Bereavement interventions to support informal caregivers in the intensive care unit: a systematic review

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Abstract

Background: Informal caregivers of critically ill patients in intensive care unit (ICUs) experience negative psychological sequelae that worsen after death. We synthesized outcomes reported from ICU bereavement interventions intended to improve informal caregivers’ ability to cope with grief.

Data sources: MEDLINE, EMBASE, CINAHL and PsycINFO from inception to October 2020.

Study selection: Randomized controlled trials (RCTs) of bereavement interventions to support informal caregivers of adult patients who died in ICU.

Data extraction: Two reviewers independently extracted data in duplicate. Narrative synthesis was conducted.

Data synthesis: Bereavement interventions were categorized according to the UK National Institute for Health and Clinical Excellence three-tiered model of bereavement support according to the level of need: (1) Universal information provided to all those bereaved; (2) Selected or targeted non-specialist support provided to those who are at-risk of developing complex needs; and/or (3) Professional specialist interventions provided to those with a high level of complex needs. Outcome measures were synthesized according to core outcomes established for evaluating bereavement support for adults who have lost other adults to illness.

Results: Three studies of ICU bereavement interventions from 31 ICUs across 26 hospitals were included. One trial examining the effect of family presence at brain death assessment integrated all three categories of support but did not report significant improvement in emotional or psychological distress. Two other trials assessed a condolence letter intervention, which did not decrease grief symptoms and may have increased symptoms of depression and post-traumatic stress disorder, and a storytelling intervention that found no significant improvements in anxiety, depression, post-traumatic stress, or complicated grief. Four of nine core bereavement outcomes were not assessed anytime in follow-up.

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Introduction
Informal caregivers (i.e., family, friends) of critically ill patients in the intensive care unit (ICU) experience negative psychological and emotional sequelae [1, 2] that worsen after patient death [3, 4]. Despite how common death is among patients admitted to the ICU [5, 6], preparing informal caregivers to cope with their grief is challenging [7]. Withholding and withdrawing life-sustaining treatment while mitigating suffering in the ICU is extremely complex [8]. Several groups have taken a leading role in developing national, cultural-specific guidelines and recommendations for healthcare professional to support the bereavement process in daily practice within different ethical environments [9–11].

A 2019 narrative review reported inconsistent evidence for the association between bereavement support in adult ICU and informal caregiver outcomes, noting methodological shortcomings in the evidence [12]. Since 2019, a set of core outcomes was developed to address inconsistent evaluation of bereavement services and models of support for informal caregivers in adult palliative care [13]. The scope of the core outcomes set (e.g., ability to cope with grief, quality of life and mental well-being) is for bereavement research and clinical practice generally, and was designed to assess bereavement interventions for adults whose adult friends and family members have died. The core outcomes set is comprised of 21 caregiver-level outcomes representing nine categories (e.g., negative and overwhelming grief, communication and connectedness) within two primary domains (i.e., ability to cope with grief; quality of life and mental well-being). The core outcomes set developed for adult palliative care settings [13] is relevant for use in ICU given that death in ICU is common and that bereavement interventions to prepare informal caregivers to cope with their grief may be appropriate across the entire critical illness trajectory [14].

The aims of this review were to map bereavement interventions to established core outcomes for evaluating bereavement support among informal caregivers, and to identify grief support interventions that improve informal caregivers’ ability to cope with the grief.

Methods
This protocol-based systematic review (PROSPERO ID: CRD42020202908) was reported in accordance with the Preferred Reporting Items for Systematic Review and Meta-analyses (PRISMA) guideline [15] (Supplemental Table 1).

Identification and selection of studies
We searched MEDLINE, EMBASE, CINAHL and PsycINFO from inception to October 01, 2020. A medical librarian (D.L.L.) assisted with the development, piloting, and execution of searches (Supplemental Table 2). No language or date restrictions were applied. Reference lists of included papers were reviewed to identify potentially missed studies.

Study eligibility
Two reviewers (S.J.M. and T.G.P.) independently evaluated all records for eligibility in two stages. In the title and abstract stage, any record selected by either reviewer as meeting one (or more) eligibility criteria progressed to the full-text review stage. Studies were eligible for inclusion if both reviewers agreed that the study met all eligibility criteria following review of the full-text. Disagreements were resolved through consensus with another author (K.W.).

