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**Title:** The state of bereavement support in adult intensive care: A systematic review and narrative synthesis

**Abstract**

**Purpose:** Despite advances in medical science, patient death and family bereavement are commonly encountered in adult intensive care units (ICUs). This is the first review to investigate the state of ICU bereavement support globally, and the availability and effectiveness of bereavement support interventions.

**Methods:** A systematic review and narrative synthesis. Medline, CINAHL Plus, PsycINFO, Web of Science, EMBASE were searched and inclusion/exclusion criteria were applied. Included studies were appraised using relevant appraisal tools.

**Results:** Fourteen papers formed the review; five of which were international surveys reporting variable bereavement practices and levels of support. A lack of training and resources were identified barriers. Nine papers reported the effectiveness of primarily discrete bereavement support interventions including: a personal memento, a handwritten condolence letter, a post-death meeting; storytelling, research participation, use of an ICU diary. One study evaluated a bereavement follow-up program. Generally, all identified interventions were well accepted by bereaved families.

**Conclusions:** The reviewed evidence was weak, and findings were contextually bound. As such, it is difficult to make recommendations for the most acceptable and effective bereavement support intervention(s). Bereavement support in ICU needs further exploration and clinicians must be adequately trained and supported for the delivery of evidence-informed, culturally competent care.

**Keywords:** bereavement; intensive care units; narrative synthesis; systematic review

## 1. Introduction

Although advancements in intensive and critical care have improved outcomes for many critically ill patients, a significant number of adult patients succumb to their illnesses and die in intensive care units (ICUs). An international audit of intensive care patient populations identified that overall ICU mortality rates were 16.2% (95% CI 15.5–16.9) across the whole population studied [1]. However, mortality rates vary globally, with reports indicating that 10 to 30 percent of patients die while in ICU [2,3,4]. In England, Wales and Northern Ireland, for example, the ICU mortality rate for 2016-17 was 13.7%, which equated to approximately 22,000 episodes of caring for the dying, deceased and bereaved [5]. Death and dying in ICU may be similar to other contexts, but this depends on the trajectory of death itself. Dying trajectories in ICU include: sudden death; acute illness or injury with rapid deterioration; chronic illness with gradual decline leading to withdrawal of treatment, and prolonged deterioration with patients moving in and out of serious illness [6,7,8]. Due to the unpredictable dying trajectories, the nature of critical illness and advanced technical care in ICU which aims at curing, the emotional preparation of the family for the possibility of patient death may be overlooked [9,10]. Consequently, deaths in ICU can lead to emotionally charged situations and life changing circumstances for family members [10].

The psychological impact of death in ICU for experiencing families is well recognized. Symptoms of psychiatric illness requiring professional help [11], post-traumatic stress [12,13], complicated grief [13-15], prolonged grief disorder [16] and social distress [17] are prevalent in family members whose relative died in ICU. Families of ICU decedents report that they would appreciate bereavement support [11,18], and the provision of support also extends to healthcare providers [19,20]. Several challenges surround the provision of bereavement care in the ICU [21], including reports that health professionals are not adequately prepared to address the needs of relatives following a death in ICU [11,22,23]. Hence, bereavement support has gained prominence in the literature as an essential element of end-of-life (EoL) care in ICU, and an identified clinical and research priority [21,24,25].

The aim of this review was to identify and systematically review primary research related to ICU bereavement support. The review questions we aimed to address were: What is the state of ICU bereavement support globally? What bereavement support interventions are available for ICU decedents' families and what is their effectiveness? For the purpose of this review, 'family bereavement support' was defined as 'care for grieving families at the time of patient death and post-ICU'. To our knowledge, there has not been a review that has attempted to answer the same research questions in the past.

## **2. Methods**

### **2.1 Design**

A systematic review method was selected to allow a robust and reproducible approach to structure a critical synthesis of existing research [26]. A preliminary search identified a range of evidence on the topic of interest, and provided indication of support for a narrative synthesis of the findings from heterogeneous studies [27]. The Cochrane and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed to produce and report a systematic and rigorous review [28,29,30]. The review protocol was registered with PROSPERO [31].

### **2.2 Search strategy**

Five databases were searched from their inception to April 2018: Medline; CINAHL Plus; PsycINFO (Ovid); Web of Science (Core collection); EMBASE. The PICO (Population, Intervention, Comparison, Outcome) acronym was used to identify the key terms and facilitated a systematic approach for the database searches. A librarian was consulted during this phase to ensure that the search terms were satisfactory to produce a sensitive and specific enough search. A combination of keywords and Medical Subject Headings (MeSH) were used, initially on Medline (Figure 1) and applied to subsequent database searches. Boolean terms were used as necessary to ensure retrieval of specific literature. The last database search was undertaken on the 9<sup>th</sup> of April 2018. A reference

management software (Endnote) was used to manage the retrieved literature. Duplicates were removed and titles and abstracts were screened by two reviewers (NE, WW). Full text versions were obtained for all remaining papers which were screened by two reviewers (NE, WW) who applied inclusion and exclusion criteria. All retrieved papers' reference lists were checked for any potentially related literature.

### ***2.3 Inclusion and exclusion criteria***

We included all studies reporting on the status of bereavement support in ICUs. For interventions and their impact, we included only evidence from adult ICUs, excluding coronary care units (CCUs). We included only views and experiences reported by family members. Pilot studies were included because they can provide useful and usable data in reviews, and they could ultimately imitate the full studies [32]. We included only peer reviewed studies published in English language. We excluded published conference abstracts, unpublished theses and grey literature. During full text screening, a decision was made to include papers published between 2014 and 2018, with the aim of reporting contemporaneous practice and research. Evidence preceding this date was used to support the discussion and allowed chronological comparisons with the findings of the review.

