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Journal article

Supporting families of patients who die in adult intensive care : A scoping review of interventions

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TITLE: Supporting families of patients who die in adult intensive care: a scoping review of interventions

ABSTRACT:

Background: Families who perceive themselves as prepared for an impending death experience reduced psychological burden during bereavement. Understanding which interventions promote death preparedness in families during end-of-life care in intensive care will inform future intervention development and may help limit the burden of psychological symptoms associated with bereavement.

Aim: To identify and characterise interventions that help prepare families for the possibility of death in intensive care, incorporating barriers to intervention implementation, outcome variables and instruments used.

Design: Scoping review using Joanna Briggs methodology, prospectively registered and reported using relevant guidelines.

Data sources: A systematic search of six databases from 2007 to 2023 for randomised controlled trials evaluating interventions that prepared families of intensive care patients for the possibility of death. Citations were screened against the inclusion criteria and extracted by two reviewers independently.

Results: Seven trials met eligibility criteria. Interventions were classified: decision support, psychoeducation, information provision. Psychoeducation involving physician-led family conference, emotional support and written information reduced symptoms of anxiety, depression, prolonged grief, and post-traumatic stress in families during bereavement. Anxiety, depression, and post-traumatic stress were assessed most frequently. Barriers and facilitators to intervention implementation were seldom reported.

Conclusion: This review provides a conceptual framework of interventions to prepare families for death in intensive care, while highlighting a gap in rigorously conducted empirical research in this area. Future research should focus on theoretically informed, family-clinician communication, and explore the benefits of integrating existing multidisciplinary palliative care guidelines to deliver family conference within intensive care. **Implications for clinical practice:** Intensive care clinicians should consider innovative communication strategies to build family-clinician connectedness in remote pandemic conditions. To prepare families for an impending death, mnemonic guided physician-led family conference and printed information could be implemented to prepare families for death, dying and bereavement. Mnemonic guided emotional support during dying and family conference after death may also assist families seeking closure.

Keywords: Scoping review, intensive care units, critical care, family, bereavement, psychological distress, palliative care, terminal care, end of life care

1. Background

A substantial number of patients die in acute hospital settings. In Australian adult intensive care units (ICUs), the estimated mortality rate is 11%, which equates to over 19,000 episodes of end-of-life care (Australian and New Zealand Intensive Care Society [ANZICS], 2019). Internationally, this rate is reported to be as high as 29% (Society of Critical Care Medicine, 2019). Families of intensive care patients are often faced with a rapid transition from curative treatment to end-of-life care, affording them little time to process the possible impacts of an anticipated death (Coombs et al., 2016; Hoel et al., 2014). Feelings of anticipatory grief caused by advanced disease and imminent death are considered a significant yet necessary part of the adaptation to loss process (Coelho and Barbosa, 2016; Hebert et al., 2006a; Hebert et al., 2009).

Support and care that fosters psychological wellbeing is recognised as a core feature of holistic palliative and end-of-life care and fundamental to accreditation in acute care settings (Australian College of Nursing, 2019; Australian Commission on Safety and Quality in Health Care [ACSQHC], 2017; Department of Health [DOH], 2018; DOH, 2008; National Institute for Health and Care Excellence [NICE], 2019; World Health Assembly, 2014). National and international palliative and end-of-life care policy and position statements add to the growing body of literature that provide recommendations for care and decision-making in intensive care (ANZICS, 2014; Australian and New Zealand Society of Palliative Medicine [ANZSPM], 2017; Australian College of Critical Care Nurses, 2020; ACSQHC, 2015; NICE, 2021; The Canadian Association of Critical Care Nurses, 2020). However, evidence of suboptimal care and unmet family needs suggests the delivery of end-of-life care that prepares families for a possible death in intensive care remains a challenge for healthcare systems globally (Coventry et al., 2020; Efstathiou et al., 2019; Mitchell et al., 2021). Intensive care admission, aggressive medical intervention, ventilation, problematic communication, resuscitation, and an unexpected death are associated with increased psychological morbidity in family members during bereavement (Lobb et al., 2010; Neimeyer and Burke, 2012; Sanderson et al., 2022; Tang et al., 2021). These factors, coupled with delays in family-centred goal setting, prognostication, and truth disclosure contribute to suboptimal end-of-life care that does not meet the needs of families preparing for a possible death in intensive care (Miller et al., 2022; Mitchell et al., 2021; Rawlings et al., 2021).

In palliative care literature, preparedness is defined as a feeling of readiness for an impending death (Kersting et al., 2010). In intensive care, a state of preparedness explains the circumstance in which “the family of the dying person can manage, in the best way possible for them, the death, their sadness, loss and grief” (Coventry, 2017, p.123). A prospective evaluation of death, coping and bereavement intensity in intensive care found preparedness for death to be a modifiable determinant of psychological adjustment during end-of-life care (Buckley et al., 2015). These findings are consistent with an earlier trial, which identified factors correlating family satisfaction with withdrawal of life-support, including the perception that the process was clearly explained and proceeded as the family had expected (Keenan et al., 2000).

Hebert et al. (2009) seminal research undertaken in hospice and community-based palliative care, sought to identify factors caregivers believed were important to prepare them for death and bereavement. Their *Conceptual Model of Preparedness* attempts to demonstrate the relationships between life experiences, uncertainty, communication, and preparedness. This model emphasises the primacy of communication in mitigating uncertainty and improving death preparedness across cognitive, affective, and behavioural dimensions (Hebert et al., 2009). The *Model of Preparedness for the Delivery of Family-Centred End-of-Life Care* describes what needs to be in place from the perspective of families', to establish preparedness for death in intensive care (Coventry et al., 2020). The key features described were end-of-life communication, patient dignity, and comfort, feeling supported, and after-death care (Coventry et al., 2020). When these complex support and care needs were met during end-of-life care, families' experienced improved coping responses (Coventry et al., 2020). Thus, understanding which interventions promote psychological wellbeing in families when death is a possibility is crucial to improving the delivery end-of-life care in intensive care settings. This knowledge will inform future practice and may help limit the burden of psychological symptoms experienced by intensive care families during bereavement, such as complicated grief, anxiety, depression, and post-traumatic stress.

An array of interventions have been synthesised that aim to address the physical, spiritual, social, and psychological needs of families in intensive care, targeting areas such as shared decision-making (Kryworuchko et al., 2013), inclusive ward rounds (Kydonaki et al., 2021), communication (Oczkowski et al., 2016; Reifarh, et al., 2023; Rhoads, 2019; Scheunemann et al., 2011), bereavement care (Bloomer et al., 2022; Brekelmans et al., 2022; Efstathiou et al., 2019; Galazzi et al., 2021; Moss et al., 2021; Osorio et al., 2018; Rait et al., 2021; Zante et al., 2020) and palliative care involvement (Aslakson et al., 2014; Metaxa et al., 2021; Roczen et al., 2016; Schram et al., 2017). However, uncertainty remains about which are the most appropriate interventions to prepare families for the possibility of death, the optimal mode of their delivery, and how to measure the success of these interventions to foster psychological wellbeing in families after the death of a patient in intensive care settings (Efstathiou et al., 2019; Erikson et al., 2020; Hay et al., 2019; Kentish-Barnes, 2019).

2. Methods

2.1 Aim

The aim of this scoping review was to identify and characterise interventions that help prepare families for the possibility of death in intensive care, barriers to intervention implementation, and to assess the content, and outcomes of the interventions.

2.2 Research questions

- 1) What interventions have been used to prepare families for the possibility of death in the ICU?

- 2) What are the outcomes of the interventions on family member psychological wellbeing?
- 3) What are the characteristics of the interventions in terms of (a) purpose, type, and components, (b) outcome variables, (c) instruments used, (d) evaluation timepoints, and (e) are they theoretically informed?
- 4) What intervention barriers and enablers are reported (incorporating factors such as acceptability, fidelity, feasibility, scalability, and sustainability)?

2.3 Design

A scoping review was considered an appropriate methodology to identify and map the available evidence and to identify gaps on this topic (Munn et al., 2018). This review was conducted in accordance with scoping review methodology from the Joanna Briggs Institute (Peters et al., 2020), and reported using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). A protocol was registered a priori on Open Science Framework (<https://osf.io/qpnza>) (Centre for Open Science, 2022).

2.4 Study eligibility criteria

The population, concept, and context framework was used to structure the eligibility criteria (Peters et al., 2020). We focused on interventions that fostered death preparedness in families of intensive care patients. Death preparedness in intensive care was described as the “circumstance in which the family of the dying person can manage, in the best way possible for them, the death and their sadness, loss and grief” (Coventry, 2017, p.123). Family was defined as those who are closest to the patient and may include family, significant others, and friends (Palliative Care Australia, 2005). Randomised controlled trials (RCTs), including multi-armed, cluster and pilot trials were considered eligible for inclusion, as these are the most rigorous trial designs to evaluate interventions (National Health and Medical Research Council, 2009). Mapping this precise body of literature will identify gaps and opportunities for future trials. Detailed inclusion and exclusion criteria used are provided in Table 1.

2.5 Search strategy

Keywords were identified from an initial limited search of CINAHL and Medline. Specific MeSH headings and synonyms that described the concepts ‘end-of-life’, ‘intensive care’, ‘family’, and ‘randomised controlled trial’ were combined, with guidance from the Cochrane Handbook for Systematic Reviews of Interventions and a senior research librarian (Higgins et al., 2021). The search strategy was adapted across six databases (Medline, CINAHL, Embase, APA Psych INFO, Emcare and Cochrane Central Register of Controlled Trials) using Polyglot Search Translator (Clark et al., 2020), to generate the full search strategy (Supplemental file 1). The six databases were searched from January 2007 to January 17, 2023, to identify contemporary

articles on the topic. Results were limited to trials published in English language and the reference lists of all included sources and key systematic reviews were screened for additional papers.

Table 1: Inclusion and exclusion criteria

Criteria	Included	Excluded
Population	<ul style="list-style-type: none"> Adult family members (≥ 18 years) of adult patients (≥ 18 years) identified to be at risk of death in the adult ICU. 	<ul style="list-style-type: none"> Family members of patients in the adult ICU who were not identified to be at risk of death, or when the family member or patient was < 18 years.
Concept	<ul style="list-style-type: none"> Interventions that fostered death preparedness when a patient was identified to be at risk of death. Outcome variables that measured the impact of the intervention on family member psychological wellbeing. Validated instruments. 	Trials reporting interventions that: <ul style="list-style-type: none"> Did not target death preparedness, or the psychological wellbeing of family members, or Were associated with organ donation, or Were evaluated using other outcome variables (i.e., measures of satisfaction, or physical health outcomes).
Context	<ul style="list-style-type: none"> Adult intensive care 	<ul style="list-style-type: none"> Any setting other than adult ICU.
Types of studies/publications	<ul style="list-style-type: none"> RCTs, including multi-armed, cluster and pilot RCTs. 	<ul style="list-style-type: none"> Any study design that was not a RCT (i.e., quasi-randomised and non-randomised study designs) and conference abstracts.
Language	<ul style="list-style-type: none"> English language 	
Search period	<ul style="list-style-type: none"> 2007-2023 	

2.6 Study selection

Search results were uploaded to EndNote v20.5 (Clarivate Analytics, 2023), exported into Covidence (Veritas Health Innovation, 2023) then duplicates were removed. Titles and abstracts were screened by two independent reviewers against the inclusion and exclusion criteria. Potentially relevant sources were retrieved in full and uploaded into Covidence for double blind full text review. Reasons for exclusion at full text were provided (Supplemental file 2). Disagreements were adjudicated by a third reviewer.

2.7 Data extraction

A data extraction form was developed (Supplemental file 3). Data relevant to the review questions were independently extracted by two reviewers. Disagreements were resolved through discussion.

2.8 Data analysis and presentation

Data were summarised and reported in narrative and tabular form, using text to systematically highlight important similarities and differences (Peters et al., 2006; Ryan, 2013). The Template for Intervention Description and Replication (TIDieR) was used to synthesise and describe interventions in tabular form under the recommended headings: why was the intervention undertaken; what materials and procedures were used; who provided the intervention; how, where when and how much; and if tailoring or modifications occurred (Supplemental file 4). This template outlines the minimum data required for systematic intervention reporting (Hoffmann et al., 2014).

