Effectiveness of interventions to prevent or treat prolonged grief symptoms among families of patients who die in intensive care units: a systematic review protocol

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ABSTRACT

Objective: The objective of this review is to evaluate the effectiveness of interventions to prevent or treat prolonged grief symptoms among families of patients who die in the intensive care unit (ICU).

Introduction: Up to 52% of families of patients who die in an ICU may be at risk of experiencing prolonged grief symptoms. This psychological morbidity should be addressed as early as possible through effective interventions.

Inclusion criteria: Studies of adult family members (≥18 years) of adult patients (≥18 years) who died in the ICU after a treatment withdrawal or withholding decision will be considered for inclusion. Family members must be exposed to tailored interventions to prevent or treat prolonged grief symptoms before, during, and/or after the patient's death. Randomized and non-randomized controlled trials; before and after studies; and interrupted time-series, cohort, and case-control studies will be considered.

Methods: The JBI methodology for systematic reviews of effectiveness will be followed. Databases to be searched include CINAHL, Academic Search Complete, Psychology and Behavioral Sciences Collection, Cochrane Central Register of Controlled Trials, and APA PsycINFO (all via EBSCOhost), as well as PubMed, Web of Science Core Collection, and Scopus. Two independent reviewers will perform the study selection, critical appraisal, and data extraction. Studies will be pooled in meta-analysis, if possible. Heterogeneity will be assessed using the standard χ^2 and I^2 tests. Statistical analyses will be performed using the random-effects model. The fixed-effects model will be used if fewer than 5 studies are included. The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) approach will be used to grade the certainty of evidence, and a Summary of Findings will be presented.

Review registration: PROSPERO CRD42024528308

Keywords: effectiveness; family; intensive care units; intervention; prolonged grief disorder

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Introduction

Family members of patients who die in the intensive care unit (ICU) may be at risk of experiencing prolonged grief symptoms, such as difficulty accepting the loss, bitterness, intense yearning, inability to trust others, emotional numbness, and the feeling of being trapped in grief.[1] While the formal diagnosis of prolonged grief disorder occurs several months after the loss, many family members exhibit symptoms of prolonged grief during their time in the ICU and shortly thereafter.[1,2] The transition from curative treatment to end-of-life care, aggressive medical

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interventions, difficulties with communication, unexpected death, or treatment withdrawal/withholding decisions can be distressing for families, who often have limited time to process the possible impact of an anticipated death.[3,4] When families face withdrawing life-sustaining treatment decisions, feelings of stress, doubt, and guilt can arise.[5] Guilt often makes it difficult for family members to reconcile with their decision, preventing them from processing their grief in a healthy way.[5]

Although there is significant variability in treatment withdrawal and withholding decisions across countries, withdrawal is considered an active process requiring documentation, whereas withholding is the absence of action and often does not require formal orders. In such cases, the ICU team may choose not to consider certain aggressive treatments when caring for patients at the end of life.[4,5] Whether real or anticipated, the experience of loss is an event that has a profound impact on a family's mental health and can lead to symptoms of prolonged grief.[1,3,6] Although most individuals gradually learn to cope with the loss of a loved one, a minority of people experience severe and persistent grief symptoms, known as prolonged grief, that extends beyond the typical period of mourning and significantly interferes with a person's daily functioning.[7] Prolonged grief symptoms encompass: i) feeling as though a part of oneself has died; ii) a marked sense of disbelief about the death; iii) avoidance of reminders that the person has died; iv) intense emotional pain (anger, bitterness, sorrow); v) difficulty with reintegration into life after the death; vi) emotional numbness (particularly concerning an emotional connection to others); vii) feeling that life is meaningless; and viii) intense loneliness.[7]

Following a period of at least 6 months according to the International Classification of Diseases (ICD-11), or 12 months according to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition, Text Revision (DSM-5-TR), a condition known as prolonged grief disorder may be diagnosed.[7,8] Although personal factors are associated with an increased risk of developing prolonged grief symptoms, the place of death, particularly in the ICU compared with a hospital or home, significantly impacts the grief process and further increases the likelihood of experiencing these symptoms.[9] Studies show that up to 52% of relatives of patients who die in the ICU experience prolonged grief symptoms when assessed at 6 months after the death.[1,10,11] They may also experience prolonged, grief-related symptoms, such as anxiety, depression, and post-traumatic stress.[6] The prevalence of post-traumatic stress symptoms in this population has been reported to range from 26% to 44%.[1,10,11] A bidirectional relationship between prolonged grief and post-traumatic stress symptoms is also suggested, as prolonged grief symptoms at 6 months post-death may contribute to the exacerbation of post-traumatic stress symptoms.[6] Given the psychological morbidity in this vulnerable group, there is a pressing need to develop tailored interventions addressing prolonged grief symptoms in the ICU.[12] To date, cognitive behavioral therapy (CBT), specifically designed to address prolonged grief and its underlying mechanisms, has shown to be effective.[13,14] However, little is known about the mechanisms of change (eg, empowerment, resilience, beliefs) and for whom the interventions are most effective.