### ***2.4 Outcome of databases' search***

The five database searches resulted in 1,990 citations. Following removal of 985 duplications, a further 972 papers were deemed irrelevant based on title and abstract screening. Of the remaining papers, 19 were excluded based on inclusion and exclusion criteria. The inclusion of the remaining 14 papers in the review was agreed by the review team (Figure 2). Five papers reported on the status of ICU bereavement in five countries and nine papers reported results from views and experiences of families related to bereavement support interventions.

### **2.5 Data extraction and analysis**

A data extraction form was developed a priori and pilot tested with two studies to accommodate extraction of information from the diverse papers included in the review. Information extracted included general information about the studies, study design, data collection and analysis methods, sampling strategy and characteristics of the participants, findings and limitations as identified by the authors.

Data analysis was undertaken to develop a preliminary narrative synthesis of the results of included studies [27]. For the studies reporting on the ICU bereavement status, an analysis of tabulated study findings was undertaken to identify and explore patterns in the data and themes. The studies evaluating ICU bereavement support interventions were grouped into two categories of 'discrete interventions' and 'multi-component interventions' to provide a narrative synthesis of: the types of bereavement support interventions that have been studied; the study designs used and the juxtaposition of study findings. Some interventions were studied in the context of a larger study or wider investigation. Therefore, only findings relevant to the focus of the review were extracted during data analyses.

### **2.6 Quality assessment**

We used the AXIS appraisal tool for surveys and the Critical Appraisal Skills Programme (CASP) tools for qualitative studies and randomised control trials to assess the quality of the studies included in this review, [33,34]. These research design-specific tools address both specific methodological and general issues in studies. Quality assessment was undertaken by two reviewers (NE, BV) independently. Disagreements related to quality assessment were resolved through discussion. In the development of the review protocol it had been determined a priori, that despite quality assessment, that no study would be excluded based on the quality. Rather, the aim of the quality assessment was to be able to comment on the quality of evidence specific to this topic.

### **3. Results**

#### ***3.1 Quality Assessment***

Of the 14 papers included in the review, eight papers were assessed using the AXIS appraisal tool for surveys [35-42], four were assessed using the CASP tool for qualitative studies [42-46], and two were assessed using the CASP tool for randomised control trials [47,48].

The quality of the surveys was mixed. While 13 of the AXIS criteria were clearly met by in the included studies, seven assessment criteria highlighted limitations related to the following: sample size justification, measures undertaken to address and categorise non-responders, clarity with respect to the determination of statistical significance and/or precision estimates, other reporting regarding non-responders, reporting of internal consistency, and finally, funding and/or conflict of interest disclosure. The quality of the qualitative studies was generally very good. Of the four qualitative articles assessed, the main area of weakness was a failure to report the relationship between the researcher and the participants. One qualitative paper had additional weaknesses which included lack of clarity regarding the design of the study, whether the data was collected in a way that addressed the research issue as well as lack of clarity regarding the analysis and the study findings [46]. The quality of the randomised control trials was high. A limitation identified in one of the studies was with respect to reporting the treatment effect and the estimation of the treatment effect, however this was a pilot study and that was not expected [47]. (Supplementary tables for more detailed information regarding the quality assessment are available by request)

#### ***3.2 The state of ICU bereavement support globally***

Five papers were retrieved reporting on the state of ICU bereavement support across the world. The studies originated in Australia, New Zealand (NZ), Denmark, United Kingdom (UK), and United States (US) (Table 1). All researchers used online surveys to collect data and the responses represented 617 ICUs. In Denmark, Australia and NZ, almost all responding units allowed families to view the deceased in ICU [38, 41]. A large number of the units held information about bereavement support

services which were provided to the deceased's family. In the US, almost two thirds (62.4%) of participating units did not offer any bereavement support while most (83%) of UK ICUs provided follow up information to relatives [36,40]. The most common bereavement support services offered included a condolence letter or sympathy card (US=62.9%, NZ=54.2%, Denmark=28%, Australia=20.8%), phone call to the family (NZ=92.3%, Australia=76.5%, US=36%, Denmark=26%), a meeting with medical staff as routine (NZ=61.5%, Australia=39.4%, Denmark=24%), a brochure on hospital bereavement services (NZ=66.7%, Australia=64.8%), a brochure on community bereavement services (NZ=58.3%, US=48%, Australia=45.6%) or a brochure on either hospital or community bereavement services (UK=76%) [36,38,40,41]. Educational provision was very important to support ICU staff to offer bereavement care [37]. However, in the UK, Berry et al. reported that more than half of the participants were denied access to bereavement care training [36]. Almost half of the participants in the US study identified a lack of education as a barrier to offering bereavement services [40]. Organisational challenges, such as lack of funding and lack of time, were also reported as barriers to bereavement care [37,40].

### ***3.3 Bereavement interventions and their impact***

Nine papers, four qualitative and five quantitative studies, reported on ICU bereavement support interventions and their impact (Table 2). These studies originated from Canada, France, Sweden and US. The studies that formed this aspect of the review were predominantly focused on post-ICU bereavement support interventions for family members of ICU decedents. The majority examined the efficacy of a single bereavement support intervention, and most reported positive outcomes. Study outcomes were based on experiential perceptions, in the form of narrative [43-45], descriptive numerical data [35,39,42], or a combination of both [46,47]. One exception was a randomised trial which reliably tested efficacy and reported treatment outcomes [48]. The array of interventions included: use of an ICU diary, a personal memento, storytelling, a post-death meeting, research participation, a handwritten condolence letter, and a bereavement follow-up program.

