UNIVERSITY OF BIRMINGHAM
University of Birmingham Research at Birmingham

The state of bereavement support in adult intensive care

Efstathiou, Nikolaos; Walker, Wendy; Metcalfe, Alison; Vanderspank-Wright, Brandi

DOI:
10.1016/j.jcrc.2018.11.026

License:
Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

Document Version
Peer reviewed version

Citation for published version (Harvard):
Efstathiou, N, Walker, W, Metcalfe, A & Vanderspank-Wright, B 2019, 'The state of bereavement support in adult intensive care: a systematic review and narrative synthesis', *Journal of Critical Care*, vol. 50, pp. 177-187. https://doi.org/10.1016/j.jcrc.2018.11.026

Link to publication on Research at Birmingham portal

Publisher Rights Statement:
Checked for eligibility 15/01/2019

https://doi.org/10.1016/j.jcrc.2018.11.026

General rights
Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

•Users may freely distribute the URL that is used to identify this publication.
•Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
•User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
•Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy
While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Download date: 25. Apr. 2024

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 9th 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 1,499 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©; 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©, 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.

Acknowledgements

We would like to acknowledge Susan Stevens, Research Skills Advisor at the University of Birmingham, for her assistance in developing the systematic search strategy.

References

1. Vincent JL, Marshall JC, Ñamendys-Silva SA, François B, Martin-Loeches I, Lipman J, Reinhart K, Antonelli M, Pickkers P, Njimi H, Jimenez E, Sakr Y, on behalf of the ICON investigators. Assessment of the worldwide burden of critical illness: the Intensive Care Over Nations (ICON) audit. Lancet Respir Med 2014; 2(5):380-86. DOI: 10.1016/S2213-2600(14)70061-X
2. Coombs M, Addlington-Hall J, Long-Sutehall T. Challenges in transition from intervention to end of life care in intensive care: a qualitative study. Int J Nurs Stud 2012; 49:519-27. DOI: 10.1016/j.ijnurstu.2011.10.019.
3. Society of Critical Care Medicine. Critical Care Statistics, http://learnicu.net/Communications/Pages/CriticalCareStats.aspx; not dated [accessed 26 September 2018].
4. Wennberg JE, Fisher ES, Stukel TA, Skinner JS, Sharp SM, Bronner KK. Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. BMJ 2004; 328:607. https://doi.org/10.1136/bmj.328.7440.607
5. Intensive Care National Audit & Research Centre. Case Mix Programme Summary Statistics 2016-17. ICNARC: https://www.icnarc.org/Our-Audit/Audits/Cmp/Reports/Summary-Statistics; 2018 [accessed 20 July 2018]
6. Long-Sutehall T, Willis H, Palmer R, Ugboma D, Addington-Hall J, Coombs M. Negotiated dying: a grounded theory of how nurses shape withdrawal of treatment in hospital critical care units. Int J Nurs Stud 2011; 48(12):1466-74. doi: 10.1016/j.ijnurstu.2011.06.003.
7. Kalowes F. Improving End-of-Life care prognostic discussions: Role of advanced practice nurses. AACN Adv Crit Care 2015; 26(2):151-66. doi: 10.1097/NCI.0000000000000086.
8. Higginson IJ, Rumble C, Shipman C, Koffman J, Sleeman KE, Morgan M, Hopkins P, Noble J, Bernal W, Leonard S, Dampier O, Prentice W, Burman R, Costantini M. The value of uncertainty in critical illness? An ethnographic study of patterns and conflicts in care and decision-making trajectories. BMC Anesthesiol 2016; 16:11. doi: 10.1186/s12871-016-0177-2.
9. Campbell ML, Thill MR. Bereavement follow-up to families after death in the intensive care unit. Crit Care Med 2000; 28(4):1252-3.
10. Valks K, Mitchell ML, Inglis-Simons C, Limpus A. Dealing with death: an audit of family bereavement programs in Australian intensive care units. Aust Crit Care 2005;18(4):146, 148-51.
11. Downar J., Barua R., Sinuff T. The desirability of an Intensive Care Unit (ICU) clinician-led bereavement screening and support program for family members of ICU decedents (ICU Bereave). J Crit Care 2014; 29(2):311 e319-311 e316. DOI: 10.1016/j.jcrc.2013.11.024
12. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, Annane D, Bleichner G, Bollaert PE, Darmon M, Fassier T, Galliot R, Garrouste-Orgeas M, Goulenok C, Goldgran-Toledano D, Hayon J, Jourdain M, Kaidomar M, Laplace C, Larché J, Liotier J, Papazian L, Poisson C, Reignier J, Saidi F, Schlemmer B; FAMIREA Study Group. 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. DOI: 10.1164/rccm.200409-1295OC
13. Anderson WG, Arnold RM, Angus DC, Bryce CL. Posttraumatic stress and complicated grief in family members of patients in the intensive care unit. J Gen Intern Med 2008; 23(11):1871-6. doi: 10.1007/s11606-008-0770-2.
14. Siegel MD, Hayes E, Vanderwerker LC, Loseth DB, Prigerson HG. Psychiatric illness in the next-of-kin of patients who die in the intensive care unit. Crit Care Med 2008; 36: 1722-1728. doi: 10.1097/CCM.0b013e318174da72
15. Kentish-Barnes N, Chaize M, Seegers V, Legriel S, Cariou A, Jaber S, Lefrant JY, Floccard B, Renault A, Vinatier I, Mathonnet A, Reuter D, Guisset O, Cohen-Solal Z, Cracco C, Seguin A,