Interventions informed by CBT principles, such as storytelling, diaries, sympathy letters, and phone calls in the ICU, have all been reported in the literature.[15–17] Recently, a conceptual framework has been proposed to organize and characterize interventions that support families of patients who die in the ICU, classifying them into psychoeducation, decision support, and information-provision interventions.[13] Evidence suggests that implementing such tailored interventions is beneficial for those who may or may not present symptoms of prolonged grief. A randomized controlled trial conducted on families of dying patients in 34 ICUs in France reported positive outcomes on mental health, perception of difficult end-of-life experiences, and quality of death and dying. This study compared standard care with a 3-step support strategy for families throughout the dying process.[1] In the control group, the usual care for support and communication with relatives of dying patients was applied, while the intervention group held 3 meetings: i) a family conference to prepare the relatives for the imminent death, ii) an ICU-room visit to provide active support, and iii) a meeting after the patient's death to offer condolences and closure.[1] The results showed that the intervention significantly reduced prolonged grief and post-traumatic stress symptoms in the experimental group.

A preliminary evaluation of EMPOWER—an Enhancing and Mobilizing the POtential for WEllness and Resilience 6-module program[2] that targets symptoms of peritraumatic stress and anticipatory grief

leading to adverse health outcomes such as prolonged grief disorder or post-traumatic stress disorder—reported a large effect on prolonged grief symptoms at 3-months post-baseline. However, a single-center, randomized, 3 parallel-group trial[17] involving bereaved family members showed non-significant differences in the main outcomes of prolonged grief, anxiety, depression, and post-traumatic stress symptoms. In this study, relatives received bereavement follow-up 4 weeks after the death through either a condolence letter (group 1), a short telephone call (group 2), or no contact (group 3).[17]

There is a need for more in-depth knowledge of existing interventions to prevent or treat prolonged grief symptoms, as well as a greater understanding of which interventions are most effective, for whom, at what time, and in what context.[18] This review is particularly relevant because its insights can guide the implementation of effective, tailored interventions to prevent or treat prolonged grief symptoms in the ICU, contributing to evidence-based practice, fostering interdisciplinary collaboration, emphasizing family-centered care, and supporting the bereaved families.

A preliminary search of PROSPERO, PubMed, the Cochrane Database of Systematic Reviews, and *JBI Evidence Synthesis*, as well as a hand-search on Google, was conducted. The systematic reviews found[18–21] were tangential to the topic, having a different scope, population, objectives, and outcomes (eg, sadness, somatization, psychological distress, anxiety, depression), reflecting the different research questions addressed in each review. This systematic review aims to evaluate evidence on the effectiveness of interventions to prevent or treat prolonged grief symptoms among families of the patients who die in the ICU.

Review question

What is the effectiveness of interventions to prevent or treat prolonged grief symptoms among families of patients who die in the ICU?

Inclusion criteria

Participants

This review will consider studies that include adult (≥18 years) family members of patients who died in the ICU. An ICU is a department that provides comprehensive and continuous care, addressing specific medical and surgical conditions through specialized medical and nursing care for patients with severe or life-threatening illnesses, such as respiratory failure, coronary conditions, or burn injuries.[22]

Studies with family members of adult patients (≥18 years), regardless of their length of stay or diagnosis, who died in the ICU after a treatment withdrawal/withholding decision by the ICU team, will be eligible for inclusion. Family members may be biologically related or unrelated (eg, spouses, partners, adult children), and may or may not present symptoms of prolonged grief at baseline.[23] This definition of family recognizes the diversity of families and emphasizes its functional aspects, such as mutual support, emotional bonds, economic cooperation, and socialization. They must be individuals with whom the patient has a significant relationship and who are involved with the ICU team.[24] As caregivers are often family members, caregivers will also be included. There will be no restrictions concerning the gender, ethnicity, education, or socioeconomic status of the participants.

