u>Settings:</u> ICU/Single center/United States	<ul style="list-style-type: none"> The Inventory of Complicated Grief-Revised (ICG) The Impact of Events Scale-Revised (IES) Center for Epidemiological Studies Depression (CES-D) Family Member Experiences at End of Life (FEEL) 	<ul style="list-style-type: none"> For ICU patients, families had distressing end-of-life experiences, such as 1) lack of responsiveness by loved one 2) making the decision to stop life-prolonging treatment 3) felt their loved ones had enough suffering. For non-ICU patients, families had distressing end-of-life experiences that they were unable to say goodbye and patients were weakness/inability to move and had severe pain/grimacing. There were no significant differences in rates of levels of CG, PTSD, or depression reported by families between hospital settings.
24	Rajamani et al., 2015 ⁵⁷	To evaluate end-of-life protocol bundles <u>Intervention:</u> Followed by a discussion between the	Prospective observational study	<u>Patients:</u> N = 23 <u>Families:</u> N = 25	<ul style="list-style-type: none"> Used family survey developed by Cheung et al. (2010) 	<ul style="list-style-type: none"> Problems identified included poor documentation of family meetings and symptom management.

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		intensivist and the family, a decision regarding withdrawing treatment is made by the family with a palliative consultant, a social worker and the patient's nurse in the conference in a designated private meeting room.	<u>Theory</u> : Not reported	<u>Settings</u> : General ICU/ Single center/ Australia		<ul style="list-style-type: none"> Emotional/spiritual support was not offered to families (39%). The overall level of end-of-life care was good.
25	Real de Asúa, Alcalá-Zamora, & Reyes, 2013 ⁷⁴	To determine the degree of agreement between physicians and families on end-of-life decisions <u>Variables</u> : End-of-life decision on life-sustaining treatment (LST) withheld/withdrawn	Observational retrospective study <u>Theory</u> : Not reported	<u>Patients</u> : N = 371 <u>Families</u> : N = 256 <u>Settings</u> : ICU/ Single center/ Spain		<ul style="list-style-type: none"> 16.7% died in the ICU. Patients whose LST was withheld or withdrawn were older, had high number of comorbidities, and were admitted with higher APACHE scores than the general ICU population. An agreement between staff and families was reached 85.7% but 5.7% of ICU patients had LST withheld/withdrawn. Families were not involved in 8.1% cases.
26	Robert et al., 2017 ⁵⁸	To compare merits of immediate extubation with terminal weaning for mechanical ventilation withdrawal <u>Intervention</u> : methods of ventilator withdrawal	Prospective observational study <u>Theory</u> : Not reported	<u>Patients</u> : N = 458 <u>Families</u> : N = 402 <u>Settings</u> : ICUs/ Multi center/ France	<ul style="list-style-type: none"> The Impact of Events Scale-Revised (IES-R) The Hospital Anxiety and Depression Scale (HADS) The Inventory of Complicated Grief (ICG) 	<ul style="list-style-type: none"> PTSD scores (IES-R) after 3 months were not significantly different between groups; nor were there any differences in complicated grief, anxiety, or depression score.
27	Sadler et al., 2014 ⁷⁵	To examine patient and institution factors associated with the quality of end-of-life care <u>Variables</u> : Location of end-of-life care	Prospective observational study <u>Theory</u> : Not reported	<u>Patients</u> : N = 272 <u>Families</u> : N = 92 <u>Settings</u> : ICU/ Multi center/ Canada	<ul style="list-style-type: none"> The Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire 	<ul style="list-style-type: none"> Families who believed their loved ones died in their preferred location were 1.7 times more likely to be satisfied with end-of-life care that was provided. Overall, 67.4% of families were very or completely satisfied with the overall quality of care their beloved ones received.

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					<ul style="list-style-type: none"> • 71.4% of families who thought their beloved ones did not die in their preferred location favored an out-of-hospital location of death. • A common location of death was the intensive care unit (47.7%). • Items identified as high-priority targets for improvement included: 1) relationships with, and characteristics of health care professionals; 2) illness management; 3) communication; 4) end-of-life decision-making. 	
28	Stajduhar et al., 2017 ⁷⁶	<p>To compare families' satisfaction across four different settings</p> <p>Variables: Location of end-of-life care (Extended care unit; ICU; Medical care unit; Palliative care unit)</p>	<p>Cross-section study</p> <p>Theory: Not reported</p>	<p>Patients: N = 1254 Families: N = 388</p> <p>Settings: ICU/ Multi center/ Canada</p>	<ul style="list-style-type: none"> • The Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire • Texas Revised Inventory of Grief (TRIG) • Life Orientation Test- Revised • The Resilience Scale 	<ul style="list-style-type: none"> • Family members experienced significantly lower satisfaction in ICUs than in the palliative care unit. • Family members also reported lower satisfaction in 1) doctor and nurse care, 2) illness management, 3) health service and 4) communication in ICUs than in the palliative care unit. • Families' resilience was attributed to the satisfaction of end-of-life care.
29	Tawil et al., 2014 ³³	<p>To evaluate if a family presence educational intervention during brain death evaluation improves understanding of brain death without affecting psychological distress</p> <p><u>Intervention:</u> Family presence during brain death evaluation</p>	<p>RCT</p> <p><u>Theory:</u> N/A</p>	<p><u>Patients:</u> N = 17 <u>Families:</u> N = 58 (38 in intervention; 20 in control group)</p> <p><u>Settings:</u> medical ICU, neurological ICU, trauma/surgical ICU and PICU/ Single center/ United States</p>	<ul style="list-style-type: none"> • Impact of Event Scale (IES) • General Health Questionnaire – 12 (GHQ-12) 	<ul style="list-style-type: none"> • Families who were present during brain death evaluation achieved perfect postintervention “understanding” scores, compared with families who were not present. • There were no apparent adverse impact on psychological well-being for families who were present during brain death evaluation.