### **3.3.1 Discrete bereavement support interventions**

Johansson et al. used the research interview to qualitatively explore how family members of ICU decedents experienced the use of a diary of the events that occurred during the patient's ICU stay [43]. Nine bereaved family members of eight patients were recruited from three ICUs in Sweden. At the time of the interview, four participants had read the diary after their relative's death, four suggested they would do so after more time had passed, and one said they would not. However, all participants were familiar with the content as they had been writing and reading this during the patient's stay in the ICU. Subjective family perceptions and authors' interpretations suggested the diary was an important source of information that could act as bereavement support by helping the family to gain a rational and emotional understanding of the death of the patient. Overall, the diary was experienced '*as a bridge that connected the past with the future*' (p.235) representing the time leading up to the patient's death and the post-death bereavement period [43].

An evaluation of care offered to the family as they transition from anticipatory grieving to bereavement was the primary aim of a descriptive survey by Beiermann et al. [35]. Potential participants had accepted an ECG Memento<sup>®</sup>; a mounted strip of the patient's heart rhythm and a card that included sentiments from health care staff. One survey item was included to explicitly evaluate the impact of this nurse-initiated intervention. Of the 50 family members who received the ECG Memento<sup>®</sup>, 28 completed the survey. The majority of respondents (86%,  $n=24$ ) positively evaluated the memento. Most (61%,  $n=17$ ) stated that it was extremely/very helpful in the context of coping with the death of their relative/friend, and qualitative comments suggested it was a source of comfort to some families in their grief.

Schenker et al. developed and pilot tested a post-ICU intervention based on evidence of the benefits of storytelling after traumatic events [46]. A specific goal of the intervention was to reduce distress for recently bereaved family members involved in decisions to limit life-sustaining treatment. The storytelling intervention explored three domains of the family member's experience of the patient's illness and death: antecedents, ICU experience and aftermath. The intervention

entailed a therapeutic goal since the facilitator attended to emotional disclosure and distress. Self-rated subjective units of distress were measured pre- and post-intervention. Resulting scores of five to 60 after the storytelling intervention were found to be no higher than the scores obtained before the intervention. All six participants endorsed the storytelling intervention as acceptable, and five reported that it was helpful to talk about their experience. Subsequently, in a Phase 2 study, the feasibility, acceptability and tolerability of storytelling among bereaved relatives were assessed in a single-blind trial [47]. All *a priori* benchmarks were met or exceeded, including enrolment, completion and follow-up rates which confirmed feasibility. Consistent with Phase 1 pilot results [46], acceptability of the storytelling intervention was determined, with 9/13 (69%) control participants and 16/17 (94%) family members who received storytelling feeling 'better' or 'much better' at 6-months, and none felt 'much worse'. Three participants provided negative feedback; one control subject and one storytelling subject said participation was burdensome, and one control subject wished they had not taken part. In terms of tolerability, no subjects required acute referral to mental health services as a result of participating in the study.

A post-ICU bereavement support intervention which took the form of a routine follow-up meeting was the focus of a survey by Kock et al. [39]. A physician, a nurse and an assistant nurse met with the family at approximately four to six weeks post patient death to explain and elucidate events during the ICU period, including the cause of death. A two-part questionnaire was sent to 84 family members of 56 deceased patients; Part A aimed to evaluate the follow-up meeting and Part B enquired if the family member could be contacted again for a post-ICU bereavement support research project. Of the 46 respondents who had attended the follow-up meeting and completed Part A, most (78%,  $n=36$ ) were satisfied/very satisfied with their meeting and valued the presence of the physician (91%,  $n=42$ ) and the nurse (70%,  $n=32$ ) as important. The authors suggested family appreciation of this service was unambiguous, and even family members who had been dissatisfied with their own meeting were among the 91% ( $n=42$ ) who answered that it was important to

continue with this routine intervention. A total of 54 respondents answered Part B, and 63% ( $n=34$ ) were in agreement to be contacted again for a research project.

Kentish-Barnes et al. sought to understand why ICU family members participate in bereavement research and to ascertain the perceived benefits of participation [44]. Qualitative telephone interview data (54 narratives) were collected as part of a multicentre prospective observational study investigating EoL experiences in the ICU and family members' grieving experiences after death in the ICU. Participants also volunteered written information (annotations on 150 questionnaires and in 52 letters to the research team) and this provided additional sources of data for analysis. Thematic findings from this study suggested that research participation may be beneficial for bereaved family members. Reasons for taking part in the study as well as perceived benefits of participation were: to say thank you to the ICU team, to help other bereaved family members, to express self from a distance, to not feel abandoned, to share difficult emotions and to make meaning of the death, and to receive support and care. The findings revealed that in more than half of the interviews (32 of 54) family members felt they could not share what happened in the ICU with others such as relatives, friends and colleagues, and they experienced the offer to participate in research as the ICU team's acknowledgement of their pain, suffering, and need to express themselves. The research interview was also experienced as a form of beneficial care, and family members' perceptions of having been '*taken care of*' and '*listened to*' give credence to the researchers' interpretations. Kentish-Barnes et al. concluded that care for the bereaved family may need to be developed in the form of post ICU meetings, phone calls or condolence letters [44].