Interventions

This review will consider studies that assess the effectiveness of interventions to prevent or treat prolonged grief symptoms.[12,13] Tailored non-pharmacological interventions to prevent or treat prolonged grief symptoms before, during, and/or after the patient's death, alone or in combination with pharmacological interventions, will be considered, regardless of the type, frequency, duration, or format of the intervention. The term *tailored* refers to personalized interventions that are customized to meet the specific needs and circumstances of individuals or groups.[25,26] These interventions are selected and designed to address specific determinants that may influence their implementation within a particular context.[25,26] As such, this review will include tailored interventions based on CBT that incorporate components such as psychoeducation (eg, emotional support, counseling), decision support (eg, shared decision-making), or information provision (eg, pamphlets), characterized as approaches that support families of patients who die in the ICU.[13] These interventions may not explicitly be labeled as traditional CBT but are informed by its principles.

Comparators

This review will consider usual care or other types of interventions as the comparators. Usual care will be defined as the standard, routine care typically provided to patients and their families in a specific clinical setting.[27] It encompasses the conventional practices,

procedures, and interventions regularly administered based on established guidelines and protocols.[27] Other types of interventions will include non-pharmacological interventions that are not tailored to address prolonged grief symptoms in the ICU. Studies with tailored, non-pharmacological interventions will also be included if they meet the review inclusion criteria in at least 1 of the study arms.

Outcomes

This review will consider the following primary outcome: prolonged grief symptoms, according to the DSM-5-TR or ICD-11 (ie, feeling as though a part of oneself has died; a marked sense of disbelief about the death; avoidance of reminders that the person has died; intense emotional pain such as anger, bitterness, or sorrow; difficulty with reintegration into life after the death; emotional numbness; feeling that life is meaningless; and intense loneliness) as assessed by any validated instrument, such as Prolonged Grief-13. The bereaved families are also at risk of anxiety, depression, and post-traumatic stress symptoms[3,6,10]; therefore, the secondary outcomes will be: i) anxiety symptoms and ii) depression symptoms, as assessed by any validated instrument, such as Hospital Anxiety and Depression Scale; and iii) post-traumatic stress symptoms, as assessed by any validated instrument, such as The Impact of Event Scale-Revised. Outcomes can be measured at any time point following the delivery of the intervention.

Types of studies

This review will consider randomized and non-randomized controlled trials; before and after studies; and interrupted time-series, cohort, and case-control studies.

Methods

The proposed systematic review will be conducted in accordance with the JBI methodology for systematic reviews of effectiveness[28] and reported according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[29] This protocol has been registered in PROSPERO (CRD42024528308).

Search strategy

The search strategy will aim to locate both published and unpublished studies. An initial limited search of PubMed was undertaken to identify articles on the topic. The text words in the titles and abstracts of relevant articles and the index terms used to describe the articles were used to develop a complete search strategy for PubMed (Appendix I). The search strategy, including all identified keywords and index terms, will be adapted for each included database. The reference lists of all studies selected for critical appraisal will be screened for additional studies. The databases to be searched will consist of CINAHL, Academic Search Complete, Psychology and Behavioral Sciences Collection, Cochrane Central Register of Controlled Trials, and APA PsycINFO (all via EBSCOhost), as well as PubMed, Web of Science Core Collection, and Scopus. Sources of unpublished studies and gray literature will include MedNar, while trials will be searched in ClinicalTrials.gov.

All languages will be included to reduce the risk of missing relevant sources. Languages other than English, Portuguese, or Spanish will be translated by colleagues fluent in the languages or using digital tools such as DeepL (DeepL, Cologne, Germany). No time restrictions will be set on the search.

Study selection

Following the search, all identified citations will be collated and uploaded into Rayyan (Qatar Computing Research Institute, Doha, Qatar), and duplicates will be removed. An initial pilot test of 5 evidence sources will be conducted to ensure clarity and consistency in the application of the inclusion and exclusion criteria during the title and abstract screening, along with 5 additional studies before proceeding to the full text review. Titles and abstracts will be screened against the eligibility criteria by 2 independent reviewers. The full text of potentially relevant studies will be retrieved, and their citation details will be imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).[30] The full text of selected citations will be assessed in detail against the inclusion criteria by 2 independent reviewers. Reasons for exclusion of full-text studies that do not meet the inclusion criteria will be recorded and reported in the systematic review. Any disagreements between the reviewers at each stage of the study selection process will be resolved by a third reviewer. The results of the search and study selection and inclusion process will be reported in full in the final systematic review and presented in a PRISMA flow diagram.[29]

Assessment of methodological quality

Eligible studies will be critically appraised for methodological quality and risk of bias by 2 independent reviewers using standardized critical appraisal tools from JBI.[28] This assessment will include randomized controlled trials, non-randomized controlled trials, before and after studies, interrupted time-series, cohort, and case-control studies. A pilot test of the critical appraisal process will be conducted on 2 articles for each methodological design included in the review by 2 independent reviewers.