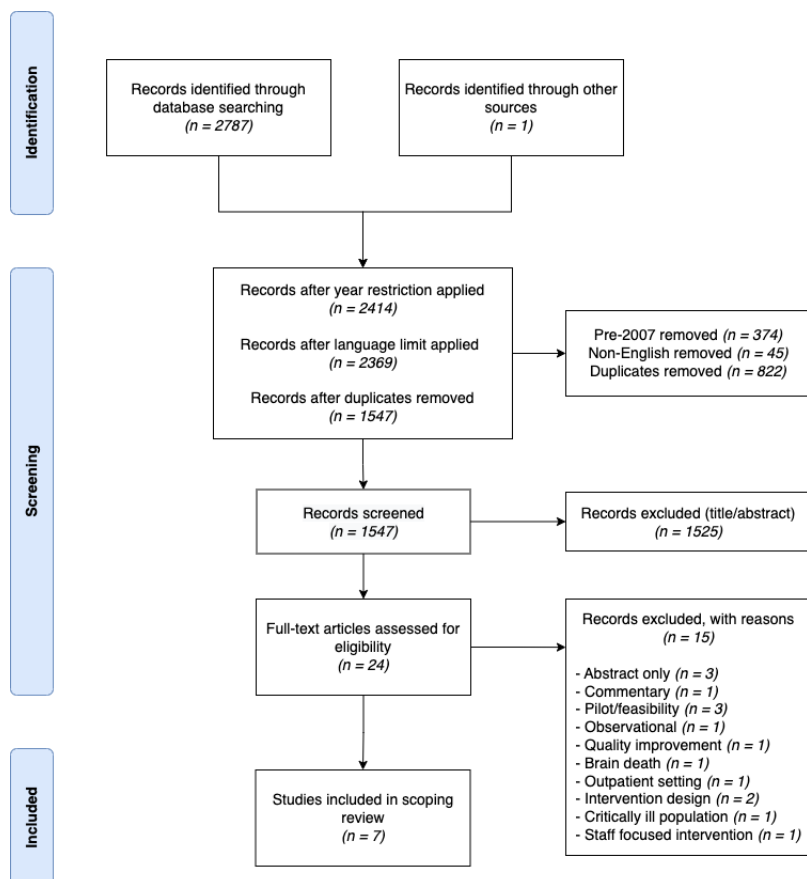
Interventions were sorted based on a classification framework from the Oncology Nursing Society (ONS, 2019), applied recently in a systematic review of interventions to reduce family caregiver strain and burden (Jadalla et al., 2020). This schema was adopted in the absence of an intensive care specific end-of-life intervention classification framework.

1. RESULTS

3.1 General description of the studies

Of the 2789 records screened, 7 trials met the inclusion criteria, including three RCTs (Curtis et al., 2016; Lautrette et al., 2007; Robin et al., 2021), two cluster RCTs (Kentish-Barnes et al., 2022; Liu et al., 2021), one stepped-wedge cluster RCT (White et al., 2018), and one pilot RCT (Kirchhoff et al., 2008). Three trials were conducted in North America (Curtis et al., 2016; Kirchhoff et al., 2008; White et al., 2018), three in France (Kentish-Barnes et al., 2022; Lautrette et al., 2007; Robin et al., 2021) and one in China (Liu et al., 2021). All trials were conducted prior to the coronavirus pandemic. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of study selection is presented in Figure 1. Collectively, 3,067 family members were enrolled from 77 ICUs and 34 hospitals.

Figure 1: PRISMA Flow Diagram



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

3.2 Types of Interventions

Seven interventions were evaluated in seven trials, six were multicomponent (Curtis et al., 2016; Kentish-Barnes et al., 2022; Lautrette et al., 2007; Liu et al., 2021; Robin et al., 2021; White et al., 2018), and all interventions targeted family-clinician communication. Two interventions were implemented once a decision to withdraw life-support was made (Kentish-Barnes et al., 2022; Kirchhoff et al., 2008), two when a withdrawal decision was anticipated (Lautrette et al., 2007; Robin et al., 2021), and three included families of patients with greater than thirty percent risk of mortality (Curtis et al., 2016; Liu et al., 2021; White et al., 2018). Table 2 provides a summary of the included studies, outcome measures, instruments used and follow-up timeframes, classified into three intervention types: decision support (Curtis, et al., 2016; Liu et al., 2021; White et al., 2018), psychoeducation (Kentish-Barnes et al., 2022; Lautrette et al., 2007), and information provision (Kirchhoff et al., 2008; Robin et al., 2021). The classifications provide a conceptual framework by which to organise and characterise interventions that prepare families for death in intensive care (Figure 2) (Jadalla et al., 2020; ONS, 2019). A detailed summary of intervention outcomes, measures and variables is provided in Supplemental files 5, 6 and 7.

Figure 2: Conceptual framework of interventions that prepare families for death in intensive care

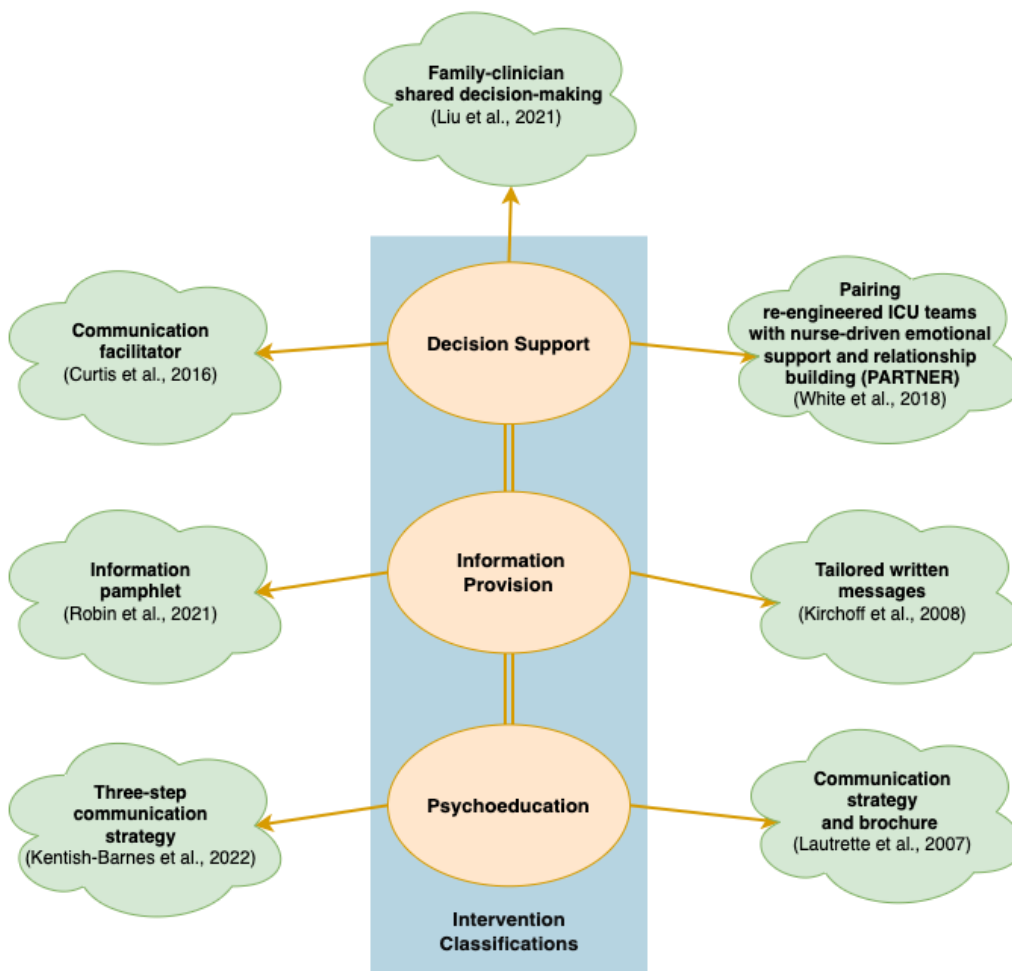


Table 2: Table of included studies and intervention classifications

Intervention classification	Intervention description	Theory	Setting	Aim	Design	Participants	Instruments	Follow-up timeframes	Outcomes of the intervention	Author, year, country
Decision support	Family-clinician shared decision-making family conference	Nil	Six ICUs, six hospitals	To investigate if a Family-Clinician Shared Decision-Making intervention benefits patients, families, and clinicians in intensive care.	Cluster randomised controlled trial	n = 548 family members of ICU patients with (1) terminal cancer; (2) cerebral haemorrhage; (3) end-stage respiratory failure; (4) advanced malignancy, or (5) APACHE II \geq 20	HADS; Anxiety, Depression	Baseline, 1, 3 and 6 months after intervention	The intervention group had a significantly lower mean depression score (95% CI, -2.67 to -0.47; P = 0.005) at 1-week, but no significant difference in anxiety or HADS total score. 1-, 3- and 6-month outcomes were not reported due to significant attrition.	Liu et al., (2021), China
Decision support	Nurse or social worker-led communication facilitation and emotional support	Social Cognitive theory	Five ICUs, two hospitals	To determine whether a communication facilitator in intensive care reduces family distress and intensity of care.	Randomised controlled trial	n = 352 family members of ICU patients \geq 30% risk mortality or SOFA score \geq 6	PHQ-9; Depression GAD-7; Anxiety PCL; PTSD	3 and 6 months after intervention	A communication facilitator may be associated with decreased family depressive symptoms at 6 months (Intervention mean 4.7 versus control 2.4 [CI -3.891 to 0.318], p=0.017), with no significant difference at 3 months or in anxiety or PTSD.	Curtis et al., (2016), North America
Decision support	Nurse-led communication facilitation and emotional support	Modern decision theory	Five ICUs, five hospitals	To compare a multicomponent family-support intervention delivered by the interprofessional intensive care team with usual care.	Stepped-wedge, cluster randomised controlled trial	n = 1106 surrogates ICU patients \geq 40% risk mortality, severe long-term functional impairment or \geq 4 days mechanical ventilation	HADS; Anxiety, Depression IES; PTSD	6 months after discharge or death	There was no significant difference between the intervention group and the control group in the surrogates' mean HADS score at 6 months (11.7 and 12.0, 95% confidence interval [CI], -1.67 to 0.99; P = 0.61) or mean IES score (21.2 and 20.3; 95% CI, -1.66 to 3.47; P = 0.49).	White et al., (2018), North America
Psychoeducation	Physician-led family conference, nurse/physician room visits and physician-led post-death conference	Nil	Thirty-four ICUs, thirty-four hospitals	To evaluate whether a communication and support intervention would improve relatives' outcomes.	Cluster randomised controlled trial	n = 875 relatives ICU patients from whom life-support was being withdrawn	PG-13; Prolonged grief HADS; Anxiety, Depression IES-R; PTSD	1, 3, and 6 months after death	The intervention significantly reduced the number of relatives with prolonged grief symptoms (66 [21%] vs 57 [15%]; p=0.035) and the median PG-13 score was significantly lower in the intervention group than in the control group (19 [IQR 14–26] vs 21 [15–29], mean difference 2.5, 95% CI 1.04–3.95).	Kentish-Barnes et al., (2022), France

Psychoeducation	Physician-led family conference and pamphlet	Nil	Twenty-two ICUs, twenty-two hospitals	To evaluate whether a proactive end-of-life conference and a pamphlet could lessen the effects of bereavement.	Randomised controlled trial	n = 126 family members of ICU patients who were expected to die within a few days	IES; PTSD HADS; Anxiety, Depression	90 days after death	Participants in the intervention group had a lower median IES score (27 [IQR, 18 to 42] vs 39 [IQR, 25 to 48], P = 0.02), and lower prevalence of PTSD-related symptoms (45% vs. 69%, P = 0.01). The median HADS score was lower in the intervention group (11 [IQR, 8 to 18], vs 17 [IQR, 11 to 25], P = 0.004), and symptoms of both anxiety and depression were less prevalent (anxiety, 45% vs. 67%; P = 0.02; depression, 29% vs. 56%; P = 0.003).	Lautrette et al., (2007), France
Information Provision	Provision of a tailored written message	Self-regulatory theory	One ICU, one hospital	To assess the feasibility of 4 tailored messages to prepare families of patients having a planned withdrawal of life-support, assess barriers to study conduct, and obtain data on measurable effects.	Pilot randomised controlled trial	n = 37 next-of-kin of ICU patients from whom life-support was being withdrawn	POM-SF; Mood scores	2-4 weeks after death	The intervention group had lower negative mood scores and higher positive mood scores than did the control group, although the difference was not significant	Kirchhoff et al., (2008), North America
Information Provision	Information pamphlet	Nil	Three ICUs, one hospital	To determine if a pamphlet describing the role of relatives in the end-of-life decision decreases risk of developing PTSD.	Randomised controlled trial	n = 93 relatives of ICU patients for whom an end-of-life decision was anticipated.	IES; PTSD HADS; Anxiety, Depression	90 days after death	The prevalence of PTSD-related symptoms was significantly lower in the intervention group (18 of 45 vs 33 of 45 (P = .001)). The mean IES and HADS scores were reduced significantly in the intervention group: 28 +/- 10 vs 38 +/- 14 (P < .001) and 13 +/- 5 vs 17 +/- 8 (P = .023), respectively.	Robin, (2021), France