We included quantitative, experimental studies reporting randomized controlled trials of bereavement interventions to support informal caregivers of adult patients who died in ICU. We excluded interventions for healthcare professionals and interventions that were conducted prior to patient death (i.e., at end-of-life). We included studies where the intervention was performed outside ICU (e.g., home follow-up). For the purposes of our review, we defined ICU bereavement interventions as services healthcare professionals provide or coordinate for informal caregivers of critically ill patients after patient death (including brain death) in the ICU [16, 17]. We defined an informal caregiver as any informal (i.e., non-clinical) person who regularly provides patient support and is in some way implicated in patient care or directly affected by patient health (e.g., family, friend) [18], and critically ill patients as any persons currently or previously admitted to ICU [18]. In addition to studies that reported on patient death, we included studies where brain death was considered as patient death [19], since previous work indicates informal caregivers accept brain death as patient death [20] and caregiver grieving processes are similar [21]. The trials investigated bereavement interventions for informal caregivers of adult patients (> 17 years) that applied at least one (or more)
support category from the UK National Institute for Health and Clinical Excellence [22, 23] three-tiered model of bereavement support, that includes: (1) *Universal information* provided to all bereaved; (2) *Selected or targeted non-specialist support* provided to those with a medium level of need who are at-risk of developing complex needs; and/or (3) *Indicated professional specialist interventions* provided to those with a high level of complex needs. Any one bereavement intervention could have applied multiple categories (i.e., types) of support, but needed to report at least category to be included in our review. Finally, to be eligible for inclusion, we required that the interventions reported on at least one of 21 caregiver-level outcomes within at least one of nine categories from the core set of outcomes for evaluating bereavement support for adult caregivers in adult care settings [13] (Supplemental Table 3). References were managed in EndNote X9 (Clarivate Analytics, Philadelphia, PA, USA).

**Data extraction and risk of Bias assessment**

Two reviewers (S.J.M., K.W.) used structured forms developed by the study team to extract information independently and in duplicate for each included study. Information on document characteristics (e.g., year of publication, geographic location), study characteristics (e.g., setting, sites), patient and caregiver characteristics (e.g., age, relationship), intervention characteristics (e.g., type of support and target population level of need, follow-up), core outcomes (e.g., negative mental and emotional state, participation in work and/or other regular activities), statistical significance (e.g., p-values, measures of variance), and authors’ conclusions were collected. Risk of bias for objective (i.e., measurement-based) outcomes was independently assessed by two reviewers (S.J.M. and K.W.) using the Cochrane Collaboration’s tool to rate studies at low, high or unclear risk of bias [24]. We (S.J.M. and K.W.) independently assessed quality of core outcomes using the BMJ Best Practice GRADE of Evidence Tool [25].

**Synthesis**

A narrative synthesis was conducted for all trials. We mapped primary and secondary outcomes reported in the included studies to the standardized core outcomes set for bereavement interventions [13] to help guide future research in ICU bereavement care [26]. To account for variability in the timing of study end-points, we used common clinically relevant follow-up periods of 1- to 3-month and 4- to 6-month follow-up. To facilitate comparison among the different instruments used to evaluate core outcomes, standardized mean differences (SMDs) with corresponding 95% confidence intervals (CIs) were calculated using a Hedges adjusted g estimator to correct for small sample bias [24]. For studies that reported medians or proportions, we contacted the primary author to obtain the corresponding mean and standard deviation (SD). For studies in which authors did not provide additional data, we estimated the mean and SD using validated estimations [27]. If necessary, individual study results were corrected for directionality such that higher coping scores represented better ability to cope, and lower wellbeing scores indicated worse wellbeing. Heterogeneity across a small number of trials precluded pooling SMDs in meta-analysis.

**Results**

**Study characteristics**

Searches identified 1960 unique records, of which 14 were potentially relevant based on initial title and abstract screening (Fig. 1). Following full-text review, three of the 14 articles were included, describing three unique adult ICU bereavement interventions for 296 informal caregivers from 31 ICUs across 22 hospitals in France [28] and 4 in the United States [29, 30] (Table 1). Reasons for exclusion of 11 articles reviewed in full-text are provided in Supplemental Table 3. One trial conducted the ICU bereavement intervention after patient death with a single follow-up time point within 1- to 3-months [30]. The other two trials conducted interventions at 2 weeks following patient death with 1- and 6-month follow-up [28], and at 4 weeks following patient death with 3- and 6-month follow-up [29]. One trial integrated all three categories of support (i.e., universal information, selected or targeted non-specialist support, and an indicated professional specialist intervention) within their bereavement intervention [30]. The other two trials incorporated either selected or targeted non-specialist support with an indicated professional specialist intervention [28], or an indicated professional specialist intervention alone [29]. Included studies assessed in sum four (of nine) core outcomes categories [14 of 21 individual outcomes] that included: (1) negative and overwhelming grief; (3) understanding, accepting and finding meaning in grief; and (3) accessing appropriate support [relating to caregiver ability to cope with grief] (Supplemental Tables 5 and 6), as well as (4) participation in work and/or other regular activities and (5) negative mental and emotional state [relating to caregiver quality of life and mental wellbeing] (Supplemental Tables 7 and 8). All trials were judged as having low risk of bias (Table 2). Overall, the quantity of evidence on bereavement interventions for informal caregivers in adult ICUs is low (Table 3).