The effect of a letter of condolence on grief symptoms among family members of patients who died in the ICU was the focus of a multicentre randomised trial conducted by Kentish-Barnes et al. [48]. Family members were randomly assigned to receive a handwritten condolence letter 15 days after the patient's death ( $n=123$ ) or not to receive a condolence letter (control group  $n=119$ ). At one month, 208 family members completed the Hospital Anxiety and Depression Scale (HADS) via a telephone interview. Although scores were higher in the intervention group, there were no

significant differences in the HADS-depression subscale, the HADS-anxiety subscale and prevalence of anxiety symptoms. At six months, the intervention was associated with an increased prevalence of depression symptoms and post-traumatic stress disorder-related symptoms. Moreover, on the basis of multivariate analysis, a high HADS score at six months was independently associated with the condolence letter. There were no complaints from family members about the condolence letter, and 50 of the intervention group gave feedback to thank the clinician for the letter. A secondary purpose of this study was to investigate bereaved relatives' experiences and reactions in receiving the letter of condolence, and this took the form of a qualitative interview study [45]. Data comprised 26 letters sent to participating ICU teams by family members who received a letter of condolence and 52 spontaneous family declarations during telephone interviews. The findings derived from thematic analyses suggested a condolence letter can help some family members feel supported and influence perceptions of a humanized medical system. However, approximately 30% of participants were surprised to receive a condolence letter and expressed ambivalent feelings of distress, suspicion and a social obligation to answer the letter. The authors concluded that the findings of the two studies are not contradictory, but make clear to clinicians that a condolence letter '*must not be sent in the intention to reduce grief symptoms, but rather to manifest support*' (p.1970) [45].

### **3.3.2 Multi-component interventions**

Santiago et al. developed and administered a formal follow-up program for family members of ICU decedents comprising: routine provision of a bereavement brochure, a sympathy card signed by nursing staff and mailed 10 days after a patient's death, a telephone follow-up call 3-weeks after patient death and invitation to a hospital memorial service held quarterly [42]. The feasibility of implementing each of the program components was tracked by the study team (evidence of activating the intervention), and bereaved family attitudes and overall satisfaction were ascertained through a survey. The results of this pilot study demonstrated feasible implementation of the program. However, feasibility was variable, with not all eligible next-of-kin ( $n=30$ ) receiving a

bereavement brochure (23/30) or contacted for a follow-up telephone call (15/30) despite three attempts. Family attitudes towards individual components were also variable among survey respondents ( $n=11$ ). The majority who received a telephone call found it helpful (4/7), 100% received a sympathy card and found it meaningful, yet less than half who received the brochure and read it, found it helpful (4/9). Four family members attended the quarterly memorial service, but no one answered the question about helpfulness of the service. On a scale of 0-10 (10 being the highest rate), the mean rating of program helpfulness was 7 (range 5-10), and 44% rated the program 7 or higher. Hence, the program acceptability threshold of 75% was not met. The results of this study led the authors to question the suitability of a standardized approach to follow-up bereavement care. Equally, they draw attention to the unique needs of individual families for optimal impact, and make recommendation to include bereaved family members at the inception of follow-up program design.

#### **4. Discussion**

Following a systematic search of five healthcare related databases, 14 papers met the inclusion criteria for this systematic review. Five of the 14 papers provided insights into the status of ICU bereavement support. Despite ICU bereavement being a global phenomenon, this review identified papers related to the state of ICU bereavement from only five western countries. The findings revealed that most of the ICUs allowed viewing the deceased and provided information about bereavement support services. However, bereavement support approaches varied between ICUs in the same country and in some ICUs no supporting services were offered. There is an expectation that the duties of healthcare staff do not end when a patient dies, and national EoL strategies identify bereavement support as an essential component of EoL care [49,50]. However, the status of bereavement support in ICU has not changed considerably over time. For example, in 2005, Valks et al. reported 30% of ICUs in Australia provided bereavement follow up and more than a decade later the provision is 27% [10,41]. In 1992, a UK survey by Jackson reported that 56% of ICUs had no follow-up services and less than a third (32%) offered informal follow-up services [51]. Recently,

Berry et al. found a continued shortfall with 17% of ICUs in the UK not providing any bereavement follow-up [36]. The preparation of staff to support bereaved ICU families was also found to be an outstanding concern. Of the 293 participants in a UK study by Granger et al., only 6% of doctors and 21% of nurses had received bereavement related training [52]. More recent data suggests 51% of ICU nurses had not received adequate bereavement training [22], and a strong wish by ICU clinicians for formal bereavement training [11,36].

All the bereavement support interventions identified in the review were generally appreciated by family members. The research revealed varied interpretations of what constitutes bereavement follow-up and service provision. We identified support in the post ICU bereavement period comprise primarily of a single intervention. It could be argued that bereavement is a natural process following a death, and this conceptualisation would fit with post-ICU bereavement support. However, evidence-informed bereavement care practices, including a family-support intervention that utilises meaningful, well-structured and timed communication between clinicians and the patient's family before death [53] and nurses' evaluation of the use of music during after death care [54] draw attention to support for grieving families' prior to and in the immediate after-math of patient death in the ICU. Walker and Trapani suggest a classification of care for grieving families in the contexts of 'EoL care prior to patient death' and 'bereavement care following patient death' in the ICU [21]. A clearer understanding of what constitutes bereavement support in the ICU is essential for future practice, policy, education and research.

Bereavement follow-up was practiced in various forms, with the intent of acknowledging the family's bereavement and/or to provide family members opportunity to reflect on their experience. However, there was some family scepticism behind the motives of post-ICU contact. Reports of family member's unwillingness to access bereavement support or non-response to invitations suggests not all ICU families are receptive to follow-up contact [11,55]. Indeed, bereavement follow-up can unearth unrecognised social needs that cannot be always addressed by ICU staff, resulting in possible family dissatisfaction [11].

A form of bereavement support involving retrospection was family participation in bereavement research [44]. Reported perceptions of benefit contribute to a growing body of evidence to support the ethical practice of family participation in bereavement research [56-59]. In previous studies, a sympathy card has been considered appropriate by bereaved families and has received positive reactions [60,61]. However, it is also reported that it can cause unnecessary distress to bereaved families [48]. The letter or card has to be personal, by those clinicians who were involved to the care of the patient. In a study, more than 50% of ICU nurses reported that newly bereaved families should only be contacted by nurses who provided care to their patient [22].