Abbreviations: ICU (Intensive Care Unit), APACHE II (Acute Physiology and Chronic Health Evaluation), SOFA (Sequential Organ Failure Assessment), PHQ-9 (Patient Health Questionnaire), GAD-7 (Generalised Anxiety Disorder Survey), PCL (Post-Traumatic Stress Disorder Checklist), HADS (Hospital Anxiety and Depression Scale), IES (Impact of Event Scale), PG-13 (Prolonged Grief Questionnaire), IES-R (Impact of Event Scale-Revised), POM-SF (Profile of Mood Short Form), PTSD (post-traumatic stress disorder)

3.3 Intervention description and analysis

Decision support interventions (n=3)

Three decision support interventions involved the use of counselling interactions and decision-support care pathways, to facilitate decision-making between clinicians and families (Curtis et al., 2016; Liu et al., 2021; White et al., 2018). All three were underpowered multicentre trials; two used communication facilitators (Curtis et al., 2016; White et al., 2018), and one used family conference to enhance family-clinician communication and decision making at the end of life (Supplemental file 4) (Liu et al., 2021). All interventions aimed to reduce the psychological burden of decision making on families, to reduce anxiety and depression (Curtis et al., 2016; Liu et al., 2021; White et al., 2018), or post-traumatic stress (Table 2) (Curtis et al., 2016; White et al., 2018). In two North American trials, communication facilitators were nurses or social workers, and both interventions were grounded in theory (Curtis et al., 2016; White et al., 2018). White et al. (2018) engaged families with a nurse trained in emotional and communication support, who facilitated meetings according to a care pathway (PARTNER Trial). No changes in symptoms of anxiety, depression or post-traumatic stress were reported as compared to the control (White et al., 2018). Curtis et al. (2016) provided nurses or social workers with training in mediation and communication, to support families to express their needs during intensive care team meetings. A significant reduction in symptoms of depression was demonstrated at 6-months, without concurrent changes in post-traumatic stress or anxiety (Curtis et al., 2016). A Chinese study, Liu et al. (2021) evaluated a physician-led shared decision-making family conference, however the 1-, 3- and 6-month outcomes were not reported due to significant attrition (78%), and the use of theory was not conveyed. Thus, there is weak evidence that decision support interventions, using nurse communication facilitators reduces symptoms of depression in family members 6-months after a death in intensive care (Supplemental file 5; Supplemental file 6) (Curtis et al., 2016).

Psychoeducation interventions (n=2)

Two powered multicentre RCTs conducted in France evaluated if psychoeducation involving mnemonic guided family conference with emotional support to prepare families for imminent death improved the psychological wellbeing of families during bereavement (Table 2) (Kentish-Barnes et al., 2022; Lautrette et al., 2007). The three-step support strategy (Kentish-Barnes et al., 2022) also included independent visits by a senior nurse and physician during dying to affirm non-abandonment, and a family conference after death, and Lautrette et al. (2007) provided written information to families about preparing for loss and grief. All family conferences were physician-led and only physicians received training (Kentish-Barnes et al., 2022; Lautrette et al., 2007). Four established communication mnemonics were used to guide communication during the psychoeducation interventions (Table 3) (Kentish-Barnes et al., 2022; Lautrette et al., 2007). While a nurse, psychologist, social worker, and pastoral care practitioner were invited to family conferences

during the three-step support strategy (Lautrette et al., 2007), their roles were not explained (Supplemental file 4). Lautrette et al. (2007) reported a significant reduction in symptoms of post-traumatic stress, depression and aggregated Hospital Anxiety and Depression Score (HADS), without a concurrent reduction in anxiety at 3-months post intervention. The three-step support strategy significantly reduced post-traumatic stress, anxiety, aggregated HADS and prolonged grief at 3- and 6-months, and depression at 6-months (Kentish-Barnes et al., 2022). Thus, there is moderate evidence that psychoeducation interventions improved the psychological wellbeing of families of patients who die in intensive care 3- and 6-months after death (Supplemental file 5; Supplemental file 7) (Kentish-Barnes et al., 2022; Lautrette et al., 2007).

Information provision interventions (n=2)

Information provision interventions involved the delivery of information (in any format) about disease process, treatment, or care. This type of intervention differs from psychoeducation in that information provision is unidirectional and they don't include components such as support or counselling (ONS, 2019). Two underpowered trials evaluated if written information, provided prior to an end-of-life decision reduced the emotional burden experienced by families during bereavement (Supplemental file 4). A single-centre pilot RCT, conducted in North America used self-regulation theory to tailor written messages that aimed to prepare families for withdrawal of life-support, using mood scores to measure emotional burden (Table 2) (Kirchhoff et al., 2008). The pilot trial was too small to demonstrate significant differences in mood scores between the intervention and the usual-care group (Kirchhoff et al., 2008). A multicentre trial conducted in France evaluated if a pamphlet describing the objective of care and role of family at the end of life, reduced anxiety, depression, and post-traumatic stress (Table 2) (Robin et al., 2021). Families who received the pamphlet had a significantly lower risk of developing symptoms of post-traumatic stress, depression, and anxiety at 3-months (Supplemental file 5; Supplemental file 7) (Robin et al., 2021). Thus, there is weak evidence that the provision of written information describing the families' role during end-of-life decisions in intensive care, reduced anxiety, depression, and post-traumatic stress in families of patients expected to die.

Table 3: Communication mnemonic title, description, and context

	Title	Description	Context
Kentish-Barnes et al., (2022)	PREPARE	Prepare, Respond, make Explicit, Presence, Anticipate, think thRough, and Encourage.	End-of-life conference to prepare family for imminent death
	RAAP	Reassure, Answer, Attentive listening, Propose support.	Room visits to provide active family support during dying
	CIAO	Condolences, Instigate questions, Acknowledge emotions, Option to contact team.	Conference with family after patient death
Lautrette et al., 2007)	VALUE	Value and appreciate what is said, Acknowledge emotions, Listen, ask questions that allow you to Understand who the patient is as a person, and Elicit questions.	End-of-life conference to prepare family for imminent death

3.4 Outcome variables, measures, and timepoints

While outcome variables, measures and timepoints were heterogenous, some commonalities were observed (Table 2). Anxiety and depression were measured in all seven trials, most commonly using the HADS. Symptoms of post-traumatic stress was measured in five trials (Curtis et al., 2016; Kentish-Barnes et al., 2022; Lautrette et al., 2007; Robin et al., 2021; White et al., 2018), most frequently using the Impact of Event Scale (IES) (Lautrette et al., 2007; Robin et al., 2021; White et al., 2018), followed by the Impact of Event Scale-Revised (IES-R) (Kentish-Barnes et al., 2022). Prolonged grief was the primary endpoint in one trial, in which the Prolonged Grief Questionnaire (PG-13) was used to measure the proportion of family members with prolonged grief 6-months after death (Kentish-Barnes et al., 2022). Evaluation timepoints ranged from 1-week to 6-months across all studies. For each metric, a higher score indicated more symptoms of the measured state. A summary of outcome variables, measures and timepoints can be found in Table 2.

3.5 Barriers and facilitators to intervention implementation

Very few barriers and facilitators to intervention implementation were reported. Facilitators to successful intervention implementation included when interventions were cost reasonable (clinician time investment) (Kentish-Barnes et al., 2022; White et al., 2018), simple to replicate (Kentish-Barnes et al., 2022), when it was feasible to train clinicians to deliver the intervention (Kentish-Barnes et al., 2022; White et al., 2018), and when implementation science strategies were adopted (White et al., 2018). In two trials, the challenge of integrating a facilitator not employed by the hospital into the clinical team was reported as a barrier (Curtis et al., 2016; Kirchhoff et al., 2008). Thus, there exists a gap in the literature, regarding barriers and facilitators to intervention implementation.

4. DISCUSSION

4.1 Main findings

In this scoping review, we identified seven trials of interventions that aimed to prepare families for death and limit psychological burden during bereavement. Interventions were organised into a conceptual framework that included three decision support, two information provision, and two psychoeducation interventions (Figure 2). Four included trials reported positive results (Curtis et al., 2016; Kentish-Barnes et al., 2022; Lautrette et al., 2007; Robin et al., 2021), four were developed without reporting the use of theory, (Kentish-Barnes et al., 2022; Lautrette et al., 2007; Liu et al., 2021; Robin et al., 2021) and only two were powered (Kentish-Barnes et al., 2022; Lautrette et al., 2007), confirming that there is limited rigorous empirical research available on this topic. Indeed, Medical Research Council guidance asserts that developing an intervention using theory is more likely to result in an effective intervention than an atheoretical intervention (Medical Research Council [MRC], 2019, Skivington et al., 2021).

Clinician-family communication was the core ingredient of all included interventions. This focus on communication is congruent with findings from a recent qualitative systematic review that family-centred communication (open, sensitive, clear, consistent, and timely communication) is integral to the facilitation of family needs and preparedness for death during end-of-life care in the ICU (Coventry et al., 2020). Family-centred communication that accounted for timing, location, format, and language was also previously established as a strong predictor of preparedness for death in a prospective study of family caregivers of persons with dementia in non-intensive care settings (Hebert et al., 2006b).

A key finding of this scoping review, was that psychoeducation interventions, reported in two powered trials, reduced symptoms of post-traumatic stress, anxiety, depression, and prolonged grief, in families of patients who were expected to die in the ICU. These psychoeducation interventions involved physician-led family conference before and after death, emotional support by nurses and physicians during dying, and printed bereavement information for families preparing for a death (Kentish-Barnes, et al., 2022; Lautrette et al., 2007). Four established communication mnemonics were used to guide communication during the psychoeducation interventions (Table 3) (Kentish-Barnes et al., 2022; Lautrette et al., 2007). In addition, we found that information provision alone, in the form of a pamphlet describing the role of family at the end of life resulted in reduced symptoms of depression and post-traumatic stress (Robin et al., 2021), confirming the usefulness of written information alongside physician-led psychoeducation. Whilst our findings suggest that physician-led family conference improved the psychological wellbeing of families of patients who died in intensive care, palliative care guidelines on multidisciplinary family conference advocate that family conferences can be facilitated by any suitably qualified clinician, including nurses, physicians, social workers, or psychologists, within a multidisciplinary framework (Hudson et al., 2020; 2008).

We only identified two trials that involved nurses and social workers directly in intervention delivery; both were underpowered trials of decision-support interventions that used nurses and social workers as communication facilitators (Curtis et al., 2016; White et al., 2018). While Curtis et al. (2016) reported a significant reduction in family depressive symptoms, both trials lacked sufficient power to detect further treatment effects (Curtis et al., 2016; White et al., 2018). In the broader literature, we identified five ongoing trials of nurse-led communication strategies, all of which more broadly targeted families of critically ill intensive care patients (rather than families of intensive care patients expected to die) (Chen, 2018; Curtis et al., 2021; Lincoln et al., 2020; Naef et al., 2022; White, 2022). Notably, primary outcomes included satisfaction with care (Chen, 2018; Naef et al., 2022), family centredness of care (White, 2022), quality of communication (Chen, 2018; Lincoln et al., 2020), and decisional conflict (Chen, 2018). Three of these ongoing trials (Curtis et al., 2021; Lincoln et al., 2020; White, 2022), build on findings from social worker and nurse-led decision support interventions included in this scoping review (Curtis et al., 2016; White et al., 2018). This move away from family psychological symptoms as primary outcome measures is consistent with

recommendations from a recent systematic review on outcomes and outcome measures used in evaluations of communication interventions (Fischer et al., 2019). In this systematic review, Fischer et al. (2019) emphasised that the choice of outcomes must be closely linked to the scope of the intervention being tested. Thus, whilst only two of the ongoing trials use family psychological symptoms as composite primary outcomes (Chen, 2018; Curtis et al., 2021), authors aim to provide important future evidence on nurse-led communication strategies and their impact on families of critically ill intensive care patients.