During the pilot test, an acceptable threshold of 75% agreement between the 2 reviewers will be set for the critical appraisal tools. This percentage will be calculated as the ratio of the number of times reviewers agree to the total number of assessments conducted. After the piloting, sample studies will be reviewed and any disagreements will be resolved through discussion. If the level of agreement cannot be reached, a third reviewer will be consulted. Authors of papers will be contacted at least 2 times via email to request missing or additional data, where required. The critical appraisal results will be reported in a table with an accompanying narrative. All studies, regardless of the results of their methodological quality and risk of bias, will undergo data extraction and synthesis.

Data extraction

The data extraction will be pilot tested on 3 evidence sources to assess reliability and consistency of the extraction. Data will be extracted from studies included in the review by 2 independent reviewers using the standardized JBI data extraction tool.[28] The extracted data will consist of specific details about the participants, intervention (timing of the intervention delivery, frequency, duration), comparator, after-intervention outcomes of significance to the review question, and study design (Appendix II). Any disagreements between reviewers will be resolved through discussion or with a third reviewer. Authors of the papers will be contacted at least 2 times to request missing or additional data, where required.

Data synthesis

Where possible, studies will be pooled with statistical meta-analysis using R software for statistical computing (R Foundation for Statistical Computing, Vienna, Austria). Effect sizes will be expressed as weighted (or standardized) final post-intervention mean differences between groups (for continuous data), and their 95% CI will be calculated for analysis. Heterogeneity will be assessed using the standard χ^2 and I^2 tests. Statistical analyses will be performed using the random-effects model.[31] If fewer than 5 studies are included in the meta-analysis, the fixed-effects model will be used where appropriate. If the intervention significantly improves any of the primary outcomes, and sufficient data are available, subgroup analyses will be conducted to explore the influence of the following factors on the results: i) timing of the intervention (eg, before, during, or after death), ii) frequency and duration of the intervention, and iii) comparator, whether the intervention is used alone or in combination with other interventions. For this purpose, at least 2 eligible studies will be needed in each category. Additional subgroup analysis will be performed to assess both methodological and clinical diversity across studies.

Meta-regression analysis will be computed to allow the investigation of the effects of continuous or categorical variables (eg, perceived poor care, untreated pain/symptoms, cause of the hospitalization, unresolved difficulties with the relationship, mistrust of the treating team) on prolonged grief symptomatology. The use of meta-regression will help to explain and identify factors that may influence the intervention's effect size.

A sensitivity analysis will be conducted to assess the influence of methodological quality and sample size on the meta-analysis. *Poor quality* will be defined using specific criteria from standardized critical appraisal tools,[28] such as high risk of bias or lack of rigorous methodology (ie, responses of "no" or "unclear" assigned to allocation concealment, blinding of outcome assessors, inadequate intention-to-treat analysis). Large and small sample sizes will be defined based on the interquartile range (IQR) of sample sizes in the included studies. Large sample sizes will be those greater than or equal to the third quartile (Q3) of the sample size distribution, and small sample sizes will be those less than or equal to the first quartile (Q1) of the sample size distribution. A funnel plot will be generated to assess publication bias and heterogeneity if there are 10 or more studies in the meta-analysis.

Statistical tests for funnel plot asymmetry (Egger test) will be performed where appropriate. Where meta-analysis is not possible, the findings will be

presented in narrative format, including tables and figures, to aid in data presentation. The narrative review will be reported using the synthesis without meta-analysis (SWiM) guidelines.[32]

Assessing certainty in the findings

The Grading of Recommendations, Assessment, Development and Evaluation (GRADE)[33] approach for grading the certainty of evidence will be followed and a Summary of Findings (SoF) will be presented using GRADEpro GDT (McMaster University, ON, Canada). The SoF will present the following information where appropriate: absolute risks for the treatment and control; estimates of relative risk; and a ranking of the quality of the evidence based on the risk of bias, directness, heterogeneity, precision, and risk of publication bias of the review results. Randomized controlled trials will start the ranking as high quality; however, they will be automatically downgraded if there are limitations in their design.[33] The outcomes reported in the SoF will be prolonged grief symptoms, anxiety, depression, and post-traumatic stress symptoms.