A multi-component intervention was identified in this review [42] which may provide support that multiple interventions could be more effective, as identified previously by another study that investigated the provision of a bereavement leaflet and longer conference times prior to a patient's death in ICU [62]. However, the findings by Santiago et al. suggest a combined programme of bereavement support interventions may be difficult to co-ordinate and may require additional resources [42]. A tool has been developed to assess relatives' experiences of death in ICU (CEASAR) which could be used to predict family members risk of developing clinical symptoms during the bereavement period [63]. This could assist with the allocation of resources to those identified as being most at risk of complicated grief or severe grief reactions to the benefit of countries with limited healthcare resources, facing austerity or with private healthcare systems. However, the CEASAR tool was developed and tested in France, and further testing and refinement would be required for its use in other countries.

Bereavement support interventions identified in this review were generally well received by bereaved families and there is support from previous evidence to show a generally positive effect on family members [64-66]. Yet, the impact of most ICU bereavement support interventions have been evaluated by small scale studies with limited scope for generalisations. Within the search parameters of this review, we identified only one trial with some potential for generalisation [48]. As the reviewed evidence is weak, it is difficult to make recommendations for the most acceptable and

effective bereavement support intervention(s). Study findings are also contextually bound, as in the case of participants in the randomised trial from a country where it is suggested that a more paternalistic approach is expected by service users [62].

Further global research is required for culturally sensitive bereavement care. Current evidence gives the impression that a single intervention might work best in practice, especially in the absence of a more complete understanding of the scope, nature and impact of ICU bereavement support interventions. Despite new developments in the provision of family-centred care in the ICU [67], none of the interventions in the reviewed studies appeared to have been developed with input from bereaved families. An important consideration for acceptability and sustainability of bereavement care in ICU care is the involvement of ICU clinicians and families as co-creators of evidence-informed interventions. The technique of experience-based co-design (EBCD) is a powerful approach to service improvement, and could be used in practice or as a research methodology to develop and explore ICU bereavement support [68]. The impact of a condolence letter serves as an example of the importance of evaluating bereavement support interventions from the experiencing person's standpoint, and the value of obtaining outcome data in quantitative and qualitative form [45,48].

#### ***4.1 Strengths and limitations***

This systematic review brought evidence together that met strict inclusion criteria following a search of five health related databases. The systematic process was undertaken by at least two reviewers at each stage. We excluded keywords such as 'end-of-life' or 'palliative' during database searches, due to retrieving non-specific results when used in preliminary searches. We also excluded research reported in languages other than English. This means that we might have missed additional relevant studies. However, hand searches of the included papers did not identify any further papers. We acknowledge that the study relating to the perceived benefits of family participation in bereavement research [44] does not denote a deliberate bereavement support intervention in the

same way as the majority reported interventions that form this review. Equally, we acknowledge there may be other interventions with bereaved families and incidental outcomes not captured by the search terms we developed and applied. We also included pilot studies which may place limits on the soundness of the review results. However, supporting evidence has been provided within the discussion to substantiate our conclusions. Both qualitative and quantitative studies were included in the review, thus providing insights into the interventions studied and their impact from different perspectives. The review reports on papers that were published in the last five years, reflecting current practice. However, the reporting of the state of bereavement support globally is restricted to countries represented in the review.

## **5. Conclusion**

This study has provided a comprehensive systematic review of the state of ICU bereavement, and the availability and effectiveness of bereavement support interventions in the western world. Research from non-western countries would have enhanced our understanding of this global phenomenon, and a need for further local, national and international research is clear. Although bereavement support is acknowledged as an important aspect of EoL care in ICU, it has not been investigated extensively and existing studies tend to be observational in nature and underpowered. Exploratory research to identify and develop family-centred bereavement care, well-designed trials to test the effectiveness of interventions, and the embedding of bereavement support in educational curricular have an equal role to play in the future development of evidence-informed, culturally competent bereavement care in the ICU.