In this scoping review, we found that a range of outcome variables, measures and timepoints were employed to evaluate the impact of interventions that help prepare families for death in the ICU. Most commonly, the triad of post-traumatic stress, anxiety and depression were measured in family members of patients expected to die in intensive care at 3- and 6-month timepoints after intervention implementation. The HADS, IES and IES-R were the three most common validated instruments used to measure these outcome variables. Finally, limited barriers and facilitators to intervention implementation were reported in the included trials, highlighting a gap in the literature in this area.

4.2 What this study adds and future research priorities

To our knowledge this is the first scoping review of RCTs to evaluate interventions that prepare families for the possibility of death in the ICU. Our review adds an understanding of which intervention types and components may hold therapeutic value in reducing the psychological burden experienced by families when a patient dies in intensive care. First, it is recommended that future interventions focus on theoretically informed, family-clinician communication, to prepare families for an impending death. This recommendation responds to the expressed needs of families (Coventry et al., 2020), aligns with intensive (Myburgh et al., 2016), and palliative care practice standards, (DOH, 2018) and recommendations from the Medical Research Council (MRC, 2019; Skivington et al., 2021). Second, psychoeducation interventions, involving mnemonic guided, physician-led family conference, with mnemonic guided emotional support during and after death, are recommended to reduce the psychological burden experienced by families of patients who are likely to die in intensive care (Kentish-Barnes et al., 2022; Lautrette et al., 2007). We advocate for future research to investigate the potential benefits of conducting family conference in intensive care, within a dedicated multidisciplinary framework (ANZICS, 2014; DOH, 2018; NICE, 2015), and in accordance with palliative care practice guidelines for conducting multidisciplinary family conferences (Hudson et al., 2008). Further, we advocate that family conferences should not be saved for 'crisis' situations, and that the multidisciplinary team should determine who facilitates the family conference, depending upon skills, knowledge of the family, and resources (Hudson et al., 2008). Third, the provision of printed information regarding death, dying and bereavement seems to be effective and should be universally adopted in the absence of evidence supporting other modalities of information provision (Hudson et al., 2008; Lautrette et al., 2007; Robin et al.,

2021). Fourth, given that all trials were conducted prior to the coronavirus pandemic, future interventions to prepare families for an impending death in intensive care should consider alternative approaches to communication and information exchange that are adaptable in remote pandemic conditions (Bloomer et al., 2020; Brooks et al., 2019; Fernández-Martínez et al., 2022). This may include the use of video conferencing and the adjustment of visitation policies to allow family engagement in face-to-face meetings. Finally, to maximise the potential efficacy of future interventions, it is necessary to better understand the barriers and facilitators to intervention implementation, including concepts like acceptability, fidelity, feasibility, scalability, and sustainability (Eldridge et al., 2016). Systematic review evidence on barriers and facilitators to palliative and end-of-life care in intensive care (Alshehri et al., 2020; Ivany and Aitken, 2019; Visser et al., 2014) and an implementation strategy developed based on such findings may further inform the success of future interventions.

4.3 Strengths and limitations

This scoping review has several strengths. The screening and extraction process was blinded and completed by at least two reviewers. In-line with scoping review methodology, a protocol was registered a priori, and appropriate reporting guidelines were followed (Tricco et al., 2018). Limitations include the risk that potentially relevant trials may have been excluded during the screening process; this was mitigated by using two independent reviewers. The exclusion of papers published prior to 2007 may mean potentially relevant trials were missed; however, the focus was on contemporary practice. We did not identify any trials in non-English languages, which may reflect the databases that we searched. Our review was limited to RCTs which resulted in the inclusion of trials from only three countries, which may limit the generalisability of the findings. However, the focus was to include only the most rigorously conducted trials that help prepare families for the possibility of death in intensive care, to inform the development of future interventions. Finally, trials were excluded if the intervention patient population was not deemed to be at risk of death; this limitation was applied to ensure only the most relevant interventions were included given the focus on preparing families for the possibility of death.

5. CONCLUSION

This scoping review provides a comprehensive description of interventions that help prepare families for the possibility of death in intensive care, including outcomes, measures, and barriers to intervention implementation. Outcomes measures were heterogenous, and limited barriers and facilitators to intervention implementation were reported. Only two trials were sufficiently powered confirming there is limited rigorous empirical research available on this topic. Psychoeducation involving mnemonic guided, physician-led family conference before and after death, mnemonic guided emotional support to during dying, and printed bereavement information is recommended to reduce symptoms of post-traumatic stress,

anxiety, depression, and prolonged grief, in families of patients who were expected to die in intensive care. Future research is needed to explore the potential benefits of integrating existing palliative care guidelines on multidisciplinary family conference, where the multidisciplinary team will determine who facilitates the family conference, depending upon skills, knowledge, and resources in the adult ICU.

References

- Alshehri, H.H., Olausson, S., Öhlén, J., Wolf, A., 2020. Factors influencing the integration of a palliative approach in intensive care units: a systematic mixed-methods review. *BMC Palliat Care*. 19, 1-18. 10.1186/s12904-020-00616-y
- Aslakson, R., Cheng, J., Vollenweider, D., Galusca, D., Smith, T.J., Pronovost, P.J., 2014. Evidence-based palliative care in the intensive care unit: A systematic review of interventions. *J Palliat Med*. 17, 219-35.
- Australian and New Zealand Intensive Care Society [ANZICS], 2014. ANZICS statement on care and decision-making at the end of life for the critically ill. <http://www.anzics.com.au/> (accessed 21.03.23).
- Australian and New Zealand Intensive Care Society [ANZICS], 2019. Centre for Outcome and Resource Evaluation Annual Report [CORE]. Melbourne, Australia: ANZICS CORE. <https://www.anzics.com.au/annual-reports/> (accessed 21.03.23).
- Australian and New Zealand Society of Palliative Medicine [ANZSPM], 2017. ANZSPM Position statement on quality end-of-life care – Part 1: Essential elements for quality, safety and appropriate clinical care at the end of life. Canberra ACT, Australia: ANZSPM. <http://www.anzspm.org.au> (accessed 21.03.23).
- Australian College of Critical Care Nurses [ACCCN] position statement working group, Bloomer, M., Ranse, K., Butler, A., Brooks, L.A., 2020. ACCCN position statement on adult end-of-life care in critical care. <https://www.acccn.com.au/> (accessed 21.03.23).
- Australian College of Nursing [ACN], 2019. Achieving quality palliative care for all: The essential role of nurses—A white paper by ACN 2019. Canberra: ACN. <https://www.acn.edu.au/> (accessed 21.03.23).
- Australian Commission on Safety and Quality in Health Care [ACSQHC], 2015. National consensus statement: Essential elements for safe and high-quality end-of-life care. Sydney, Australia: ACSQHC. <https://www.safetyandquality.gov.au/> (accessed 21.03.23)
- Australian Commission on Safety and Quality in Health Care [ACSQHC], 2017 (2nd ed.). National safety and quality health service standards. Sydney, Australia: ACSQHC. <https://www.safetyandquality.gov.au/> (accessed 21.03.23).
- Bloomer, M.J., Ranse, K., Brooks, L.A., Adams, L., Coventry, A., 2022. “Time and life is fragile” – An integrative review of nurses’ experiences after patient death in adult critical care. *Aust Crit Care*. <https://doi.org/10.1016/j.aucc.2022.09.008>
- Bloomer, M.J., Yates, P., Balson, J., Coventry, A., Hewitt, J., Jeong, SY-S., et al, 2020. Optimising person- and family-centred end-of-life care during a pandemic [Position Statement]. Australian College of Nursing, Canberra. (accessed 21.03.23).
- Brekelmans, A.C.M., Ramnarain, D., Pouwels, S., 2022. Bereavement support programs in the Intensive Care Unit: a systematic review. *J Pain Symptom Manage*, 64, p.e149-e157. 10.1016/j.jpainsymman.2022.05.008
- Brooks, L.A., Manias, E., Bloomer, M.J., 2019. Culturally sensitive communication in healthcare: A concept analysis. *Collegian*. 26, 383-91. 10.1016/j.colegn.2018.09.007
- Buckley, T., Spinaze, M., Bartrop, R., McKinley, S., Whitfield, V., Havyatt, J., et al., 2015. The nature of death, coping response and intensity of bereavement following death in the critical care environment. *Aust Crit Care*. 28, 64-70. 10.1016/j.aucc.2015.02.003
- Centre for Open Science, 2022. Open Science Framework [Computer software]. Centre for Open Science. <https://osf.io/> (accessed 21.03.23).
- Chen, C., 2018. Using a nurse-led communication strategy for surrogates in the intensive care unit. *Cochrane Central Register of Controlled Trials*.
- Clarivate Analytics, 2023. EndNote [Computer software]. Philadelphia, PA: Clarivate. <https://endnote.com/> (accessed 21.03.23).

- Clark, J.M., Sanders, S., Carter, M., Honeyman, D., Cleo, G., Auld, Y., et al., 2020. Improving the translation of search strategies using the Polyglot Search Translator: A randomized controlled trial. *J Med Libr Assoc.* 108, 195–207. 10.5195/jmla.2020.834
- Coelho, A., Barbosa, A., 2016. Family Anticipatory Grief: An Integrative Literature Review. *Am J Hosp Palliat Care*, 34, 774-785. 10.1177/1049909116647960
- Coombs, M.A., Parker, R., Ranse, K., Endacott, R., Bloomer, M.J., 2016. An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care. *J Adv Nurs.* 73, 39-55. 10.1111/jan.13097
- Coventry, A., 2017. End-of-life care in the intensive care unit. A meta-synthesis of qualitative studies investigating the experiences and perceptions of the patient’s family [Thesis]. Australian Catholic University; Melbourne.
- Coventry, A., Ford, R., Rosenberg, J.P., McInnes, E., 2020. A qualitative meta-synthesis investigating the experiences of the patient’s family when treatment is withdrawn in the intensive care unit. *J Adv Nurs.* 76, 2222–34. <https://doi.org/10.1111/jan.14416>
- Curtis, J.R., Kentish-Barnes, N., Brumback, L.C., Nielsen, E.L., Pollak, K.I., Treece, P.D., et al., 2021. Facilitating communication for critically ill patients and their family members: Study protocol for two randomized trials implemented in the U.S. and France. *Contemp Clin Trials.* 107, 106465. 10.1016/j.cct.2021.106465
- Curtis, J.R., Treece, P.D., Nielsen, E.L., Gold, J., Ciechanowski, P.S., Shannon, S.E., et al., 2016. Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care. *Am J Respir Crit Care Med.* 193, 154-62. 10.1164/rccm.201505-0900OC
- Department of Health [DOH], 2018. National Palliative Care Strategy 2018 <https://www.health.gov.au/> (accessed 21.03.23).
- Department of Health [DOH], 2008. End of life care strategy: Promoting high quality care for all adults at end of life. <http://www.dh.gov.uk/> (accessed 21.03.23).
- Efstathiou, N., Walker, W., Metcalfe, A., Vanderspank-Wright, B., 2019. The state of bereavement support in adult intensive care: A systematic review and narrative synthesis. *J Crit Care.* 50, 177-87. 10.1016/j.jcrrc.2018.11.026
- Eldridge, S.M., Lancaster, G.A., Campbell, M.J., Thabane, L., Hopewell, S., Coleman, C.L., et al., 2016. Defining feasibility and pilot studies in preparation for randomised controlled trials: Development of a conceptual framework. *PLoS One.* 11, e0150205-e. 10.1371/journal.pone.0150205
- Erikson, A., McAdam, J., 2020. Bereavement care in the adult intensive care unit: Directions for practice. *Crit Care Nurs Clin North Am.* 32, 281-94. 10.1016/j.cnc.2020.02.009
- Fernández-Martínez, E., Mapango, E.A., Martínez-Fernández, M.C., Valle-Barrio, V., 2022. Family-centred care of patients admitted to the intensive care unit in times of COVID-19: A systematic review. *Intensive Crit Care Nurs.* 70, 103223. <https://doi.org/10.1016/j.iccn.2022.103223>
- Fischer, F., Helmer, S., Rogge, A., Arraras, J.I., Buchholz, A., Hannawa, A., et al., 2019. Outcomes and outcome measures used in evaluation of communication training in oncology – a systematic literature review, an expert workshop, and recommendations for future research. *BMC Cancer.* 19, 808-808. 10.1186/s12885-019-6022-5
- Galazzi, A., Adamini, I., Bazzano, G., Cancelli, L., Fridh, I., Laquintana, D., et al., 2021. Intensive care unit diaries to help bereaved family members in their grieving process: A systematic review. *Intensive Crit Care Nurs.* 68, 103121. 10.1016/j.iccn.2021.103121
- Hay, A., Hall, C.W., Sealey, M., Lobb, E.A., Breen, L.J., 2021. Developing a practice-based research agenda for grief and bereavement care. *Death Stud.* 45, 331-341. 10.1080/07481187.2019.1636897
- Hebert, R.S., Dang, Q., Schulz, R., 2006a. Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *J Palliat Med.* 9, 683-93.