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This review will contribute towards a PhD in sciences and technologies of health and well-being: nursing sciences field for AR.

Author contributions

Conceptualization: AR; methodology: AR, RS, EA, FS; writing (original draft, and review and editing) and visualization: AR, AG, RS, LR, EA, FS; supervision: EA, FS

References

1. Kentish-Barnes N, Chevret S, Valade S, Jaber S, Kerhuel L, Guisset O, *et al.* A three-step support strategy for relatives of patients dying in the intensive care unit: a cluster randomised trial. Lancet 2022;399(10325):656–64.
2. Lichtenthal WG, Lief L, Rogers M, Russell D, Viola M, Winoker H, *et al.* EMPOWER: a multi-site pilot trial to reduce distress in surrogate decision-makers in the ICU. J Pain Symptom Manage 2024;67(6):512-524.e2.
3. Sanderson EAM, Humphreys S, Walker F, Harris D, Carduff E, McPeake J, *et al.* Risk factors for complicated grief among family members bereaved in intensive care unit settings: a systematic review. PLoS One 2022;17(3):e0264971.
4. Mark NM, Rayner SG, Lee NJ, Curtis JR. Global variability in withholding and withdrawal of life-sustaining treatment in the intensive care unit: a systematic review. Intensive Care Med 2015;41(9):1572–85.
5. Lind R. Sense of responsibility in ICU end-of-life decision-making: relatives' experiences. Nurs Ethics 2019;26(1):270–9.
6. Wen FH, Prigerson HG, Chou WC, Huang CC, Hu TH, Chiang MC, *et al.* How symptoms of prolonged grief disorder, posttraumatic stress disorder, and depression relate to each other for grieving ICU families during the first two years of bereavement. Crit Care 2022;26(1):336.
7. Diagnostic and statistical manual of mental disorders, fifth edition, text revision (DSM-5-TR (TM)) [internet]. American Psychiatric Association, editor. APA; 2022 [cited 2024 Jul 21]. 1120. Available from: https://www.psychiatry.org/patients-families/prolonged-grief-disorder.
8. World Health Organization. ICD-11 for mortality and morbidity statistics (ICD-11 MMS) [internet]. WHO; 2023 [cited 2024 Jul 21]. Available from: https://icd.who.int/browse/2024-01/mms/en#1183832314.
9. Probst DR, Gustin JL, Goodman LF, Lorenz A, Wells-Di Gregorio SM. ICU versus non-ICU hospital death: family member complicated grief, posttraumatic stress, and depressive symptoms. J Palliat Med 2016;19(4):387–93.
10. Kentish-Barnes N, Chaize M, Seegers V, Legriel S, Cariou A, Jaber S, *et al.* Complicated grief after death of a relative in the intensive care unit. Eur Respir J 2015;45(5):1341–52.
11. Kentish-Barnes N, Chevret S, Champigneulle B, Thirion M, Souppart V, Gilbert M, *et al.* Effect of a condolence letter on grief symptoms among relatives of patients who died in the ICU: a randomized clinical trial. Intensive Care Med 2017;43(4):473–84.
12. Breen LJ, Hall CW, Bryant RA. A clinician's quick guide of evidence-based approaches: prolonged grief disorder. Clin Psychol 2017;21(2):153–4.
13. Coventry A, Gerdtz M, McInnes E, Dickson J, Hudson P. Supporting families of patients who die in adult intensive care: a scoping review of interventions. Intensive Crit Care Nurs 2023;78:103454.
14. Bryant RA, Kenny L, Joscelyne A, Rawson N, Maccallum F, Cahill C, *et al.* Treating prolonged grief disorder. JAMA Psychiatry 2014;71(12):1332–9.
15. Johansson M, Wåhlin 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.
16. Barnato AE, Schenker Y, Tiver G, Dew MA, Arnold RM, Nunez 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 pilot feasibility trial. Crit Care Med 2017;45(1):35–46.
17. Showler L, Rait L, Chan M, Tondello M, George A, Tascone B, *et al.* Communication with bereaved family members after