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30	Trevick & Lord, 2017 ⁶²	To explore the effect of end-of-life decision making scenarios on the mental health of families of patients in the neuro-intensive care unit <u>Intervention:</u> No specific intervention	Prospective cohort study <u>Theory:</u> Not reported	<u>Patients:</u> N = 17 <u>Families:</u> N = 30 <u>Settings:</u> neuro ICU/ Single center/ United States	<ul style="list-style-type: none"> • Inventory of Complicated Grief-Revised (ICG-R) • Impact of Events Scale – Revised (IES-R) • Family Satisfaction in the ICU (FS-ICU) 	<ul style="list-style-type: none"> • Grief and stress reactions were identified in 30% of families. • Time at bedside during hospitalization and total household income had some predictive value for these psychological outcomes.
31	Turnbull, Chessare, Coffin, & Needham, 2017 ⁵⁹	To assess a brief “patient activation” intervention designed to set expectations and prepare families of ICU to communicate effectively with the clinical team <u>Intervention:</u> A brief “surrogate activation” intervention (review a booklet with ICU families for preparing families to be proxies)	Phase I study of acceptability and immediate side effects <u>Theory:</u> Not reported	<u>Patients:</u> N = 111 <u>Families:</u> N = 122 <u>Settings:</u> medical ICU/ Single center/ United States	<ul style="list-style-type: none"> • A 5-point Likert scale for appropriate/important/upsetting results 	<ul style="list-style-type: none"> • Among proxies it agreed or strongly agreed that the intervention was appropriate, 98% agreed or strongly agreed that it is important for families to know the information in the booklet, and 54% agreed or strongly agreed that parts of the booklet are upsetting.
32	Vattanavanit, Uppanisakorn, Bhurayanontachai, & Khwannimit, 2017 ⁷⁷	To compare the quality of death in an ICU between Buddhists and Muslims from the perspectives of the relatives of the patients <u>Variables:</u> Religious beliefs	Retrospective cohort study <u>Theory:</u> Not reported	<u>Patients:</u> N = 112 <u>Families:</u> N = 112 <u>Settings:</u> medical ICU/ Single center/ Thailand	<ul style="list-style-type: none"> • Single-item Quality of Dying and Death (QODD-1) 	<ul style="list-style-type: none"> • Compared to Buddhist patients, Muslim patients were more likely to have documentation in place at the time of the death of no resuscitation and withholding and withdrawing life support. • There was no difference in the QODD-1 scores between Thai Buddhists and Muslims.
33	Wright et al., 2016 ⁷⁸	To assess the association of aggressive end-of-life care with bereaved family members’ perceptions of the quality of end-of-life care <u>Variables:</u> aggressiveness of end-of-life care	Prospective observational study <u>Theory:</u> Not reported	<u>Patients:</u> N = 1146 <u>Families:</u> N = 1146 <u>Settings:</u> ICUs/ Multi center/ United States	<ul style="list-style-type: none"> • Family-reported quality of end-of-life care 	<ul style="list-style-type: none"> • Families of patients admitted to an ICU less than 30 days before death or who died in the hospital <u>less</u> often reported excellent end-of-life care quality than those admitted to an ICU more than 30 days or did not die in the hospital. • Families of patients receiving less than 3 days of hospice

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34	White et al., 2016 ⁵⁰	To determine the prevalence of physician-surrogate discordance about prognosis in ICUs <u>Intervention</u> : No specific intervention	Mixed method <u>Theory</u> : Not reported	<u>Patients</u> : N = 174 <u>Families</u> : N = 229 <u>Settings</u> : ICUs/ Single center/ United States	• N/A	services were <u>less</u> likely to report patients died in their preferred place. • Physicians' prognosis estimates were statistically significantly more accurate than surrogates. • 53% physician-surrogate discordance about prognosis. • There were two components constituting of discordance: 1) misunderstanding (45%) 2) differences in belief (20%).
35	White et al., 2018 ³⁴	To compare a multicomponent family-support intervention delivered by the interprofessional ICU team with usual care <u>Intervention</u> : a multicomponent family-support intervention (e.g., provision of emotional support and timely conduct of interdisciplinary meetings with the family)	A stepped-wedge, cluster-randomized trial <u>Theory</u> : modern decision theory (Power, Swartzman and Robinson's Cognitive-emotional decision making (CEDM))	<u>Patients</u> : N = 1420 (547 in intervention; 873 in control group) <u>Families</u> : N = 1106 (429 in intervention; 677 in control group) <u>Settings</u> : General, neurological and transplantation surgical ICUs/ Multi centers/ United States	• Hospital Anxiety and Depression Scale (HADS) • Impact of Event Scale (IES) • Quality of Communication (QOC) • Modified Patient Perception of Patient Centeredness (PPPC) scale	• No significant difference between intervention and control group in HADS and IES. • QOC and PPPC were better in the intervention group than in the control group. • Length of ICU stay was shorter in the intervention group than in the control group.