**Three-tiered model of bereavement support and assessment of Core outcomes**

Table 2 provides a summary of findings among RCTs of ICU bereavement interventions whilst SDMs with
corresponding interpretation of effect of intervention are in Supplemental Tables 5, 6, 7, and 8. Among the three included trials, no significant effect of intervention was determined for negative and overwhelming grief (assessed by the Decision Regret Scale in one study); accessing appropriate support (assessed by yes/no questions in two studies); and participation in work and/or other regular activities (assessed using the General Health Questionnaire-12 in one study). Mixed results (both negative and non-significant) were determined for understanding, accepting and finding meaning in grief (assessed by the Inventory of Complicated Grief in two studies) and negative mental and emotional state (assessed by the Impact of Event Scale; Impact of Event Scale-Revised; Hospital Anxiety and Depression-Anxiety; Hospital Anxiety and Depression-Depression; Hospital Anxiety and Depression-Total; Patient Health Questionnaire-9; and Prevalence of Post-Intensive Care Syndrome-Family in all three studies).

Two trials integrated multiple categories of bereavement support [28, 30] proposed by the UK National Institute for Health and Clinical Excellence [22] to be made available according to the level of need. Effect of family presence compared to absence at brain death evaluation investigated by Tawil et al. [30] across four ICUs within a single academic hospital, incorporated universal information [for all levels of need], selected or targeted non-specialist support [for medium level of need], and an indicated professional specialist intervention [for high and complex level of need] for 38 informal caregivers of adult patients in ICU whom the treating intensivist suspected had suffered brain death. Multiple caregivers per patient joined the evaluating physician at the patient’s bedside to observe the brain death evaluation. Caregivers were accompanied by a chaperone who
| Source                  | Hospital and ICU Settings and Types | Bereavement Intervention                                                                 | Duration of Intervention | Follow-Up Timepoints                     | Patient Demographics (of those randomized) | Caregiver Demographics (of those randomized) |
|------------------------|------------------------------------|------------------------------------------------------------------------------------------|--------------------------|------------------------------------------|--------------------------------------------|---------------------------------------------|
| Barnato et al., 2017   | 5 ICUs                             | Storytelling delivered via home visit or telephone call approximately 4 weeks following patient death that included: - non-judgmental elicitation of the story of the events leading up to the patient's ICU admission - ICU experience and decision process - aftermath of the patient's death | 1–2 h                   | Follow-up assessments conducted via telephone interview or by mail at: 3 months, 6 months | Total N = 32  
 n, intervention = 18  
 age, 67.8 yr (SD 13.7)  
 female, 50%  
 n, control = 14  
 age, 72.0 yr (SD 10.2)  
 female, 50% | Total N = 32  
 n, intervention = 18  
 age, 65.0 yr (SD 11.0)  
 female, 61.1%  
 n, control = 14  
 age, 55.9 yr (SD 12.6)  
 female, 86.7% |
| Kentish-Barnes et al., 2017 | 22 ICUs                            | Condolence letter prepared (hand-written) within 3 days after patient death and sent by standard mail 15 days after patient death that included: - recognition of the death - name of the deceased - mention of a personal impression - recognition of the family member - offer to help - express sympathy | Not reported             | Follow-up assessments conducted via telephone interview by psychologists, sociologists, and research nurses blinded to study group at: 1 month, 6 months | Total N = 242  
 n, intervention = 123  
 age, 61 yr (Rg. 54–71)  
 female, 33.3%  
 n, control = 119  
 age, 61 yr (Rg. 54–66)  
 female, 37.0% | Total N = 242  
 n, intervention = 123  
 age, 57 yr (Rg. 46–65.5)  
 female, 67.9%  
 n, control = 119  
 age, 56 yr (Rg. 44–64.5)  
 female, 71.7% |
| Tawil et al., 2014      | 4 ICUs                             | Family groups presence during brain death evaluation joined the evaluating physician at the patient’s bedside to observe the brain death evaluation including all brainstem reflex testing and the apnea test. The subjects were accompanied by a chaperone who could explain the process and answer questions during the evaluation. After the brain death evaluation was complete, the family members were notified of the results and given an opportunity to ask questions. | Average duration of brain death evaluation not stated | All family members sent hard copies of assessment surveys then telephoned by a trained research nurse who administered the surveys and recorded responses within 1- to 3-months after patient death | Total N = 17  
 n, intervention = 11  
 age, 41.7 yr (Rg. 19–67)  
 female, 55%  
 n, control = 6  
 age, 52.5 yr (Rg. 32–67)  
 female, 33% | Total N = 58  
 n, intervention = 38  
 age, 41.7 yr (Rg. 14–44)  
 female, 61.1%  
 n, control = 20  
 age, 44.6 yr (Rg. 17–67)  
 female, 83.7% |