death in the ICU: the CATHARTIC randomised clinical trial. Crit Care and Resusc 2022;24(2):116–27.
18. Moss SJ, Wollny K, Poulin TG, Cook DJ, Stelfox HT, Ordons AR des, *et al.* Bereavement interventions to support informal caregivers in the intensive care unit: a systematic review. BMC Palliat Care 2021;20(1):66.
19. Rait LI, Yeo NY, Abdelhamid YA, Showler L, Finnis ME, Deane AM. The impact of bereavement support on psychological distress in family members: a systematic review and meta-analysis. Crit Care Resusc 2021;23(2):225–33.
20. Brekelmans ACM, Ramnarain D, Pouwels S. Bereavement support programs in the intensive care unit: a systematic review. J Pain Symptom Manage 2022;64(3):e149–57.
21. Menghan HAO, Zhiyuan LI, Guoping Huang. Intervention efficacy of cognitive behavioral therapy on prolonged grief disorder: a meta-analysis. Sichuan Mental Health 2024;37 (3):289–94.
22. Marshall JC, Bosco L, Adhikari NK, Connolly B, Diaz JV, Dorman T, *et al.* What is an intensive care unit? A report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine. J Crit Care 2017;37:270–6.
23. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, *et al.* Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. Crit Care Med 2017;45 (1):103–28.
24. Kokorelias KM, Gignac MAM, Naglie G, Cameron JI. Towards a universal model of family centered care: a scoping review. BMC Health Serv Res 2019;19(1):564.
25. McHugh SM, Riordan F, Kerins C, Curran G, Lewis CC, Presseau J, *et al.* Understanding tailoring to support the implementation of evidence-based interventions in healthcare: the CUSTOMISE research programme protocol. HRB Open Res 2023;6:7.
26. Nye A, Delgadillo J, Barkham M. Efficacy of personalized psychological interventions: a systematic review and meta-analysis. J Consult Clin Psychol 2023;91(7):389–97.
27. Turner KM, Huntley A, Yardley T, Dawson S, Dawson S. Defining usual care comparators when designing pragmatic trials of complex health interventions: a methodology review. Trials 2024;25(1):117.
28. Tufunaru C, Munn Z, Aromataris E, Campbell J, Hopp L. Systematic reviews of effectiveness. In: Aromataris E, Munn Z, editors. JBI Manual for Evidence Synthesis [internet]. JBI; 2024 [cited 2024 Jul 21]. Available from: https://synthesismanual.jbi.global.
29. 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;10 (1):89.
30. Munn Z, Aromataris E, Tufanaru C, Stern C, Porritt K, Farrow J, *et al.* The development of software to support multiple systematic review types: the Joanna Briggs Institute System for the Unified Management, Assessment and Review of Information (JBI SUMARI). Int J Evid Based Healthc 2019;17(1):36–43.
31. Tufanaru C, Munn Z, Stephenson M, Aromataris E. Fixed or random effects meta-analysis? Common methodological issues in systematic reviews of effectiveness. Int J Evid Based Healthc 2015;13(3):196–207.
32. Campbell M, McKenzie JE, Sowden A, Katikireddi SV, Brennan SE, Ellis S, *et al.* Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. BMJ 2020;368:l6890.
33. Stern C, Munn Z, Barker TH, Porritt K, Stone JC, Pap R, *et al.* Implementing GRADE in systematic reviews that adhere to JBI methodological conduct. JBI Evid Synth 2024;22(3): 351–8.