- Hebert, R.S., Prigerson, H.G., Schulz, R., Arnold, R.M., 2006b. Preparing caregivers for the death of a loved one: A theoretical framework and suggestions for future research. *J Palliat Med.* 9, 1164. 10.1089/jpm.2006.9.1164
- Hebert, R.S., Schulz, R., Copeland, V.C., Arnold, R.M., 2009. Preparing family caregivers for death and bereavement. Insights from caregivers of terminally ill patients. *J Pain Symptom Manage.* 37, 3-12. 10.1016/j.jpainsymman.2007.12.010
- Higgins, J.P.T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M.J., et al. *Cochrane handbook for systematic reviews of interventions version 6.2 (updated February 2021)*. Cochrane, 2021. www.training.cochrane.org/handbook2021.
- Hoel, H., Skjaker, S.A., Haagenen, R., Stavem, K., 2014. Decisions to withhold or withdraw life-sustaining treatment in a Norwegian intensive care unit. *Acta Anaesthesiologica Scandinavica* 58, 329-36. 10.1111/aas.12246
- Hoffmann, T.C., Glasziou, P.P., Boutron, I., Milne, R., Perera, R., Moher, D., et al., 2014. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. *BMJ (Online)*. 348, g1687-g. 10.1136/bmj.g1687
- Hudson, P.L., Girgis, A., Thomas, K., Philip, J., Currow, D., Mitchell, G., et al., 2020. Do family meetings for hospitalised palliative care patients improve outcomes and reduce health care costs? A cluster randomised trial. *Palliat Med.* 31, 188-199. 10.1177/0269216320967282
- Hudson, P.L., Quinn, K., O'Hanlon, B., Aranda, S., 2008. Family meetings in palliative care: Multidisciplinary clinical practice guidelines. *BMC Palliat Care.* 7, 12. 10.1186/1472-684X-7-12
- Veritas Health Innovation, 2023. Covidence systematic review software [Computer software]. Melbourne, Australia: Covidence. www.covidence.org (accessed 21.03.23).
- Ivany, E., Aitken, L., 2019. Challenges and facilitators in providing effective end of life care in intensive care units. *Nurs Stand.* 34, 44-50. 10.7748/ns.2019.e11248
- Jadalla, A., Page, M., Ginex, P., Coleman, M., Vrabel, M., Bevans, M., 2020. Family caregiver strain and burden: A systematic review of evidence-based interventions when caring for patients with cancer. *Clin J Oncol Nurs.* 24, 31-50.
- Keenan, S., Mawdsley, C., Plotkin, D., Webster, G., Priestap, F., 2000. Withdrawal of life support: How the family feels, and why. *J Palliat Care.* 16, S40-4.
- Kentish-Barnes, N., 2019. Bereavement care and research in the intensive care unit: Opportunities and challenges. *Nurs Crit Care.* 24, 189-91. 10.1111/nicc.12457
- Kentish-Barnes, N., Chevret, S., Valade, S., Jaber, S., Kerhuel, L., Guisset, O., et al., 2022. A three-step support strategy for relatives of patients dying in the intensive care unit: A cluster randomised trial. *The Lancet (British edition)*. 399, 656-64. 10.1016/S0140-6736(21)02176-0
- Kersting, A., Brähler, E., Glaesmer, H., Wagner, B., 2010. Prevalence of complicated grief in a representative population-based sample. *J Affect Disord.* 131, 339-43. 10.1016/j.jad.2010.11.032
- Kirchhoff, K.T., Palzkill, J., Kowalkowski, J., Mork, A., Gretarsdottir, E., 2008. Preparing families of intensive care patients for withdrawal of life support: A pilot study. *Am J Crit Care.* 17, 113-22 10p.
- Kryworuchko, J., Hill, E., Murray, M.A., Stacey, D., Fergusson, D.A., 2013. Interventions for shared decision-making about life support in the intensive care unit: A systematic review. *World views on evidence-based nursing.* 10, 3-16. 10.1111/j.1741-6787.2012.00247.x
- Kydonaki, K., Takashima, M., Mitchell, M., 2021. Family ward rounds in intensive care: An integrative review of the literature. *Int J Nurs Stud.* 113, 103771-. 10.1016/j.ijnurstu.2020.103771
- Lautrette, A., Darmon, M., Megarbane, B., Joly, L.M., Chevret, S., Adrie, C., et al., 2007. A communication strategy and brochure for relatives of patients dying in the ICU. *The New England Journal of Medicine.* 356, 469-78.

- Lincoln, T., Shields, A.M., Buddadhumaruk, P., Chang, C.C.H., Pike, F., Chen, H., et al., 2020. Protocol for a randomised trial of an interprofessional team-delivered intervention to support surrogate decision-makers in ICUs. *BMJ Open*. 10, e033521-e. 10.1136/bmjopen-2019-033521
- Liu, X., Humphris, G., Luo, A., Yang, M., Yan, J., Huang, S., et al., 2021. Family-clinician shared decision making in intensive care units: Cluster randomized trial in China. *Patient Educ Couns*. 10.1016/j.pec.2021.10.004
- Lobb, E.A., Kristjanson, L.J., Aoun, S.M., Monterosso, L., Halkett, G.K., Davies, A., 2010. Predictors of complicated grief: A systematic review of empirical studies. *Death Stud*. 34, 673-98. 10.1080/07481187.2010.496686
- Medical Research Council., 2019. Developing and evaluating complex interventions. <https://mrc.ukri.org/documents/pdf/developing-and-evaluating-complex-interventions/> (accessed 21.03.23).
- Metaxa, V., Anagnostou, D., Vlachos, S., Arulkumaran, N., Besemane, S., van Dusseldorp, I., et al., 2021. Palliative care interventions in intensive care unit patients. *Intensive Care Med*. 47, 1415-25.
- Miller, E.M., Porter, J.E., Barbagallo, M.S., 2022. The experiences of health professionals, patients, and families with truth disclosure when breaking bad news in palliative care: A qualitative meta-synthesis. *Palliative and Supportive Care*. 20, 433-44. 10.1017/s1478951521001243
- Mitchell, I., Lacey, J., Anstey, M., Corbett, C., Douglas, C., Drummond, C., et al., 2021. Understanding end-of-life care in Australian hospitals. *Aust Health Rev*. 45, 540-547. 10.1071/ah20223
- Moss, S.J, Wollny, K., Poulin, T.G, Cook, D.J., Stelfox, H.T., Ordons, A.R.D., et al., 2021. Bereavement interventions to support informal caregivers in the intensive care unit: A systematic review. *BMC Palliat Care*. 20, 66. 10.1186/s12904-021-00763-w
- Munn, Z., Peters, M.D.J., Stern, C., Tufanaru, C., McArthur, A., Aromataris, E., 2018. Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Med Res Methodol*. 18, 143. 10.1186/s12874-018-0611-x
- Myburgh, J., Abillama, F., Chiumello, D., Dobb, G., Jacobe, S., Kleinpell, R., et al., 2016. End-of-life care in the intensive care unit: Report from the Task Force of World Federation of Societies of Intensive and Critical Care Medicine. *J Crit Care*. 34, 125-30. 10.1016/j.jcrc.2016.04.017
- Naef, R., Filipovic, M., Jeitziner, M.M., von Felten, S., Safford, J., Riguzzi, M., et al., 2022. A multicomponent family support intervention in intensive care units: Study protocol for a multicenter cluster-randomized trial (FICUS Trial). *Trials*. 23, 533. 10.1186/s13063-022-06454-y
- National Health and Medical Research Council. Guideline Assessment Register consultants, Merlin T., Weston A., Tooher R., Middleton P., Salisbury J., et al., 2009. NHMRC levels of evidence and grades for recommendations for developers of guidelines. NHMRC. <https://www.nhmrc.gov.au/> (accessed 21.03.23).
- National Institute for Health and Care Excellence [NICE], 2015. Care of dying adults in the last days of life quality standard [NG31]. NICE. <https://www.nice.org.uk/guidance/ng31> (accessed 21.03.23).
- National Institute for Health and Care Excellence [NICE], 2019. End of life care for adults: Service delivery [NG142]. <https://www.nice.org.uk/guidance/ng142> (accessed 21.03.23).
- National Institute for Health and Care Excellence [NICE], 2021. End of life care for adults: NICE quality standard [QS13]. NICE. <https://www.nice.org.uk/guidance/qs13> (accessed 21.03.23).
- Neimeyer, R.A., Burke, L.A. Complicated grief and the end of life: Risk factors and treatment considerations. In: Worth, J.L., editor. *Counselling Clients Near the End-of-Life*. New York: Springer Science; 2012. p. 205–24.
- Oczkowski, S.J., Chung, H.O., Hanvey, L., Mbuagbaw, L., You, J.J., 2016. Communication tools for end-of-life decision-making in the intensive care unit: A systematic review and meta-analysis. *Critical Care*. 20, 97. 10.1186/s13054-016-1264-y

- Oncology Nurses Society [ONS], 2019. Caregiver strain and burden [Evidence Summary]. <https://www.ons.org/> (accessed 21.03.23).
- Osorio, C.C.B., da Cruz, I.C.F., 2018. Guidelines for evidence-based practice on nursing intervention in support of mourning process in ICU - Systematized literature review. *Journal of Specialized Nursing Care*. 10, 1-6.
- Palliative Care Australia, 2005. Standards for providing quality palliative care for all Australians (4th ed.). <http://palliativecare.org.au/> (accessed 21.03.23).
- Peters, M.D.J., Godfrey, C., Mclnerney, P., Munn, Z., Tricco, A.C., Khalil, H. Chapter 11: Scoping Reviews (2020 version). In: Aromataris, E., Munn, Z., editors. *Joanna Briggs Institute Manual for Evidence Synthesis*: JBI, 2020.
- Peters, M.D.J., Marnie, C., Tricco, A.C., Pollock, D., Munn, Z., Alexander, L., et al., 2020. Updated methodological guidance for the conduct of scoping reviews. *JBI Evid Synth*. 18, 2119-26. 10.11124/JBIES-20-00167
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., et al., 2006. *Guidance on the conduct of narrative synthesis in systematic reviews*. Lancaster: Lancaster University.
- Rait, L.I., Yeo, N.Y., Abdelhamid, Y.A., Showler, L., Finnis, M.E., Deane, A.M., 2021. The impact of bereavement support on psychological distress in family members: A systematic review and meta-analysis. *Crit Care Resusc*. 23, 225-33. 10.3316/informit.951753557058389
- Rawlings, D., Devery, K., Tieman, J., Tait, P., Chakraborty, A., 2021. Rapid review of the literature on end-of life care. Sydney: ACSQHC. <https://www.safetyandquality.gov.au/> (accessed 21.03.2023).
- Rhoads, S., 2019. Communication at the end-of-life in the intensive care unit: A review of evidence-based best practices. *R I Dent J*. 30-3.
- Robin, S., Labarriere, C., Sechaud, G., Dessertaine, G., Bosson, J.L., Payen, J.F., 2021. Information pamphlet given to relatives during the end-of-life decision in the ICU: An assessor-blinded, randomized controlled trial. *Chest*. 159, 2301-8. 10.1016/j.chest.2021.01.072
- Roczen, M.L., White, K.R., Epstein, E.G., 2016. Palliative Care and Intensive Care Units: A Systematic Review. *J Hosp Palliat Nurs*. 18, 201-11. 10.1097/NJH.0000000000000218
- Ryan, R., 2013. Cochrane Consumers and Communication Review Group. *Cochrane consumers and communication review group: Data synthesis and analysis*. <http://cccrg.cochrane.org> (accessed 21.03.2023).
- Sanderson, E.A.M., Humphreys, S., Walker, F., Harris, D., Carduff, E., McPeake, J., et al., 2022. Risk factors for complicated grief among family members bereaved in intensive care unit settings: A systematic review. *PLoS One*. 17, e0264971. 10.1371/journal.pone.0264971
- Scheunemann, L.P., McDevitt, M., Carson, S.S., Hanson, L.C., 2011. Randomized, controlled trials of interventions to improve communication in intensive care: A systematic review. *Chest*. 139, 543-54.
- Schram, A.W., Hougham, G.W., Meltzer, D.O., Ruhnke, G.W., 2017. Palliative Care in Critical Care Settings: A Systematic Review of Communication-Based Competencies Essential for Patient and Family Satisfaction. *Am J Hosp Palliat Care*. 34, 887-95. 10.1177/1049909116667071
- Skivington, K., Matthews, L., Simpson, S.A., Craig, P., Baird, J., Blazeby, J.M., et al., 2021. A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *BMJ*. 374, n2061. 10.1136/bmj.n2061
- Society of Critical Care Medicine, 2019. *Critical care statistics: Morbidity and mortality*. <https://www.sccm.org/> (accessed 21.03.23).
- Tang, S.T., Huang, C.C., Hu, T.H., Lo, M.L., Chou, W.C, Chuang, L.P., et al., 2021. End-of-life-care quality in ICUs is associated with family surrogates' severe anxiety and depressive symptoms during their first 6 months of bereavement. *Crit Care Med*. 49, 27-37. 10.1097/CCM.0000000000004703