ICU intensive care unit; RG range; SD standard deviation; YR year
explained the process and were available to answer questions during the evaluation. Caregivers randomized to be absent during the evaluation waited in an adjacent room, accompanied by a chaperone. After the brain death evaluation was complete, informal caregivers were notified of the results and given an opportunity to ask questions. All informal caregivers were sent infographics and hard copies of assessment surveys, then telephoned by a trained research nurse who administered the surveys and recorded responses within 1- to 3-months after patient death. Investigators found no significant improvement in emotional or psychological distress, or participation in work and/or other regular activities (e.g., daily tasks, social activities) up to 3-months. Investigators concluded that informal caregiver presence during brain death evaluation is feasible and safe.

Kentish-Barnes et al. [28] conducted a randomized parallel-group trial across 22 ICUs within 22 hospitals (11 academic and 11 non-academic). They facilitated two categories of bereavement support (i.e., selected or targeted non-specialist support [for medium level of need] with an indicated professional specialist intervention [for high and complex level of need]) to contribute evidence on two core outcomes (i.e., understanding, accepting and finding meaning in grief and negative mental and emotional state). They prepared a handwritten condolence letter for 123 informal caregivers sent within 15 days after patient death that included: (1) recognition of the death; (2) name of the deceased; (3) mention of a personal impression; (4) recognition of the informal caregiver; (5) offer to help; and (6) expression of sympathy. Their 1- and 6-month telephone follow-up

### Table 2

| Study                         | Random sequence generation | Allocation concealment | Blinding of participants, researchers | Blinding of outcome assessment | Incomplete outcome data | Selective reporting |
|-------------------------------|----------------------------|------------------------|---------------------------------------|-------------------------------|-------------------------|---------------------|
| Barnato et al., 2017 [29]     | Low                        | Low                    | High                                  | Low                           | High                    | Low                 |
| Kentish-Barnes et al., 2017 [28] | Low                        | Low                    | High                                  | Low                           | High                    | Low                 |
| Tawil et al., 2014 [30]       | Low                        | Low                    | High                                  | Unclear                       | High                    | Low                 |

1 Determined by the Cochrane Risk of Bias Assessment Tool
2 Overall attrition above 20% represents high risk of attrition bias; attrition below 20% and unequal between intervention and control group represents high risk of attrition bias; ratings of unclear represent that either overall attrition or attrition between groups was not reported

### Table 3

| Outcome                                               | Assessed By                      | Follow-Up Range          | No. Studies | No. Caregivers | GRADE of Evidence |
|-------------------------------------------------------|----------------------------------|--------------------------|-------------|----------------|-------------------|
| Ability to Cope with Grief                            |                                  |                          |             |                |                   |
| Negative and overwhelming grief                       | Decision Regret Scale             | 6-month                  | 1           | 30             | Low               |
| Communication and connectedness                       | None                             | N/A                      | 0           | 0              | N/A               |
| Understanding, accepting and finding meaning in grief | Inventory of Complicated Grief    | 1-month to 6-month       | 2           | 220            | Moderate          |
| Finding balance between grief and life going forwards | None                             | N/A                      | 0           | 0              | N/A               |
| Accessing appropriate support                         | Single Yes/No Question            | 3-month to 6-month       | 1           | 30             | Low               |
| Quality of Life and Mental Wellbeing                  |                                  |                          |             |                |                   |
| Participation in work and/or other regular activities | General Health Questionnaire-12   | 1-month to 3-months      | 1           | 58             | Low               |
| Relationships and social functioning                  | None                             | N/A                      | 0           | 0              | N/A               |
| Positive mental wellbeing                             | None                             | N/A                      | 0           | 0              | N/A               |
| Negative mental and emotional state                   | Impact of Event Scale; Impact of Event Scale-Revised; Hospital Anxiety and Depression-Anxiety, Hospital Anxiety and Depression-Depression; Hospital Anxiety and Depression-Total; Patient Health Questionnaire-9; Post-Intensive Care Syndrome-Family | 1-month to 6-month | 3           | 278            | Moderate          |

N/A not applicable
1 At last timepoint of follow-up
2 Determined by the BMJ Best Practice GRADE of Evidence Assessment Tool; reasons for downgrade related mainly to lack of evidence
assessments were conducted by any one of a psychologist, sociologist or research nurse. Condolence letters had no effect on any core outcome at 1-month follow-up. At 6-month follow-up they reported that among informal caregivers of patients who died in ICU, a condolence letter failed to alleviate grief symptoms and increased depression and and post-traumatic stress disorder-related symptoms.