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Appendix 4. Newcastle Ottawa Scale for Quality Appraisal of Quantitative Research between Two Raters

[illegible]

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Appendix 5. Joanna Briggs Institute Quality Appraisal Checklist of Qualitative Research between Two Raters

The Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research																	
Yes = 1; No or Not report = 0																	
Article – Rater 1	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Is there congruity between the stated philosophical perspective and the research methodology?	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y
2. Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5. Is there congruity between the research methodology and the interpretation of results?	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
6. Is there a statement locating the researcher culturally or theoretically?	N	N	N	N	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	N	N
7. Is the influence of the researcher on the research, and vice- versa, addressed?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
8. Are participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total Scores	9	9	9	9	10	9	10	9	8	9	10	9	10	10	10	9	9
Article – Rater 2	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
11. Is there congruity between the stated philosophical perspective and the research methodology?	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y
12. Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
13. Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
14. Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
15. Is there congruity between the research methodology and the interpretation of results?	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
16. Is there a statement locating the researcher culturally or theoretically?	N	N	N	N	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	N	N

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17. Is the influence of the researcher on the research, and vice- versa, addressed?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	Y	Y
18. Are participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
19. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
20. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total Scores	9	9	9	9	10	8	10	8	8	8	10	8	10	10	10	9	9	

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Appendix 6. Confidence in Cumulative Evidence from Qualitative Evidence

Objective: To identify research evidence on end-of-life care in the ICU through families' perspectives.							
Perspective: Experiences of families about end-of-life care							
Inclusion Criteria: (1) primary, original research (2) published in a peer-reviewed journal (3) published in English language (4) published between 2013 and 2018 (5) adult patients (age 18 or older) (6) study reporting views of adults who lost loved ones in the ICU (age 18 or older)							
Exclusion Criteria: (1) pediatric participants (age 18 or younger) (2) review articles (3) case report (4) study focusing on euthanasia, physician-assisted suicide or organ donation							
Review Finding	Studies contributing to the Review Finding	Assessment of Methodological Limitations	Assessment of Relevance	Assessment of Coherence	Assessment of Adequacy	Overall CERQual Assessment of Confidence	Explanation of Judgement
Distressing emotions	40-46	Minor methodological limitations	Minor concerns about relevance (Studies of families in the ICU from four countries and three continents: US, UK, New Zealand, and Norway)	Minor concerns about coherence (data reasonably consistent)	Minor concerns about adequacy (seven studies that together offered moderately rich data)	Moderate confidence	This finding was graded as moderate confidence because of minor concerns regarding methodological limitations, relevance, coherence, and adequacy.
	42,45,47-51	Moderate methodological limitations (one study had minor and three studies had moderate methodological limitations)	Substantial concerns about relevance (Only 3 out of 7 studies exclusively reported surrogates' views of end-of-life decision making)	Minor concerns about coherence (data reasonably consistent)	Minor concerns about adequacy (four studies that together offered moderately rich data)	Low confidence	This finding was graded as low confidence because of substantial concern regarding relevance, moderate concern regarding methodologic limitations and minor concerns regarding coherence and adequacy)
Shared decision making							

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Proactive communication	43,44,49,51-54	Minor methodological limitations	Minor concerns about relevance (Studies of families in the ICU from four countries and three continents: UK, New Zealand, South Africa, and Netherland)	Minor concerns about coherence (data reasonably consistent)	Minor concerns about adequacy (six studies that together offered moderately rich data)	Moderate confidence	This finding was graded as moderate confidence because of minor concerns regarding methodological limitations, relevance, coherence, and adequacy.
Personalized end-of-life care	40,44,53-56	Moderate methodological limitations (one study had minor and three studies had moderate methodological limitations)	Substantial concerns about relevance (only one study with surrogate decision makers as the participants)	Minor concerns about coherence (data reasonably consistent)	Minor concerns about adequacy (four studies that together offered moderately rich data)	Low confidence	This finding was graded as low confidence because of substantial concern regarding relevance, moderate concern regarding methodologic limitations and minor concerns regarding coherence and adequacy)
Valuing of nursing care	40,41,46,47,51,53,54, 56	Minor methodological limitations	Minor concerns about relevance (Studies of families in the ICU from five countries and three continents: US, UK, New Zealand, South Africa, and Netherlands)	Minor concerns about coherence (data reasonably consistent)	Minor concerns about adequacy (eight studies that together offered moderately rich data)	Moderate confidence	This finding was graded as high confidence because of minor concerns regarding methodological limitations, relevance, coherence, and adequacy.