- The Canadian Association of Critical Care Nurses [CACCN], 2020. Providing end of life care in critical care [Position Statement]. CACCN. <https://caccn.ca/> (accessed 21.03.23).
- Tricco, A.C., Lillie, E., Zarin, W., O'Brien, K.K., Colquhoun, H., Levac, D., et al., 2018. PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Ann Intern Med.* 169, 467-73. 10.7326/M18-0850
- Visser, M., Deliens, L., Houttekier, D., 2014. Physician-related barriers to communication and patient- and family-centred decision-making towards the end of life in intensive care: A systematic review. *Critical Care.* 18. 10.1186/s13054-014-0604-z
- White, D.B., 2022. Multi-component family support tool intervention (FST). <https://www.clinicaltrials.gov/ct2/show/NCT05019261> (accessed 21.03.2023).
- White, D.B., Angus, D.C., Shields, A.M., Buddadhumaruk, P., Pidro, C., Paner, C., et al., 2018. A Randomized trial of a family-support intervention in intensive care units. *The New England Journal of Medicine.* 378, 2365-75. 10.1056/NEJMoa1802637
- World Health Assembly (67), 2014. Strengthening of palliative care as a component of comprehensive care throughout the life course. World Health Organisation. <https://who.int/> (accessed 21.03.23).
- Zante, B., Camenisch, S.A., Schefold, J.C., 2020. Interventions in post-intensive care syndrome-family: A systematic literature review. *Crit Care Med.* 48, e835-e40. 10.1097/CCM.0000000000004450

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Supplemental file 1: Search strategy

MEDLINE (Ovid)

#	Query	Results
1	(end of life or eolc or die* or death or dying or palliat* or bereave* or withdra*).ti,ab,kf.	2042803
2	Terminal Care/	30921
3	Palliative Care/	60576
4	Bereavement/	6326
5	1 or 2 or 3 or 4	2067689
6	(intensive care or critical care or intensive therapy unit or ICU or ITU).ti,ab,kf.	228986
7	Intensive Care Units/	66285
8	Critical Care/	58385
9	Critical Care Nursing/	2571
10	6 or 7 or 8 or 9	260844
11	(Famil* or caregiv* or carer or surrogate* or spouse).ti,ab,kf.	1355794
12	Family/	82565
13	11 or 12	1382914
14	randomized controlled trial.pt.	570917
15	controlled clinical trial.pt.	94909
16	Randomized Controlled Trials as Topic/	155986
17	Clinical Trials as Topic/	200077
18	Pilot Projects/	141128
19	Feasibility Studies/	79811
20	(random or trial or feasibility or pilot).ti,ab,kf.	1345706
21	placebo.ti,ab.	235342
22	trial.ti,ab.	702179
23	groups.ti,ab.	2393744
24	random*.ti,ab,kf.	1328963
25	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24	4242279
26	animals/ not humans/	4984937
27	25 not 26	3699235
28	5 and 10 and 13 and 27	806
29	limit 28 to yr="2007 - 2022"	669
30	limit 29 to English language	650

CINAHL (EBSCOhost)

#	Query	Results
S1	((TI "end of life" OR AB "end of life" OR SU "end of life") OR (TI eolc OR AB eolc OR SU eolc) OR (TI death OR AB death OR SU death) OR (TI dying OR AB dying OR SU dying) OR (TI die* OR AB die* OR SU die*) OR (TI palliat* OR AB palliat* OR SU palliat*) OR (TI bereave* OR AB bereave* OR SU bereave*) OR (TI withdra* OR AB withdra* OR SU withdra*))	624,328
S2	(MH "Terminal Care")	19,447
S3	(MH "Palliative Care")	40,406
S4	S1 OR S2 OR S3	628,284
S5	((TI "intensive care" OR AB "intensive care" OR SU "intensive care") OR (TI "critical care" OR AB "critical care" OR SU "critical care") OR (TI "intensive therapy unit" OR AB "intensive therapy unit" OR SU "intensive therapy unit") OR (TI ICU OR AB ICU OR SU ICU) OR (TI ITU OR AB ITU OR SU ITU))	148,196
S6	(MH "Intensive Care Units")	42,692
S7	(MH "Critical Care")	25,085
S8	(MH "Critical Care Nursing")	22,063
S9	S5 OR S6 OR S7 OR S8	148,196
S10	((TI Famil* OR AB Famil* OR SU Famil*) OR (TI caregiv* OR AB caregiv* OR SU caregiv*) OR (TI carer OR AB carer OR SU carer) OR (TI surrogate* OR AB surrogate* OR SU surrogate*) OR (TI spouse OR AB spouse OR SU spouse))	514,828
S11	(MH Family)	45,192
S12	S10 OR S11	514,828
S13	MH randomized controlled trials	126,149
S14	MH double-blind studies	52,466
S15	MH single-blind studies	15,466
S16	MH random assignment	72,885
S17	MH pretest-posttest design	48,734
S18	MH cluster sample	4,921
S19	TI (randomised OR randomized)	124,847
S20	AB (random*)	367,239
S21	TI (trial)	161,072
S22	MH (sample size) AND AB (assigned OR allocated OR control)	4,307
S23	1 MH (placebos)	0
S24	MH (placebos)	13,261
S25	PT (randomized controlled trial)	139,520
S26	AB (control W5 group)	131,086

S27	MH (crossover design) OR MH (comparative studies)	442,778
S28	5 AB (cluster W3 RCT)	0
S29	AB (cluster W3 RCT)	444
S30	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29	938,130
S31	S4 AND S9 AND S12 AND S30	536
S32	S31 Limiters - Published Date: 20070101-20221231	458
S33	S32 Limiters - English Language	448

EMBASE (Ovid)

#	Query	Results
1	("end of life" or eolc or "EOL care" or palliat* or bereave* or withdra*).tw,kf.	249805
2	terminal care/	30921
3	1 or 2	264257
4	("intensive care" or "critical care" or "intensive therapy unit" or ICU or ITU).tw,kf.	228986
5	exp intensive care unit/	100310
6	4 or 5	256307
7	(Famil* or caregiv* or carer or surrogate* or spouse).tw,kf.	1355794
8	family/	82565
9	7 or 8	1382914
10	Randomized controlled trial/	570917
11	Controlled clinical study/	465090
12	random\$.ti,ab.	1325087
13	randomization/	106854
14	intermethod comparison/	280320
15	placebo.ti,ab.	235342
16	(compare or compared or comparison).ti.	446270
17	((evaluated or evaluate or evaluating or assessed or assess) and (compare or compared or comparing or comparison)).ab.	1654461
18	(open adj label).ti,ab.	50718
19	((double or single or doubly or singly) adj (blind or blinded or blindly)).ti,ab.	183544
20	double blind procedure/	192646
21	parallel group\$1.ti,ab.	21397
22	(crossover or cross over).ti,ab.	93835

23	((assign\$ or match or matched or allocation) adj5 (alternate or group\$1 or intervention\$1 or patient\$1 or subject\$1 or participant\$1)).ti,ab.	267968
24	(assigned or allocated).ti,ab.	350383
25	(controlled adj7 (study or design or trial)).ti,ab.	303063
26	(volunteer or volunteers).ti,ab.	199007
27	human experiment/	566745
28	trial.ti.	264570
29	or/10-28	3710408
30	(random\$ adj sampl\$ adj7 ('cross section\$' or questionnaire\$1 or survey\$ or database\$1)).ti,ab. not (comparative study/ or controlled study/ or randomi?ed controlled.ti,ab. or randomly assigned.ti,ab.)	8957
31	Cross-sectional study/ not (randomized controlled trial/ or controlled clinical study/ or controlled study/ or randomi?ed controlled.ti,ab. or control group\$1.ti,ab.)	413933
32	((case adj control\$) and random\$) not randomi?ed controlled).ti,ab.	14709
33	(Systematic review not (trial or study)).ti.	180644
34	(nonrandom\$ not random\$).ti,ab.	15815
35	'Random field\$'.ti,ab.	3097
36	(random cluster adj3 sampl\$).ti,ab.	1172
37	(review.ab. and review.pt.) not trial.ti.	1068695
38	'we searched'.ab. and (review.ti. or review.pt.)	40633
39	'update review'.ab.	119
40	(databases adj4 searched).ab.	48836
41	(rat or rats or mouse or mice or swine or porcine or murine or sheep or lambs or pigs or piglets or rabbit or rabbits or cat or cats or dog or dogs or cattle or bovine or monkey or monkeys or trout or marmoset\$1).ti. and animal experiment/	1139567
42	Animal experiment/ not (human experiment/ or human/)	2492214
43	or/30-42	3900536
44	29 not 43	5031379
45	3 and 6 and 9 and 44	666
46	limit 45 to yr="2007 - 2022"	618
47	limit 46 to English language	611

APAPsych INFO (Ovid)

#	Query	Results
1	("end of life" or eolc or palliat* or bereave* or withdra*).ti,ab,id.	245719
2	palliative care/	60576
3	"death and dying"/	0

4	bereavement/	6326
5	1 or 2 or 3 or 4	266535
6	("intensive care" or "critical care" or "intensive therapy unit" or ICU or ITU).ti,ab,id.	222537
7	intensive care/	58385
8	6 or 7	243048
9	(Famil* or caregiv* or carer or surrogate* or spouse).ti,ab,id.	1327271
10	family/	82565
11	9 or 10	1355044
12	exp Randomized Controlled Trials/	159817
13	exp Clinical Trials/	0
14	(random* or trial or feasibility or pilot or placebo or groups).ti,ab,id.	3905322
15	12 or 13 or 14	3952465
16	5 and 8 and 11 and 15	424
17	limit 16 to yr="2007 - 2022"	362
18	limit 17 to english language	358

Ovid EMCARE

#	Query	Results
1	(end of life or eolc or palliat* or bereave* or withdra*).ti,ab,kf.	72805
2	terminal care/	30921
3	exp palliative therapy/	60576
4	bereavement/	6326
5	1 or 2 or 3 or 4	282609
6	(intensive care or critical care or intensive therapy unit or ICU or ITU).ti,ab,kf.	228986
7	intensive care unit/	66285
8	intensive care nursing/	2571
9	intensivist/	1687
10	6 or 7 or 8 or 9	241859
11	(Famil* or caregiv* or carer or surrogate* or spouse).ti,ab,kf.	1355794
12	family/	82565
13	11 or 12	1382914
14	randomized controlled trial/	570917
15	controlled clinical trial/	94909
16	Randomized Controlled Trials as Topic/	155986
17	clinical trial as topic/	200077
18	feasibility study/	79811
19	pilot study/	141128

20	clinical trial/	535394
21	trial.ti.	264570
22	(random* or trial or feasibility or pilot).ti,ab,kf.	1961458
23	placebo.ti,ab.	235342
24	groups.ti,ab.	2393744
25	14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24	4383595
26	animal/	7128728
27	human/	20555672
28	26 not 27	4984937
29	25 not 28	820772
30	5 and 10 and 13 and 29	95
31	limit 30 to yr="2007 - 2022"	79
32	Limit 31 to english language	78