A pilot single-blind trial across five ICUs within three hospitals (one academic) incorporated one category of bereavement support providing one professional specialist intervention for a high and complex level of need [29]. The storytelling intervention delivered by Barnato et al. [29] to 18 caregivers via home visit or telephone approximately 4 weeks following patient death consisted of: (1) non-judgmental elicitation of the story of the events leading up to the patient’s ICU admission; (2) description of the ICU experience and decision process; and (3) summary of the aftermath of the patient’s death. Follow-up was performed at 3- and 6-months, with rationale to assess selection bias rather than to provide additional opportunity for support. The authors reported that their storytelling intervention met all a priori feasibility, tolerability and acceptability targets and there were no significant improvements in anxiety, depression, post-traumatic stress or complicated grief at any time-point of follow-up. The authors noted that their sample size was too small to make any inferences about the effect of the storytelling intervention on individual psychological symptoms.

**Core outcomes not assessed**
No trial reported on the effect of an ICU bereavement intervention on four of nine core outcomes categories at any time of follow-up that included: (1) communication and connectedness; (3) finding balance between grief and life going forwards; and (4) relationships and social functioning; and (5) positive mental wellbeing.

**Discussion**
This systematic review and narrative synthesis of bereavement interventions for informal caregivers of adult patients who died in ICU identified family presence during brain death evaluation and storytelling were feasible and acceptable among caregivers, although none were found to improve their emotional and psychological wellbeing up to 3-month and 6-months in follow up, respectively. Condolence letters provided to caregivers may worsen depression and post-traumatic stress disorder-related symptoms at 6-month follow-up. No included bereavement intervention alleviated grief symptoms or improved ability to cope.

Overall, despite the low risk of bias of these trials, the body of evidence on bereavement interventions for informal caregivers in adult ICUs is too modest to know whether bereavement interventions initiated following ICU patient death adequately prepare caregivers to cope with their grief. Other relevant outcomes that could be incorporated in future interventions is underscored by how four of nine categories from the core outcomes set for evaluating bereavement interventions remain to be investigated in RCTs in this field, including (1) communication and connectedness; (2) finding balance between grief and life going forwards; and (3) relationships and social functioning; and (4) positive mental wellbeing.

This systematic review adds to the literature by: (1) categorizing bereavement interventions according to the three-tiered model of bereavement support from the UK National Institute for Health and Clinical Excellence [22] and (2) mapping available evidence to a core set of standardized outcomes reported from bereavement interventions in adult ICUs [13]. Our aggregate, narrative synthesis on categories of bereavement support and assessment of core outcomes offers considerations for future trials on ICU bereavement interventions [26]. Our results should be interpreted cautiously given the dearth of research on this topic, underscoring the need for further studies to develop and evaluate effective bereavement interventions in adult ICU.

Though the bereavement interventions we reviewed were generally appreciated by informal caregivers, all authors noted that what constitutes appropriate bereavement care and adequate follow-up is unclear. Clinicians are uncertain how to provide ICU bereavement interventions to manifest support rather than to reduce grief symptom outcomes [28]. The phenomenon of worsened psychological outcomes after mental health interventions has previously been reported in relation to psychological debriefing for preventing post-traumatic stress disorder [31]. Individuals cope differently with loss, such that any intervention that changes coping trajectories has the potential to do harm [32]. The available evidence suggests that clinicians should consider adopting the approach from bereavement therapy [33] that considers grief as a natural process with a variety of healthy responses to loss. It is possible that there are many effective ways to support bereaved informal caregivers in the ICU.

**Strengths and weaknesses**
Though we used a broad definition to identify trials that employed bereavement interventions consistent with any one of the support categories from the three-tiered model of bereavement support, [22] bereavement interventions in adult ICU have been evaluated by few studies. In the absence of more extensive global research on this topic, findings on bereavement interventions need to be considered within the context of the individual studies in which they were performed. For example, in
France, physicians have final authority regarding decisions to forgo life-sustaining treatments [2, 34], meaning that effectiveness of bereavement interventions may vary according to sociocultural circumstances, including the degree of family involvement and sense of responsibility in shared decision making [35, 36].

This review has several limitations and our results should be interpreted cautiously. First, we excluded quasi-experimental, observational and qualitative studies, many of which have suggested or demonstrated benefits of bereavement care and provided insights from different perspectives [37–39]. Second, this review did not include conventional palliative care interventions (neither early nor at end-of-life) despite prevailing views that palliative care interventions are appropriate throughout the critical illness trajectory [14]. Third, quantitative results from these studies should be interpreted cautiously given that they were underpowered; furthermore, the design of these three RCTs precluded a quantitative meta-analysis. Fourth, we used the Cochrane Risk of Bias tool to perform risk of bias assessments, which is not designed to consider multi-component behavior change interventions [24]. Fifth, though we did not employ language or date restrictions, our review is restricted to countries represented by the included studies and should not be taken to represent a generalizable, global report on the state of bereavement interventions for informal caregivers. Sixth, we did not include preliminary findings from conference proceedings or planned interventions from protocols [40, 41].