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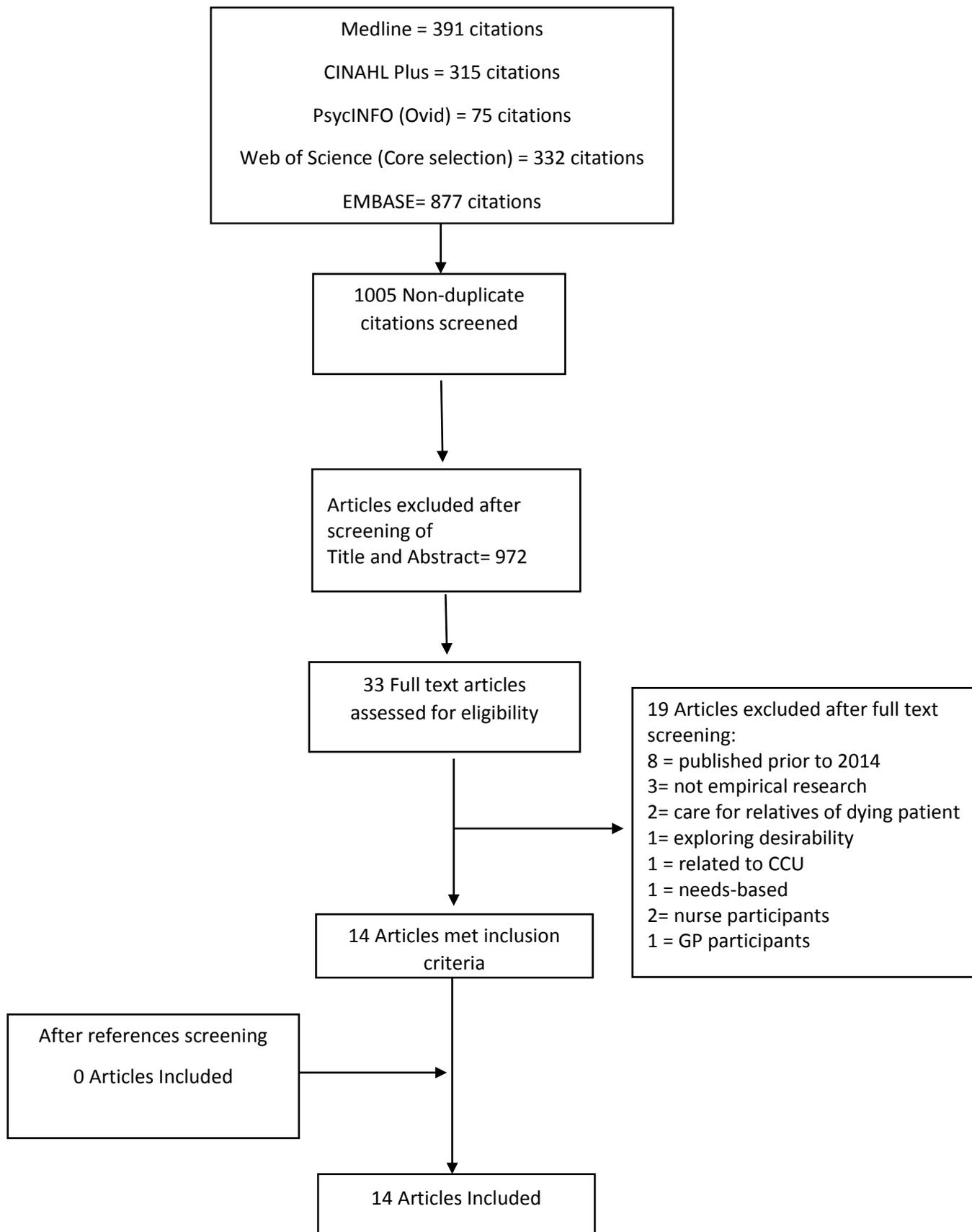
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**Figure 1** Medline (Ovid) MeSH and keyword search

Bereavement (MeSH) **OR** Grief (MeSH) **OR** Mourning (keyword) **OR** 'Personal Loss' (keyword)

**AND**

Critical Care (MeSH) **OR** Intensive Care Units (MeSH) **OR** ITU (keyword) **OR** ICU (keyword)



**Figure 2** Diagram of database searches and process of elimination

**Table 1** State of ICU bereavement support

<b>Author/s Year Country</b>	<b>Aim</b>	<b>Methods</b>	<b>Sampling Participants Response Rate (RR)</b>	<b>Sites</b>	<b>Data Analysis</b>	<b>Findings</b>
Berry et al. 2017 UK	To assess the provision of ICU bereavement care in England, focusing particularly on the offered services, the existing governance structure, and the availability of training and staff support, as outlined in the 1998 Intensive Care Society document	Online Survey	Purposive; 179 ICUs met inclusion criteria; 113 completed surveys; RR 63%	179 adult ICUs in England	Descriptive statistics	96% of units had a bereavement information booklet available; 76% of units provided a structured booklet that included organisations providing bereavement follow-up; 17% of units provided no bereavement information; 45% of units had a written bereavement support policy; 53% of the units did not have access to bereavement care training; 81% of units had a bereavement folder available for staff; 19% of the units were performing regular bereavement support services audits.
Coombs et al. 2017 New Zealand and Australia	To qualitatively describe the type of bereavement care provided in ICUs across Australia and New Zealand and the	Online survey with free text responses	Purposive; 229 ICUs met inclusion criteria (A=188, NZ=41); 68 completed surveys (A=54, NZ=14); RR 30%	229 adult, paediatric, neonatal ICUs in Australia and New Zealand	Inductive content analysis	From the 124 free-text responses, a total of 187 individual codes were identified focussing on bereavement care practices (n = 145, 77.5%), educational provision to support

	challenges experienced					<p>staff (n = 15, 8%) and organisational challenges (n = 27, 14.4%).</p> <p>Bereavement care practices described use of memory boxes, cultural specificity, annual memorial services and use of community support services. Educational provision identified local in-service programmes, and national bereavement courses for specialist bereavement nurse coordinators.</p> <p>Organisational challenges focussed on lack of funding, especially for provision of bereavement follow-up.</p>
Egerod et al. 2018 Denmark	To describe current bereavement follow-up services in adult ICUs	Online questionnaire	Purposive; 48 ICUs met inclusion criteria; 46 completed surveys; RR 96%	48 ICUs in Denmark	Descriptive statistics and comprehensive summary of free text comments.	<p>100% offered viewing of the deceased in ICU;</p> <p>72% of units provided information about hospital-based follow up;</p> <p>59% of ICUs offered bereavement follow-up services (these included: 41% ICU visit for family, 30% meeting with medical staff by request, 28% condolence letter, 26% phone call to family, 24% referral to priest or clergyman, 24% meeting with medical staff as routine, 11% referral to other</p>

						counselling, 4% referral to psychologist); 20% of the units were evaluating bereavement follow ups.
McAdam & Erikson 2016 USA	To describe current bereavement follow-up services in adult ICUs.	Online questionnaire	Convenience; 1003 ICUs in AACN register; 237 completed questionnaires; RR 24%	1003 adult ICUs in the United States	Descriptive statistics and binary logistic regression	62.4% of the units did not offer bereavement services; 37.6% offered bereavement follow up services (these included: 62.9% condolence cards, 43.8% brochures, 36% phone call to family); 74% of the units offering bereavement services were evaluating them. Barriers to offering bereavement services: 48% lack of education, 47.3% lack of money, 39.9% lack of knowledge on family bereavement needs, 38.5% not feeling qualified to offer the service, 32.4% no time. If the hospital had a palliative care service, it was 8 times more likely to offer bereavement follow-up services; If the hospital provided bereavement support, the ICU was 4 times more likely to offer bereavement follow-up; Surgical ICUs were 3 times more likely to offer bereavement services.
Mitchell et al.	To investigate the	Online	Purposive;	188	Descriptive	96.6% offered routinely viewing