Cochrane

#	Query	Results
1	((“end of life” OR eolc OR palliat* OR bereave* OR withdra#)):ti,ab,kw	57263
2	MeSH descriptor: [Terminal Care] this term only	376
3	MeSH descriptor: [Palliative Care] this term only	1748
4	MeSH descriptor: [Bereavement Care] this term only	136
5	#1 OR #2 OR #3 OR #4	57341
6	((“intensive care” OR “critical care” OR “intensive therapy unit” OR ICU OR ITU)):ti,ab,kw Word variations have been searched	35964
7	MeSH descriptor: [Intensive Care Units] this term only	2581
8	MeSH descriptor: [Critical Care] this term only	1844
9	MeSH descriptor: [Critical Care Nursing] this term only	48
10	#6 OR #7 OR #8 OR #9	35964
11	((Famil* OR Caregiv* OR surrogate* or spouse)):ti,ab,kw Word variations have been searched	69789
12	MeSH descriptor: [Family] this term only	1597
13	#11 OR #12	69789
14	#5 AND #10 AND #13	319
15	#5 AND #10 AND #13 With publication Year from 2007 to 2022, in Trials	275

Supplemental file 2: Table of excluded studies with reasons

#	Reference	Reason
1	Alghanim, F., Zakaria, S., Furqan, M., Prichett, L., & Tao, X. (2019). Increasing Communication and Trust in the ICU: The Critical Care Collaboration and Communication (C4) Project [Abstract]. <i>American Journal of Respiratory and Critical Care Medicine</i> , 199(A4152).	Abstract only
2	Carson, S. S., Cox, C. E., Wallenstein, S., Hanson, L. C., Danis, M., Tulskey, J. A., Chai, E., & Nelson, J. E. (2016). Effect of Palliative Care-Led Meetings for Families of Patients With Chronic Critical Illness: A Randomized Clinical Trial. <i>JAMA</i> , 316(1), 51-62. https://doi.org/10.1001/jama.2016.8474	Critically ill population
3	Chen, C., Sullivan, S. S., Lorenz, R. A., Wittenberg, E., Li, C. S., & Chang, Y. P. (2021). COMFORT communication in the ICU: Pilot test of a nurse-led communication intervention for surrogates. <i>Journal of Clinical Nursing</i> . https://doi.org/10.1111/jocn.16132	Pilot study
4	Cox, C. E., Olsen, M. K., Casarett, D., Haines, K., Al-Hegelan, M., Bartz, R. R., Katz, J. N., Naglee, C., Ashana, D., Gilstrap, D., Gu, J., Parish, A., Frear, A., Krishnamaneni, D., Corcoran, A., & Docherty, S. L. (2020). Operationalizing needs-focused palliative care for older adults in intensive care units: Design of and rationale for the PCplanner randomized clinical trial. <i>Contemporary Clinical Trials</i> , 98, 106163-106163. https://doi.org/10.1016/j.cct.2020.106163	Intervention design
5	Curtis, J. R., Treece, P. D., Nielsen, E. L., Downey, L., Shannon, S. E., Braungardt, T., Owens, D., Steinberg, K. P., & Engelberg, R. A. (2008). Integrating Palliative and Critical Care: Evaluation of a Quality-Improvement Intervention [Abstract]. <i>American Journal of Respiratory and Critical Care Medicine</i> , 178(3), 269-275.	Quality improvement project
6	Curtis, J. R., Nielsen, E. L., Treece, P. D., Downey, L., Dotolo, D., Shannon, S. E., Back, A. L., Rubenfeld, G. D., & Engelberg, R. A. (2011). Effect of a Quality-Improvement Intervention on End-of-Life Care in the Intensive Care Unit: A Randomized Trial. <i>American Journal of Respiratory and Critical Care Medicine</i> , 183(3), 348-348-355.	Intervention targets staff
7	Delgado, E. M., Callahan, A., Paganelli, G., Reville, B., Parks, S. M., & Marik, P. E. (2009). Multidisciplinary Family Meetings in the ICU Facilitate End-of-Life Decision Making. <i>AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE</i> , 26(4), 295-302. https://doi.org/10.1177/1049909109333934	Abstract only
8	Jones, T. (2007). A proactive communication strategy reduced post-traumatic stress disorder symptoms in relatives of patients dying in the ICU. <i>Evidence-Based Nursing</i> , 10(3), 85-85. https://doi.org/10.1136/ebn.10.3.85	Commentary
9	Lichtenthal, W. G., Viola, M., Rogers, M., Roberts, K. E., Lief, L., Cox, C. E., Brewin, C. R., Xu, J. C., Maciejewski, P. K., Pan, C. X., Coats, T., Ouyang, D. J., Rabin, S., Vaughan, S. C., Breitbart, W., Marenberg, M. E., & Prigerson, H. G. (2021). Development and preliminary evaluation of EMPOWER for surrogate decision-makers of critically ill patients. <i>Palliative & supportive care</i> , 1-11. https://doi.org/10.1017/S1478951521000626	Open trial
10	Mosenthal, A. C., Murphy, P. A., Barker, L. K., Lavery, R., TRetano, A., & Livingston, D. H. (2008). Changing the Culture Around End-of-Life Care in the Trauma Intensive Care Unit. <i>The Journal of Trauma</i> , 64(6), 1587-1593.	Observational study
11	Muehlschlegel, S., Goostrey, K., Flahive, J., Zhang, Q., Pach, J. J., & Hwang, D. Y. (2022). A Pilot Randomized Clinical Trial of a Goals-of-Care Decision Aid for Surrogates of Severe Acute Brain Injury Patients. <i>Neurology</i> , 99(14), e1446-1455. https://doi.org/10.1212/WNL.0000000000200937	Critically ill population

12	Scharf, B., Zhu, S., Tomlin, S., Cheon, J., Mooney-Doyle, K., Baggs, J. G., & Weigand, D. (2021). Feasibility of an Intervention Study to Support Families When Their Loved One Has Life-sustaining Therapy Withdrawn. <i>Journal of Hospice and Palliative Nursing</i> , 23(1), 89-97. https://doi.org/10.1097/NJH.0000000000000717	Feasibility study
13	Suen, A. O., Butler, R. A., Arnold, R. M., Myers, B., Witteman, H. O., Cox, C. E., McComb, J. G., Buddadhumaruk, P., Shields, A.-M., Morse, N., Argenas, A., & White, D. B. (2020). A Pilot Randomized Trial of an Interactive Web-based Tool to Support Surrogate Decision-makers in the ICU. <i>Annals of the American Thoracic Society</i> .	Feasibility study
14	Sulmasy, D. P., Hughes, M. T., Yenokyan, G., Kub, J., Terry, P. B., Astrow, A. B., Johnson, J. A., Ho, G., & Nolan, M. T. (2017). The Trial of Ascertaining Individual Preferences for Loved Ones' Role in End-of-Life Decisions (TAILORED) Study: A Randomized Controlled Trial to Improve Surrogate Decision Making. <i>Journal of Pain and Symptom Management</i> , 54(4), 455-465.	Outpatient clinic setting
15	Tawil, I., Brown, L. H., Comfort, D., Crandall, C. S., West, S. D., Rollstin, A. D., Dettmer, T. S., Malkoff, M. D., & Marinaro, J. (2014). Family Presence During Brain Death Evaluation: A Randomized Controlled Trial. <i>Critical Care Medicine</i> , 42(4), 934-942. https://doi.org/10.1097/CCM.0000000000000102	Brain death
16	Torke, A. M., Varner-Perez, S. E., Burke, E. S., Taylor, T. A., Slaven, J. E., Kozinski, K. L., Maiko, S. M., Pfeffer, B. J., & Banks, S. K. (2022). Effects of Spiritual Care on Well-being of Intensive Care Family Surrogates: A Clinical Trial. <i>Journal of Pain and Symptom Management</i> . https://doi.org/10.1016/j.jpainsymman.2022.12.007	Critically ill population
17	Wendlandt, B., Ceppe, A., Summer, C., Nelson, J. E., Cox, C. E., Hanson, L., Danis, M., Tulsy, J., & Carson, S. S. (2019). The association of provider support and communication with post-traumatic stress disorder symptoms for family caregivers of patients with chronic critical illness [Abstract]. <i>American Journal of Respiratory and Critical Care Medicine</i> , 199(9). https://www.atsjournals.org/doi/10.1164/ajrccm-conference.2019.199.1_MeetingAbstracts.A4152	Abstract only/Quality improvement

Supplemental file 3: Data extraction form

Author, year	Aim &/or research question	Country, setting & context	Sample & sample size	Methodology & method	Inclusion/exclusion criteria	Participant characteristics (age, sex, religion, ethnicity)	Description of the intervention	Relevant outcome variable/s, instrument/s & timeframe	Results	Barriers & Enablers to intervention uptake	Limitations	Recommendations

Supplemental file 4: TIDieR Intervention summary

BRIEF NAME	WHY? <i>'Rationale, theory or goal'</i>	WHAT? <i>'Materials'</i>	WHAT? <i>'Procedures'</i>	WHO PROVIDED?	HOW, WHERE WHEN and HOW MUCH?	TAILORING? <i>'Local adaptations'</i>	MODIFICATION? <i>'Changes during trial'</i>	HOW WELL? <i>'Fidelity'</i>
Decision support interventions								
Family-clinician shared decision-making. (Liu et al., 2021)	Using a shared decision-making intervention that respects the patient's values and preferences, families' opinion and choice will reduce family distress at the end-of-life in intensive care and lessen the burden families experience during bereavement.	Training materials referenced but not provided.	(1) Intensivist explains the patient's condition, treatments, prognosis; (2) confirm family understanding; (3) elicit families' perspectives on the patient's medical care; (4) explore the patient's perspectives on death and dying; (5) explain options for medical care; (6) clinicians and families openly discuss their own views; (7) clinicians listening attentively, and express empathy at least once; (8) focus on patient-centeredness, respecting wishes, and reaching a care decision supported by clinicians and families.	Delivered by attending physician. Conference attended by attending physician, junior physician, and nurse. A 2-day intensive train-the-trainer workshop covering communication, conflict resolution, change management, teams, trust, leadership and delivering the intervention.	At least one face-to-face family conference during the patients stay in intensive care.	No tailoring reported.	No modifications reported.	25 family conferences recorded at random to check fidelity. Outcomes not reported as significant loss to follow up (1-month and 3-month follow-up abandoned).
Communication facilitator. (Curtis et al., 2016)	By increasing families' and clinicians' self-efficacy (based on self-efficacy theory) expectations, a trained communication facilitator will reduce family distress and intensity of end-of-life care.	Staff training resource - Table E1. Examples of use of attachment theory (online supplement).	Facilitators: (1) Interviewed family to understand concerns, needs, and communication characteristics; (2) Met with clinicians offering a summary of concerns, needs, and communication characteristics; (3) Provided communication and emotional support based on family attachment style (Table E1); (4) Participated in family conferences; and (5) Followed-up with family 24-hours after patient discharge or death (guides in supplemental materials)	Delivered by an externally employed nurse or social worker. Two-day facilitator training on attachment styles, family-clinician communication, and mediation.	Face-to-face family conference; daily and 24-hours after discharge or death.	Communication and emotional support adapted to family member attachment style (Table E1)	No modifications reported.	Quarterly meetings to review cases and confirm fidelity.
Pairing Re-engineered ICU Teams with Nurse-Driven Emotional Support and Relationship-Building (PARTNER) (White et al., 2018)	Emotional and communication support (modern decision theory, to address both affective and cognitive challenges) will lessen surrogate psychological burden, improve the quality of surrogate decision-making, family-clinician communication, and reduce non-beneficial treatment in the intensive care.	Communication training program and question prompt list (online supplement).	(1) PARTNER nurses met daily with families following a standardised protocol; (2) Clinician-family conference arranged within 48 hours and every 5 to 7 days thereafter; (3) Intensive support for implementation was provided to incorporate the family-support pathway into workflows.	The intervention was delivered by members of the interprofessional team and overseen by 4-6 nominated nurses (PARTNER nurses), who were thought to possess strong communication skills. PARTNER nurses received 2-days of advanced communication training (lectures, modelling, simulation, and feedback).	Face-to-face meeting; daily with PARTNER nurse, within 48 hours and every 5-7 days with the intensive care team.	No tailoring reported.	No modifications reported.	Weekly fidelity monitoring, coaching, implementation support and emotional support for nurses.