Unanswered questions and future research
Bereavement interventions in adult ICU remains an active area of research with many gaps in our understanding. Given the complexities and inconsistencies in limited bereavement interventions, we were unable to determine effective components of bereavement interventions and how specific categories of support targeted to the caregivers’ level of need might affect their ability to cope. Single-component bereavement interventions offer a potentially resource-efficient means of preparing informal caregivers to cope with grief and sustain mental wellbeing following death of a loved one in ICU [42, 43]. However, it is possible that multi-component bereavement interventions bundles might be more effective [44].

From an intervention perspective, future research is needed to identify efficacious components of bereavement care. Informal caregivers may require different bereavement intervention components at different timepoints along the critically illness trajectory. Future trials should consider active comparisons of different components of ICU bereavement care strategies. From an outcomes perspective, to consolidate robust evidence corresponding to core outcomes, future studies should use standardized and validated measures appropriate for informal caregivers at clinically relevant follow-up time points. Four of nine categories from the core outcomes set for evaluating bereavement interventions in palliative care remain to be investigated in adult ICUs, including three coping-related outcomes and two mental wellbeing outcomes. From a process evaluation perspective, future studies should describe intervention fidelity, dose, and reach, to ensure interventions are consistently provided as intended and reliably adhered to as required for optimized impact of bereavement care.

Conclusions
In our systematic review and narrative synthesis of RCTs evaluating bereavement interventions in adult ICUs targeting for informal caregivers, we found that the evidence is modest in scope. Deeper understanding of what interventions are most effective, for whom, at what time, and in which contexts, is required. Based on currently available trial data, there are not any specific bereavement interventions that can be firmly recommended to help prepare caregivers of critically ill patients to cope with their grief.

Supplementary Information
The online version contains supplementary material available at https://doi.org/10.1186/s12904-021-00763-w.

Additional file 1.

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Authors’ contributions
All those designated as authors (SJM, KW, TGP, DJC, HTS, ARO, KMF) have met all ICMJE criteria for authorship: Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND. Drafting the work or revising it critically for important intellectual content; AND. Final approval of the version to be published; AND. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. SJM and KMF had full access to all of the data in the study and take full responsibility for the integrity of the data and the accuracy of the data analysis. Concept and design: SJM, KW, ALR. Acquisition, analysis, or interpretation of data: SJM, KW, TGP. Drafting of the manuscript: SJM, ALR, DJC, HTS, KMF. Critical revision of the manuscript for important intellectual content: all authors. Statistical analysis: SJM, KW, TGP. Administrative technical, or material support: HTS, KMF.

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Availability of data and materials
Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

Declarations

Ethics approval and consent to participate
Not applicable. All the work was developed using published data.

Consent for publication
Not applicable.

Competing interests
None.