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2017 New Zealand and Australia	provision of family bereavement support in ICU across New Zealand and Australia	questionnaire	229 senior ICU nurses were contacted (A=188, NZ=41); 153 completed questionnaires; RR 67%	Australian and New Zealand ICUs	statistics	of the deceased in ICU; 65.1% offered information about hospital bereavement services; 47.7% offered information about community bereavement services; 26.2% were sending a sympathy card (A=20.8%, NZ=54.2%); 31.9% offered a bereavement follow-up service (A=28.3%, NZ=50%); 80.9% offered phone call to family (A=76.5%, NZ=92.3%); 45.7% offered routinely meeting with medical staff (A=39.4%, NZ=61.5%).
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Abbreviations: A= Australia, NZ=New Zealand, AACN= American Association of Critical Care Nurses

**Table 2** ICU bereavement support interventions and their impact

<b>Author/s Year Country</b>	<b>Aim</b>	<b>Methods</b>	<b>Sampling Strategy Participants Response Rate (RR)</b>	<b>Sites</b>	<b>Intervention Data Collection</b>	<b>Data Analysis</b>	<b>Findings</b>
Barnato et al. 2017 USA	To assess the feasibility, acceptability, and tolerability of storytelling among bereaved surrogates involved in a decision to limit life support in the ICU.	Single-blind trial. Referred as pilot study.	Purposive, non-random sequential. Bereaved surrogates of ICU patients n=32: 14/32 control; 18/32 intervention. Mean age 55.5 Most were making decisions for parent (47%), followed by spouse (28%). Recruited during the emotionally-charged period of an ICU admission.	Five ICUs across three hospitals in one health system	Post-ICU bereavement intervention 'surrogate storytelling'. Subjects received the same written materials as control subjects, plus a 1-2hr home visit at approximately 4 weeks after death by a trained interventionist who elicited the surrogate's story. Telephone assessment at 14 (baseline), 30 and 180 days. Variety of scales/measures used to elicit data, plus participant narrative through	Descriptive statistics	At 6 months, 9/13 (69%) control participants and 16/17 (94%) storytelling subjects reported feeling "better" or "much better" and none felt "much worse". One control subject (8%) and one storytelling subject (6%) said that the study was burdensome, and one control subject (8%) wished they had not participated. The prevalence of PICS-F (symptom burden) at the final assessment was lower in the storytelling group. No subjects required acute mental health

					use of prescribed interview protocol content objectives.		services referral. Participants reported altruistic benefits from the opportunity to participate in research that might benefit others.
Beiermann et al. 2017 USA	The primary aim was to study the bereavement experience for families in the ICU; secondary aim was to measure nurses' perception of end-of-life care, and a third was to evaluate the impact of the ECG Memento© by families and nurses.	Prospective descriptive design with post survey methodology. Referred as pilot study.	Convenience; 50 patient/family dyads, 28 returned Satisfaction with Bereavement Questionnaire (SBEQ) RR=56%	ICU and Intermediate Cardiac Care Unit of one teaching hospital	ECG Memento© card; a laminated ECG strip mounted inside a note card. 24-item questionnaire (SBEQ). Two items added to the questionnaire to assess family response to the ECG Memento©.	Descriptive statistics; Frequency distributions.	Family SBEQ, highly satisfied. Families (86%) responded positively to the ECG Memento©; of those - 61% stated that it was extremely helpful/helpful; 25% thought it was somewhat or slightly helpful. 41% viewed it daily 6 to 8 weeks after death of the loved one.
Johansson et al. 2018 Sweden	To explore how family members experienced the use of a diary when a relative does not survive the stay in the intensive care unit (ICU).	Qualitative study. Gadamerian hermeneutic approach	Convenience/Purposive; Nine family members of eight patients with diaries who did not survive their stay in ICU.	One University, and two county hospitals' ICUs	Patient diary. Interviews.	Thematic content analysis (hermeneutic technique inspired by Geanellos).	Overall theme: 'the diary was experienced as a bridge that connected the past with the future' Three themes and six subthemes: 1. The diary promoted a rational understanding: The

							diary provided information/The diary reflected the patient's everyday activities. 2. The diary promoted an emotional understanding: The diary reflected emotions/The diary provided comfort. 3. The diary promoted social interactions: The diary maintained communication/The diary maintained a relationship.
Kentish-Barnes et al. 2015 France	To understand why family members participate in bereavement research and the benefits of participating in such research.	Qualitative study.	Convenience/Purposive; 54 interviews, 52 letters, and written annotations on 150 questionnaires.	41 ICUs	Participation in bereavement research. Interviews; Letters; Open comments on questionnaire.	Thematic analysis	Six themes: to say thank you; to help others; to express myself at a distance; to not feel abandoned; to share difficult emotions; to receive support and care.
Kentish-Barnes et al. 2017 France	To test the hypothesis that a condolence letter, compared to no condolence letter, alleviated grief symptoms in relatives of	Multicentre, randomised, parallel-group trial.	Random; 242 patients, 123 randomly assigned to intervention letter, 119 to control group (1 family member per patient). Randomization	22 hospitals' ICUs (11 University and 11 non-University), belonging to the French FAMIREA	Condolence letter. Intervention group - letter sent 15 days after the patient's death. Telephone interview/Hospital Anxiety and	Intent-to-treat approach. Descriptive statistics. Wilcoxon rank-sum, Chi square or	No relatives complained about receiving a condolence letter. 30 days: HADS score 16 for intervention and 14 for control (p=0.35). Relatives with