Psychoeducation interventions								
Three-step support strategy (Kentish-Barnes et al., 2022)	Addressing three key communication opportunities with families will improve end-of-life communication and reduce the post-intensive care burden families, specifically the development of prolonged grief 6-months after the death.	Checklists (Supplement) Training pamphlet summarising key points of verbal and non-verbal communication [not available]	(1) Conference to prepare family for imminent death (PREPARE: Prepare, Respond, make Explicit, Presence, Anticipate, think thRough, and Encourage), (2) Room visits to provide active support (RAAP: Reassure, Answer, Attentive listening, Propose support), and (3) After death conference (CIAO: Condolences, Instigate questions, Acknowledge emotions, Option to contact team.	Conferences were physician-led, room visits by physician and nurse in charge. Facilitator training included a workshop on end-of-life communication and a video [in French] https://www.grrroh.fr/famirea-study	Face-to-face conference prior to withdrawal, bedside visits during dying, after-death conference	Post-death conference can occur before family leave the unit, or later, face-to-face or via telephone	No modifications reported.	Fidelity checklist completed by clinicians and independently by sociologist; fidelity results not reported.
Communication strategy and pamphlet (Lautrette et al., 2007)	A proactive communication strategy that consisted of an end-of-life family conference conducted according to specific guidelines and the provision of a pamphlet will reduce stress related symptoms, anxiety, and depression in families 90-days after death.	Bereavement support leaflet [In French and English] (online supplement)	Structured end-of-life family conference, intensivist explained diagnosis, prognosis, and treatment and discussed the appropriateness of treatment limitations. VALUE mnemonic used during conference: Value and appreciate things family said, Acknowledge emotions, Listen, ask questions that allow you to Understand who the patient is as a person, and Elicit questions from the family. A bereavement pamphlet was provided at the conclusion of the conference.	Delivered by senior intensivist (investigator). Conference attended by physicians, nurses, a psychologist, other health professionals, and family members. Social worker or pastoral care invited if requested by the family. Intensivists were briefed on VALUE guidelines and given documentation. Nurses were not trained.	Face-to-face conference with family prior to death	No tailoring reported.	No modifications reported.	Fidelity not assessed.
Information provision interventions								
Information pamphlet (Robin et al., 2021)	A pamphlet describing the role of family in the end-of-life decision will decrease families' risk of post-traumatic stress disorder, anxiety, and depression.	Information pamphlet given to family (online supplement).	Withdrawal of life-support explained verbally by physician during a family conference, reinforced by a written pamphlet: (1) Objective of ICU care, (2) French Leonetti law of April 22, 2005, on end-of-life care, (3) Role of family, and (4) Palliative care during the end-of-life process.	Conference involved in-charge nurse and physician (roles not defined). The physicians received unspecified training implying the intervention was physician-led.	One face-to-face family conference prior to withdrawal, unclear who delivered the pamphlet.	No tailoring reported.	No modifications reported.	Did not assess if families read or understood the pamphlet.
Tailored written messages. (Kirchhoff et al., 2008)	Providing tailored messages of what to expect after withdrawal of life-support (based on self-efficacy theory) will facilitate family coping by reducing ambiguity; this will reduce family emotional burden.	None reported	(1) Generic beginning - anticipated time until death, assurance that care would continue after withdrawal, and the choice to be present at the bedside during withdrawal; (2) Tailored middle (see 'TAILORING'); (3) Generic end - actions of the family members, such as talking to or touching the patient, validate emotional responses.	Delivered by research nurse. No training reported	Face-to-face, 10-15 minutes prior to withdrawal of treatment, research nurse delivered the written message.	Tailored middle addressed pathophysiology and signs of impending death (based on anticipated time until death and intubation status).	No modifications reported.	Fidelity not assessed.

Supplemental file 5: Summary of outcomes, measures, and variables by intervention type

	Decisional support			Information provision		Psychoeducation	
	Family-clinician shared decision-making (Liu et al., 2021)	Communication facilitator (Curtis et al., 2016)	Pairing Re-engineered ICU Teams with Nurse-Driven Emotional Support and Relationship-Building (White et al., 2018)	Information pamphlet (Robin et al., 2021)	Tailored written messages (Kirchoff et al., 2008)	Three-step communication strategy (Kentish-Barnes et al., 2022)	Communication strategy and pamphlet (Lautrette et al., 2007)
Depression 3-months	HADS-subscale Not reported	●—● PHQ-9		↓ HADS-subscale $p = 0.004$		●—● HADS-subscale $p = 0.07$	↓ HADS-subscale $p = 0.003$
Depression 6-months	HADS-subscale Not reported	↓ PHQ-9 $p = 0.017$				↓ HADS-subscale $p = 0.037$	
Anxiety 3-months	HADS-subscale Not reported	●—● GAD-7		●—● HADS-subscale $p = 0.06$		↓ HADS-subscale $p = 0.18$	●—● HADS-subscale
Anxiety 6-months	HADS-subscale Not reported	●—● GAD-7				↓ HADS-subscale $p = 0.002$	
Post-Traumatic Stress Disorder 3-months	N/A	●—● PCL		↓ IES $p = 0.001$		↓ IES-R $p = 0.005$	↓ IES $p = 0.01$
Post-Traumatic Stress Disorder 6-months	N/A	●—● PCL	●—● IES			↓ IES-R $p = 0.014$	
Hospital Anxiety and Depression Score 3-months	Aggregated HADS Not reported			↓ Aggregated HADS $p = 0.023$		↓ $p = 0.0009$	↓ HADS $p = 0.004$
Hospital Anxiety and Depression Score 6-months	Aggregated HADS Not reported		●—● Aggregated HADS			↓ $p = 0.003$	
Other					●—● Mood Disturbance POMS	↓ Prolonged Grief PG-13, 6 months $p = 0.003$	

Abbreviations: HADS (Hospital Anxiety and Depression Score), PHQ-9 (Patient Health Questionnaire), GAD-7 ((Generalised Anxiety Disorder Survey), PCL (Post-Traumatic Stress Disorder Checklist), IES (Impact of Event Scale), POMS (Profile of Mood States), IES-R (Impact of Event Scale- Revised), PG-13 (Prolonged Grief Questionnaire)

●—● = No statistically significant difference

↓ = Decrease

Supplemental file 6: Decisional support intervention outcomes

	Curtis et al., 2016		White et al., 2018		Liu et al., 2021	
	Control	Intervention	Control	Intervention	Control	Intervention
	Mean* 95% CI		Mean 95% CI			
Depression-3-months	4.9 (PHQ-9)	3.1 $\Delta = -1.786$ [-3.891 to 0.318] $p = 0.096$	N/A	N/A	Not Reported (HADS-subscale)	
Depression-6-months	4.7 (PHQ-9)	2.4 $\Delta = -2.365$ [-4.305 to -0.425] $p = 0.017$	N/A	N/A	Not Reported (HADS-subscale)	
Anxiety-3-months	3.0 (GAD-7)	2.3 $\Delta = -0.742$ [-2.911 to 1.427] $p = 0.502$	N/A	N/A	Not Reported (HADS-subscale)	
Anxiety-6-months	2.7 (GAD-7)	1.8 $\Delta = -0.890$ [-3.100 to 1.320] $p = 0.430$	N/A	N/A	Not Reported (HADS-subscale)	
PTSD-3-months	31.6 (PCL)	29.8 $\Delta = -1.768$ [-6.658 to 3.121] $p = 0.478$	N/A	N/A	N/A	N/A
PTSD-6-months	30.6 (PCL)	27.1 $\Delta = -3.515$ [-7.124 to 0.095] $p = 0.056$	N/A	N/A	N/A	N/A
Anxiety and Depression 6-months	N/A	N/A	12.0 [11.3 to 12.8] (HADS)	11.7 [10.7 to 12.7] $\Delta = -0.34$ [-1.67 to 0.99] $p = 0.61$	Not Reported (HADS)	
Post-Traumatic Stress Disorder 6-months	N/A	N/A	20.3 [18.8 to 21.9] (IES)	21.2 [19.3 to 23.2] $\Delta = 0.90$ [-1.66 to 3.47] $p = 0.49$	N/A	N/A

Abbreviations: HADS (Hospital Anxiety and Depression Score), PHQ-9 (Patient Health Questionnaire), GAD-7 ((Generalised Anxiety Disorder Survey), PCL (Post-Traumatic Stress Disorder Checklist), IES (Impact of Event Scale), POMS (Profile of Mood States), IES-R (Impact of Event Scale- Revised), PG-13 (Prolonged Grief Questionnaire), Δ = Effect size (95% CI)

Supplemental file 7: Information provision and psychoeducation intervention findings

		Prolonged Grief 6-months (PG-13≥30)	Prolonged Grief 6-months	Depression-3-months (HADS-Subscale)	Depression-6-months (HADS-Subscale)	Anxiety-3-months (HADS-Subscale)	Anxiety-6-months (HADS-Subscale)	HADS total score-3-months	HADS total score-6-months	PTSD-3-months (IES/IES-R)	PTSD-6-months (IES/IES-R)
Information provision intervention											
Robin et al., 2021	Control Mean (SD)	Not Assessed	Not Assessed	8 (5) Subscale>8 = 25 (56%)	Not Assessed	8 (5) Subscale>8 = 20 (44%)	Not Assessed	17 (8)	Not Assessed	IES 38 (14) IES>30 =33 (73%)	Not Assessed
	Int. Mean (SD)	Not Assessed	Not Assessed	7 (3) <i>p</i> = 0.07 Subscale>8 = 10 (25%) <i>p</i> = 0.004	Not Assessed	6 (3) <i>p</i> = 0.036 Subscale>8 = 10 (25%) <i>p</i> = 0.06	Not Assessed	13 (5) <i>p</i> = 0.023	Not Assessed	IES 28 (10) <i>p</i> < 0.001 IES>30 =18 (40%) <i>p</i> = 0.001	Not Assessed
Psychoeducation interventions											
Kentish-Barnes et al., 2022	Control Median (IQR)	PG-13≥30 = 66 (21%)	21 (15-29)	5 (2-9) Subscale >7 =109 (35%)	4 (1-8) Subscale>7 =82 (27%)	7 (4-11) Subscale>7 =149 (48%)	7 (4-10) Subscale>7 =121 (32%)	13 (8-19)	11 (7-17)	IES-R 20 (10-31) IES-R>33 =68 (22%)	IES-R 13 (5-25) IES-R>33 =51 (17%)
	Int. Median (IQR)	PG-13≥30 = 57 (15%) Δ = -2.5 [-4.0to -1.0] <i>p</i> = 0.035	19 (14-26) Δ = -2.5 [-4.0to -1.0] <i>p</i> = 0.003	4 (1-8) Δ = -0.9 [-1.6to -0.2] <i>p</i> = 0.016 Subscale>7 =113 (29%) <i>p</i> = 0.07	3 (107) Δ = 0.9 [-1.6to -0.2] <i>p</i> = 0.02 Subscale>7 =74 (20%) <i>p</i> = 0.037	7 (4-9) Δ = -0.7 [-1.4 to 0.0] <i>p</i> = 0.051 Subscale>7 =166 (42%) <i>p</i> = 0.18	6 (3-9) Δ = 1.2 [-1.9to -0.5] <i>p</i> = 0.002 Subscale>7 =140 (45%) <i>p</i> = 0.002	11 (7-17) Δ = -1.6 [-2.8to -0.4] <i>p</i> = 0.009	9 (4-15) Δ = -2.0 [-3.3to -0.7] <i>p</i> = 0.003	IES-R 15(7-24) Δ = 4.9 [-7.5to -2.3] <i>p</i> = <0.0001 IES-R>33 =47 (12%) <i>p</i> = 0.005	IES-R 10(4-20) Δ = -3.9 [-6.6to -1.2] <i>p</i> = 0.013 IES-R>33 =32 (8%) <i>p</i> = 0.014
Lautrette et al., 2007	Control Median (IQR)	Not Assessed	Not Assessed	Subscale >8 =29 (56%)	Not Assessed	Subscale>8 =35 (67%)	Not Assessed	17 [11-25]	Not Assessed	IES 39 [25-48] IES>30 =36 (69%)	Not Assessed
	Int. Median (IQR)	Not Assessed	Not Assessed	Subscale >8 =16 (29%) <i>p</i> = 0.003	Not Assessed	Subscale>8 =25 (45%) <i>p</i> = 0.02	Not Assessed	11 [8-18] <i>p</i> = 0.004	Not Assessed	IES 27 [18-42] <i>p</i> = 0.02 IES>30 =25 (45%) <i>p</i> = 0.01	Not Assessed

Abbreviations: HADS (Hospital Anxiety and Depression Score), PHQ-9 (Patient Health Questionnaire), GAD-7 ((Generalised Anxiety Disorder Survey), PCL (Post-Traumatic Stress Disorder Checklist), IES (Impact of Event Scale), POMS (Profile of Mood States), IES-R (Impact of Event Scale- Revised), PG-13 (Prolonged Grief Questionnaire), Δ = Effect size (95% CI)