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References
1. Johnson CC, Suchyta MR, Darowski ES, Collar EM, Kielh AL, Van J, et al. Psychological Sequelae in family caregivers of critically ill intensive care unit patients: A systematic review. Ann Am Thorac Soc. 2019;16(7):894–909. https://doi.org/10.1513/AnnalsATS.201808-5405R.
2. Azoulay E, Pochard F, Kentish-Barnes N, Chevet S, Aboub J, Adrie C, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. Am J Respir Crit Care Med. 2005;171(9):987–94. https://doi.org/10.1164/rccm.200409-1290OC.
3. Kross EK, Engelberg RA, Gries CJ, Nielsen EL, Zatzick D, Curtis JR. ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. Chest. 2011;139(4):795–801. https://doi.org/10.1378/chest.10-0652.
4. Gries CJ, Engelberg RA, Kross EK, Zatzick D, Nielsen EL, Downey L, et al. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. Chest. 2010;137(2):280–7. https://doi.org/10.1378/chest.09-1291.
5. Örban JC, Walrave Y, Mongardon N, Allauchoiche B, Argual L, Aubrun F, et al. Causes and characteristics of death in intensive care units: a prospective multicenter study. Anesthesiology. 2017;126(3):862–9. https://doi.org/10.1097/ALN.0000000000000162.
6. Downar J, Koo E, Des Orchans AR, Smith Q, Cock D, Golan E, et al. Prevalence and predictors of severe grief reactions and desire for support following a death in the intensive care unit: a multicentre observational study. Intensive Care Med. 2018;44(4):521–2. https://doi.org/10.1007/s00134-019-05707-2.
7. Rodríguez Villar S, Sanchez Casado M, Prigerson HG, Mesa Garcia S, Rodríguez Villar M, Hortiguela Martin VA, et al. Prolonged grief disorder in the next of kin of adult patients who die during or after admission to intensive care. Chest. 2012;141(6):1635–6. https://doi.org/10.1378/chest.11-3099.
8. Metaxa V, Anagnostou D, Vlachos S, Arulkumaran N, van Dusseldorp I, Bensemane S, et al. Palliative care interventions in intensive care unit patients - a systematic review protocol. Syst Rev. 2019;8(1):148. https://doi.org/10.1186/s13643-019-1064-y.
9. Myburgh J, Abilalla F, Chiumello D, Dobb G, Jacobo S, Kleinpell R, et al. 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. 2016;34:125–30. https://doi.org/10.1016/j.jcrc.2016.04.017.
10. Egerod I, Kaldan G, Albaran J, Coombs M, Mitchell M, Latour JM. Elements of intensive care bereavement follow-up services: a European survey. Nurs Crit Care. 2019;24(4):201–8. https://doi.org/10.1111/ncc.12459.
11. van Mol MMC, Wagener S, Latour JM, Boelen PA, Sronk PE, den Uil CA, et al. Developing and testing a nurse-led intervention to support bereavement in relatives in the intensive care (BRIC study): a protocol of a pre-post intervention study. BMC Palliat Care. 2020;19(1):130. https://doi.org/10.1186/s12904-020-00636-8.
12. Elshathou W, Walker M, Metcalfe A, Vanderspank-Wright B. The state of bereavement support in adult intensive care: a systematic review and narrative synthesis. J Crit Care. 2019;50:177–87. https://doi.org/10.1016/j.jcrc.2019.11.026.
13. Harrop E, Scott H, Swell S, Seddon K, Fitzgibbon J, Morgan F, et al. Coping and wellbeing in bereavement: two core outcomes for evaluating bereavement support in palliative care. BMC Palliat Care. 2020;19(1):29. https://doi.org/10.1186/s12904-020-00532-4.
14. Sepulveda C, Marlin A, Yoshida T, Ulbrich A. Palliative care the World Health Organization’s global perspective. J Pain Symptom Manag. 2002;24(2):91–6. https://doi.org/10.1016/S0885-3924(00)04040-2.
15. Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. J Clin Epidemiol. 2009;62(10):1006–12. https://doi.org/10.1016/j.jclinepi.2009.06.005.
16. Aoun SM, Brassier RL, Howling DA, Rumbold B, McNamara B, Hegney D. Who needs bereavement support? A population based survey of bereavement risk and support need. PLoS One. 2015;10(3):e0121101. https://doi.org/10.1371/journal.pone.0121101.
17. Aoun SM, Brassier LJ, O’Connor M, Rumbold B, Nordstrom C. A public health approach to bereavement support services in palliative care. Aust N Z J Public Health. 2013;36(1):14–6. https://doi.org/10.1111/1753-6485.20120085x.
18. Fiest KM, McIntosh CJ, Demiantschuk D, Leigh JP, Stelfox HT. Translating evidence to patient care through caregivers: a systematic review of caregiver-mediated interventions. BMC Med. 2018;16(1):105. https://doi.org/10.1186/s12916-018-1097-4.
19. Buntle CM, Sharp RR, Wijdicks EF. Why brain death is considered death and why there should be no confusion. Neurology. 2014;83(16):1464–9. https://doi.org/10.1212/WNL.0000000000000883.
20. Tessmer CS, da Silva AR, Barcelos FC, Araujo CL, da Costa JD, Rohke M. Do people accept brain death as death? A study in Brazil. Prog Transplant. 2007;17(1):63–7. https://doi.org/10.1152/jcrl.00248070.200701110.
21. Long T, Sque M, Addington-Hall J. What does a diagnosis of brain death mean to family members approached about organ donation? A review of the literature. Prog Transplant. 2008;18(2):118–25; quiz 126. https://doi.org/10.1177/15269248080180239.
22. Guidelines for Bereavement Support. In. Edited by Group CaMPaEoLCNA. Online: UK National Institute for Health and Clinical Excellence; 2020.
23. Wise J. GPs should provide tailored support to people bereaved by suicide, says NICE. BMJ. 2019;366:l5498.
24. Higgins JPTTJ, Chandler J, Cumpston M, Li T, Page MJ, Welch VA, editors. Cochrane handbook for systematic reviews of interventions, 2nd edn. Chichester (UK): The Cochrane Collaboration; 2020.
25. Guyatt GH, Oxman AD, Vist GE, Kunz R, Falck-Ytter Y, Alonso-Coello P, et al. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. BMJ. 2008;336(7650):94–8. https://doi.org/10.1136/bmj.39489.470347.AD.
26. Berry M, Brink E, Metaxa V. Time for change? A national audit on bereavement care in intensive care. J Intensive Care Soc. 2017;18(1):11–6. https://doi.org/10.1177/1751143716653770.
27. Wan X, Wang W, Liu J, Tong T. Estimating the sample mean and standard deviation from the sample size, median, range and/or interquartile range. BMC Med Res Methodol. 2014;14(1):135. https://doi.org/10.1186/1471-2261-14-135.
28. Kentish-Barnes N, Chevet S, Champigneulle B, Thivion M, Souppart V, Gilbert M, et al. Effect of a conscience letter on ICU bereavement support in relatives of patients who died in the ICU: a randomized clinical trial. Intensive Care Med. 2017;43(4):473–84. https://doi.org/10.1007/s00134-016-4669-9.
29. Barnato AE, Schenker Y, Tiver G, Dey MA, Arnold RM, Nuñez ER, et al. Storytelling in the early bereavement period to reduce emotional distress among surrogates involved in a decision to limit life support in the ICU: a
30. Tawil I, Brown LH, Comfort D, Crandall CS, West SD, Rollstin AD, et al. Family presence during brain death evaluation: a randomized controlled trial*. Crit Care Med. 2014;42(4):934–42. https://doi.org/10.1097/CCM.000000000000102.