	patients who had died in ICU.		occurred within 24hr of patient's death. Sample powered for the primary outcome. Day 30 RR=86% Day 180 RR=78.5%	study group.	Depression Scale (HADS)/Impact of Event Scale-Revised (IES-R)/Inventory of Complicated Grief (ICG)/CAESAR instrument to assess the quality of dying and death. The primary endpoint was HADS at 30 days. Secondary endpoints included HADS, ICG, and IES-R at 180 days.	exact Fisher test. Effect sizes. Multivariable logistic regression. Significance level set at 0.05	symptoms of depression: 56% for intervention and 42.4% for control (p=0.05). 180 days: HADS score 13 for intervention and 9 for control (p=0.04). Relatives with symptoms of depression 36.6% for intervention and 24.7% for control (p=0.05). Relatives with PTSD related symptoms 52.4% for intervention and 37.1% for control (p=0.03).
Kentish-Barnes et al. 2017 France	To understand bereaved family members' experience of receiving a letter of condolence.	Qualitative study. Designed to provide insight into the results of a larger randomized, controlled, multicentre study.	Convenience/Purposive; 52 spontaneous declarations during telephone interviews (30 declarations at 30 days and 22 declarations at 180 days) and 26 letters.	22 ICUs	Condolence letter. Interviews; Letters.	Thematic analysis.	Six themes emerged: a feeling of support; humanization of the medical system; an opportunity for reflection; an opportunity to describe their loved one; continuity and closure; doubts and ambivalence. Possible difficulties emerged, notably the

							re-experience of the trauma, highlighting the absence of further support.
Kock et al. 2014 Sweden	To find out if a follow-up meeting post death (FUMPD) with physicians and staff for family members of patients who died in ICU was appreciated by the family members.	Survey.	Convenience; 84 family members of 56 deceased patients. 52 responded RR=62% Out of 52 respondents, six had not attended FUMPD and were excluded. Therefore 46 respondents.	8 bedded unit in a University hospital.	Follow-up meeting with ICU physicians and staff. Questionnaire with closed and open questions.	Descriptive statistics and Mann-Whitney test for comparisons between groups.	36/46 (78%) were satisfied or very satisfied with FUMPD; 42/46 (91%) felt it was important to continue with the FUMPD; Nobody felt it was not necessary. 31/46 (67%) thought that FUMPD should take place 2-6 weeks after death; 23/46 (50%) preferred to meet with more than one person; 42/46 (91%) valued as important the presence of physician. Medical questions were the most common question family members wanted to address during FUMPD.
Santiago et al. 2017 Canada	1) To develop and administer a formal bereavement	Observational study, survey. Referred as pilot study.	Convenience/Purposive. 30 family members were enrolled in the study.	24 bedded medical-surgical ICU in a	Bereavement programme, consisting of bereavement	Descriptive statistics. For responses to	9/11 (82%) had received the brochure and the majority had read it;

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<p>program to family members of patients who die in the ICU consisting of a bereavement brochure, sympathy card, telephone follow-up, and an invitation to a hospital memorial service</p> <p>2) To measure the feasibility of implementing each of the program components</p> <p>3) To determine family member attitudes towards the program and each component.</p>	<p>11 responded RR=37%</p>	<p>University-affiliated hospital.</p>	<p>brochure, sympathy card, telephone follow-up, invitation to hospital memorial service.</p> <p>A 23-item questionnaire, purposefully developed for this study; pilot-tested.</p>	<p>open questions synthesis of responses by identifying common themes.</p>	<p>3/7 (43%) found the brochure helpful, while 4/7 (57%) were neutral.</p> <p>11/11 (100%) reported receiving the sympathy card and finding it meaningful (comments: "touched that someone took the time", "thankful because they were not forgotten", "surprised", "relieved", "happy and sad", "cared for".</p> <p>7/11 (64%) reported receiving the telephone call, 4/6 (67%) found it helpful (comments: the verbal support gave them hope, the call was a thoughtful and caring gesture).</p> <p>14 invitations were sent to the memorial service, only 4/14 (29%) attended.</p> <p>No response was received about the helpfulness of the memorial service.</p>
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Schenker et al. 2015 USA	To (1) describe a conceptual framework underlying the beneficial mental health effects of storytelling, and (2) present formative work developing a storytelling intervention.	A case series. Referred as pilot study.	Convenience; Six bereaved surrogates.	One medical ICU.	Story telling. Debriefing interviews after each storytelling session. Subjective units of distress (SUDS).	Not stated.	All subjects endorsed acceptability; 5/6 reported that it was helpful to talk about their experience; One said he enjoyed the opportunity to "help others" through his participation One said "I think that that helped me to talk to somebody that wasn't judging me" and later noting, "There's a lot of things I didn't even know that were hurting me, you know? This is feeling good." One said "For me, it helps to talk about it and to tell the story, because it's my way of going through it again. I think sometimes you have to look back and understand and walk

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through it to get past and move on.” SUDS scores ranged from five to 60 and were not higher than the scores prior the intervention.

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