Appendix I: Search strategy

PubMed

Search conducted: October 19, 2024

Search	Query	Records retrieved
#13	("family"[MeSH Terms] OR "spouses"[MeSH Terms] OR "caregivers"[MeSH Terms] OR "adult children"[MeSH Terms] OR ("famil*"[Title/Abstract] OR "spous*"[Title/Abstract] OR "caregiver*"[Title/Abstract] OR "adult child*"[Title/Abstract] OR "relativ*"[Title/Abstract] OR "family member*"[Title/Abstract] OR "husband"[Title/Abstract] OR "partner"[Title/Abstract])) AND ("intensive care units"[MeSH Terms] OR "critical care"[MeSH Terms] OR "coronary care units"[MeSH Terms] OR "respiratory care units"[MeSH Terms] OR "burn units"[MeSH Terms] OR ("intensive care"[Title/Abstract] OR "critical care"[Title/Abstract] OR "coronary care unit*"[Title/Abstract] OR "respiratory care unit*"[Title/Abstract] OR "burn unit*"[Title/Abstract] OR "ICU"[Title/Abstract] OR "stroke unit*"[Title/Abstract])) AND ("cognitive behavioral therapy"[MeSH Terms] OR "psychosocial intervention"[MeSH Terms] OR "counseling"[MeSH Terms] OR "communication"[MeSH Terms] OR "access to information"[MeSH Terms] OR "decision making"[MeSH Terms] OR ("cognitive behavioral therap*"[Title/Abstract] OR "psychosocial intervention"[Title/Abstract] OR "counseling"[Title/Abstract] OR "communication"[Title/Abstract] OR "access to information"[Title/Abstract] OR "decision making"[Title/Abstract] OR "cognitive behavior"[Title/Abstract] OR "psychological intervention*"[Title/Abstract] OR "psychoeducation"[Title/Abstract] OR "psychotherap*"[Title/Abstract] OR "letter*"[Title/Abstract] OR "strateg*"[Title/Abstract] OR "support*"[Title/Abstract] OR "phone call*"[Title/Abstract] OR "diaries"[Title/Abstract] OR "storytelling"[Title/Abstract] OR "practice*"[Title/Abstract] OR "program*"[Title/Abstract] OR "intervention*"[Title/Abstract])) AND ("prolonged grief disorder"[MeSH Terms] OR ("depressive disorder"[MeSH Terms] OR "depression"[MeSH Terms]) OR "anxiety"[MeSH Terms] OR "stress disorders, post traumatic"[MeSH Terms] OR ("prolonged grief"[Title/Abstract] OR "complicated grief"[Title/Abstract] OR "bereave*"[Title/Abstract] OR "depressi*"[Title/Abstract] OR "depressive disorder"[Title/Abstract] OR "anxiety"[Title/Abstract] OR "post traumatic stress"[Title/Abstract] OR "PTSD"[Title/Abstract]))	2101
#12	"prolonged grief disorder"[MeSH Terms] OR "depressive disorder"[MeSH Terms] OR "depression"[MeSH Terms] OR "anxiety"[MeSH Terms] OR "stress disorders, post traumatic"[MeSH Terms] OR "prolonged grief"[Title/Abstract] OR "complicated grief"[Title/Abstract] OR "bereave*"[Title/Abstract] OR "depressi*"[Title/Abstract] OR "depressive disorder"[Title/Abstract] OR "anxiety"[Title/Abstract] OR "post traumatic stress"[Title/Abstract] OR "PTSD"[Title/Abstract]	783,070
#11	"prolonged grief"[Title/Abstract] OR "complicated grief"[Title/Abstract] OR "bereave*"[Title/Abstract] OR "depressi*"[Title/Abstract] OR "depressive disorder"[Title/Abstract] OR "anxiety"[Title/Abstract] OR "post traumatic stress"[Title/Abstract] OR "PTSD"[Title/Abstract]	708,068
#10	"prolonged grief disorder"[MeSH Terms] OR "depressive disorder"[MeSH Terms] OR "depression"[MeSH Terms] OR "anxiety"[MeSH Terms] OR "stress disorders, post traumatic"[MeSH Terms]	383,182
#9	"cognitive behavioral therapy"[MeSH Terms] OR "psychosocial intervention"[MeSH Terms] OR "counseling"[MeSH Terms] OR "communication"[MeSH Terms] OR "access to information"[MeSH Terms] OR "decision making"[MeSH Terms] OR "cognitive behavioral therap*"[Title/Abstract] OR "psychosocial intervention"[Title/Abstract] OR "counseling"[Title/Abstract] OR "communication"[Title/Abstract] OR "access to information"[Title/Abstract] OR "decision making"[Title/Abstract] OR "cognitive behavior"[Title/Abstract] OR "psychological intervention*"[Title/Abstract] OR "psychoeducation"[Title/Abstract] OR "psychotherap*"[Title/Abstract] OR "letter*"[Title/Abstract] OR "strateg*"[Title/Abstract] OR "support*"[Title/Abstract] OR "phone call*"[Title/Abstract] OR "diaries"[Title/Abstract] OR "storytelling"[Title/Abstract] OR "practice*"[Title/Abstract] OR "program*"[Title/Abstract] OR "intervention*"[Title/Abstract]	7,114,944
#8	"cognitive behavioral therap*"[Title/Abstract] OR "psychosocial intervention"[Title/Abstract] OR "Counseling"[Title/Abstract] OR "communication"[Title/Abstract] OR "access to information"[Title/Abstract] OR "decision making"[Title/Abstract] OR "cognitive behavior"[Title/Abstract] OR "psychological intervention*"[Title/Abstract] OR "psychoeducation"[Title/Abstract] OR "psychotherap*"[Title/Abstract] OR "letter*"[Title/Abstract] OR "strateg*"[Title/Abstract] OR "support*"[Title/Abstract] OR "phone call*"[Title/Abstract] OR "diaries"[Title/Abstract] OR "storytelling"[Title/Abstract] OR "practice*"[Title/Abstract] OR "program*"[Title/Abstract] OR "intervention*"[Title/Abstract]	6,766,168
#7	"cognitive behavioral therapy"[MeSH Terms] OR "psychosocial intervention"[MeSH Terms] OR "counseling"[MeSH Terms] OR "communication"[MeSH Terms] OR "access to information"[MeSH Terms] OR "decision making"[MeSH Terms]	685,553
#6	"intensive care units"[MeSH Terms] OR "critical care"[MeSH Terms] OR "coronary care units"[MeSH Terms] OR "respiratory care units"[MeSH Terms] OR "burn units"[MeSH Terms] OR "intensive care"[Title/Abstract] OR "critical care"[Title/Abstract] OR "coronary care unit*"[Title/Abstract] OR "respiratory care unit*"[Title/Abstract] OR "burn unit*"[Title/Abstract] OR "ICU"[Title/Abstract] OR "stroke unit*"[Title/Abstract]	332,816