31. Rose SC, Bisson J, Churchill R, Wessely S. Psychological debriefing for preventing post traumatic stress disorder (PTSD). Cochrane Database Syst Rev. 2002;2002(2):CD000560.

32. Kagee A. Concerns about the effectiveness of critical incident stress debriefing in ameliorating stress reactions. Crit Care. 2002;6(1):88. https://doi.org/10.1186/cc1459.

33. Doughty EA, Hoskins, W.J.: Death education: an internationally relevant approach to grief counseling. J Int Counselor Education 2011, 3:25–39.

34. Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, Adrie C, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med. 2007;356(5):469–78. https://doi.org/10.1056/NEJMoa063446.

35. Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Ticee PD, Rubenfeld GD. Missed opportunities during family conferences about end-of-life care in the intensive care unit. Am J Respir Crit Care Med. 2005;171(8):844–9. https://doi.org/10.1164/ccc.200409-1267OC.

36. McDonagh JR, Elliott TB, Engelberg RA, Ticee PD, Shannon SE, Rubenfeld GD, et al. Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction. Crit Care Med. 2004;32(7):1484–8. https://doi.org/10.1097/01.CCM.0000127262.16690.65.

37. Beiermann M, Kalowes P, Dyo M, Mondor A. Family Members’ and intensive care unit Nurses’ response to the ECG memento(c) during the bereavement period. Dimens Crit Care Nurs. 2017;36(6):317–26. https://doi.org/10.1097/DCC.0000000000000269.

38. Johansson M, Wahlén I, Magnusson L, Runeson I, Hanson E. Family members’ experiences with intensive care unit diaries when the patient does not survive. Scand J Caring Sci. 2018;32(1):233–40. https://doi.org/10.1111jsc.12454.

39. Schenker Y, Dew MA, Reynolds CF, Arnold RM, Tiver GA, Barnato AE. Development of a post-intensive care unit storytelling intervention for surrogates involved in decisions to limit life-sustaining treatment. Palliat Care. 2015;13(3):451–63. https://doi.org/10.1017/S14789955153001211.

40. Kentish-Barnes N, Chevret S, Azoulay E. Guiding intensive care physicians’ communication and behavior towards bereaved relatives: study protocol for a cluster randomized controlled trial (COSMIC-EOL). Trials. 2018;19(1):598. https://doi.org/10.1186/s13063-018-3094-7.

41. Prigerson H. Enhancing&MobilizingthePotential for Wellness & Emotional Resilience (EMPOWER) among surrogate decision- makers of ICU patients: Preliminary findings. In: 17th American Psychosocial Oncology Society Annual Conference: March 11-13, 2020 2020, vol. 2020. Portland, OR, US: John Wiley & Sons, Ltd. p. 5–65.

42. Oman AD, Thomson MA, Davis DA, Haynes RB. No magic bullets: a systematic review of 102 trials of interventions to improve professional practice. CMAJ. 1995;153(10):1423–31.

43. Squires JE, Sullivan K, Eccles MP, Worswick J, Grimshaw JM. Are multifaceted interventions more effective than single-component interventions in changing health-care professionals’ behaviours? An overview of systematic reviews. Implement Sci. 2014;9(1):152. https://doi.org/10.1186/s13021-014-0152-6.

44. Spoon D, Rietbergen T, Huis A, Heinen M, van Dijk M, van Bodegom-Vos L, et al. Implementation strategies used to implement nursing guidelines in daily practice: a systematic review. Int J Nurs Stud. 2020;111:103748. https://doi.org/10.1016/jijnurstu.2020.103748.