(*Continued*)

Search	Query	Records retrieved
#5	"intensive care"[Title/Abstract] OR "critical care"[Title/Abstract] OR "coronary care unit*"[Title/Abstract] OR "respiratory care unit*"[Title/Abstract] OR "burn unit*"[Title/Abstract] OR "ICU"[Title/Abstract] OR "stroke unit*"[Title/Abstract]	284,910
#4	"intensive care units"[MeSH Terms] OR "critical care"[MeSH Terms] OR "coronary care units"[MeSH Terms] OR "respiratory care units"[MeSH Terms] OR "burn units"[MeSH Terms]	164,502
#3	"family"[MeSH Terms] OR "spouses"[MeSH Terms] OR "caregivers"[MeSH Terms] OR "adult children"[MeSH Terms] OR "famil*"[Title/Abstract] OR "spous*"[Title/Abstract] OR "caregiver*"[Title/Abstract] OR "adult child*"[Title/Abstract] OR "relativ*"[Title/Abstract] OR "family member*"[Title/Abstract] OR "husband"[Title/Abstract] OR "partner"[Title/Abstract]	3,424,603
#2	"famil*"[Title/Abstract] OR "spous*"[Title/Abstract] OR "caregiver*"[Title/Abstract] OR "adult child*"[Title/Abstract] OR "relativ*"[Title/Abstract] OR "family member*"[Title/Abstract] OR "husband"[Title/Abstract] OR "partner"[Title/Abstract]	3,207,171
#1	"family"[MeSH Terms] OR "spouses"[MeSH Terms] OR "caregivers"[MeSH Terms] OR "adult children"[MeSH Terms]	422,162

Appendix II: Draft data extraction instrument

Study evidence source details and characteristics	
Citation details	Author/s, publication year, title, journal, volume, issue, pages
Design and setting	Study design, randomization, blinding, outcomes assessed, country
Participants	
Recruitment methods	Who was included and how were they involved (eg, spouses, partners, adult children, or caregivers of adult patients, who had a treatment withdrawal/withholding decision)?
Demographic information	(eg, age, gender, length of stay in ICU)
Intervention	
Intervention information	How was the intervention implemented (eg, type and timing of the intervention, frequency, duration, or format)?
Co-interventions	If any (eg, pharmacological interventions)
Comparison	
Comparison information	How was the intervention implemented (eg, type and timing of the intervention, frequency, duration, or format)?
Outcomes	
Outcome measured	(ie, prolonged grief, anxiety, depression, post-traumatic stress symptoms)
Definition/assessment metric	How did the study assess/define this outcome (eg, assessment tools)?
Time of outcome assessment	When were the outcomes assessed (eg, time point following the delivery of the intervention)?
Results	For the outcomes assessed

ICU, intensive care unit