Durand-Gasselin J, Éon B, Thirion M, Rigaud JP, Philippon-Jouve B, Argaud L, Chouquer R, Adda M, Dedrie C, Georges H, Lebas E, Rolin N, Bollaert PE, Lecuyer L, Viquesnel G, Léone M, Chalumeau-Lemoine L, Garrouste M, Schlemmer B, Chevret S, Falissard B, Azoulay É. Complicated grief after death of a relative in the intensive care unit. Eur Respir J 2015; 45(5):1341-52. doi: 10.1183/09031936.00160014.

16. Rodriguez Villar SR, Sanchez Casado MS, Prigerson HG, Garcıa SM, Villar MR, Martin VAH, Schulke CMM, Vega RB, Quintana M. Prolonged grief disorder in the next of kin of adult patients who die during or after admission to intensive care. Chest 2012; 141(6):1635-1636. doi: 10.1378/chest.11-3099.
17. Downar J, Koo E, des Ordons AR, Smith O, Cook D, Golan E. 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):521-522. doi: 10.1007/s00134-017-5027-2.
18. van der Klink MA, Heijboer L, Hofhuis JG, Hovingh A, Rommes JH, Westerman MJ, Spronk PE. Survey into bereavement of family members of patients who died in the intensive care unit. Intensive Crit Care Nurs. 2010; 26(4):215-225. doi: 10.1016/j.iccn.2010.05.004.
19. Walker W, Deacon K. Nurses' experiences of caring for the suddenly bereaved in adult acute and critical care settings, and the provision of person-centred care: A qualitative study. Intensive Crit Care Nurs 2016; 33:39-47. doi: 10.1016/j.iccn.2015.12.005.
20. Vanderspank-Wright B, Efstathiou N, Vandyk A. Critical care nurses' experiences of withdrawal of treatment: A systematic review of qualitative evidence. Int J Nurs Stud 2018; 77:15-26. doi: 10.1016/j.ijnurstu.2017.09.012.
21. Walker w, Trapani J. Spotlight on bereavement care. Nurs Crit Care 2018;23(4):169-71. doi: 10.1111/nicc.12362.
22. Kurian MJ, Daniel S, James A, James C, Joseph L, Malecha AT, McCorquodale Martin E, Mick JM. Intensive care registered nurses' role in bereavement support. J Hosp Palliat Nurs 2014; 16:31-39.
23. Bloomer MJ, Morphet J, O'Connor M, Lee S, Griffiths D. Nursing care of the family before and after a death in ICU-An exploratory pilot study. Aust Crit Care 2013;26(1):23-8. doi: 10.1016/j.aucc.2012.01.001.
24. Truog RD, Campbell ML, Curtis JR, Haas CE, Luce JM, Rubenfeld GD, Rushton CH, Kaufman DC Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American Academy of Critical Care Medicine. Crit Care Med 2008;36(3):953-63. doi: 10.1097/CCM.0B013E3181659096.
25. Buckley T. End of life and bereavement care in the intensive care unit: A need for more quality empirical research. Aust Crit Care 2017;30(3):137-138. doi: 10.1016/S1036-7314(17)30182-0.
26. Munn Z, Stern C, Aromataris E, Lockwood C, Jordan Z. What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. BMC Med Res Methodol 2018;18(1):5. doi: 10.1186/s12874-017-0468-4.
27. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M. Britten N, Roen K, Duffy S. Guidance on the Conduct of Narrative Synthesis in Systematic Reviews: A Product from the ESRC Methods Programme. V1 2006. Lancaster University. DOI: 10.13140/2.1.1018.4643.
28. Higgins JPT, Green S (editors). Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from: www.handbook.cochrane.org. [Accessed: 20 November 2017].
29. Ryan R. Cochrane Consumers and Communication Review Group: Data synthesis and analysis. Available from: https://cccrg.cochrane.org/sites/cccrg.cochrane.org/files/public/uploads/AnalysisRestyled.pdf. [Accessed: 20 January 2018].

30. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 2009; 6(7): e1000097. https://doi.org/10.1371/journal.pmed.1000097
31. Efstathiou N, Walker W, Metcalfe A. Bereavement support for family members of Intensive Care Unit decedents: a systematic review and narrative synthesis. PROSPERO 2017 CRD42017076509 Available from: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017076509
32. Leon AC, Davis LL, Kraemer HC. The role and interpretation of pilot studies in clinical research. J Psychiatr Res 2011; 45 (5): 626-29. doi: 10.1016/j.jpsychires.2010.10.008.
33. Downes AC, Davis LL, Kraemer HC. Development of a critical appraisal tool to assess the quality of cross sectional studies (AXIS). BMJ Open 2016;6:e011458. doi:10.1136/bmjopen-2016-011458
34. Critical Appraisal Skills Programme. CASP Qualitative Checklist. [online] Available at: https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-Download.pdf; 2018 [Accessed:20 April 2018].
35. Beiermann M, Kalowes P, Dyo M, Mondor A. Family members' and Intensive Care Unit nurses' response to the ECG Memento© during the bereavement period. Dimens Crit Care Nurs 2017;36(6):317-326. doi: 10.1097/DCC.0000000000000269.
36. 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):11-16. doi: 10.1177/1751143716653770
37. Coombs M, Mitchell M, James S, Wetzig K. Intensive care bereavement practices across New Zealand and Australian intensive care units: a qualitative content analysis. J Clin Nurs 2017; 26(19-20):2944-52. doi: 10.1111/jocn.13624.
38. Egerod I, Kaldan G, Coombs M, Mitchell M. Family-centered bereavement practices in Danish intensive care units: a cross-sectional national survey. Intensive Crit Care Nurs 2018; 45:52-57. doi: 10.1016/j.iccn.2017.10.003.
39. Kock M1, Berntsson C, Bengtsson A. A follow-up meeting post death is appreciated by family members of deceased patients. Acta Anaesthesiol Scand 2014;58(7):891-6. doi: 10.1111/aas.12358.
40. McAdam JL, Erikson A. Bereavement services offered in adult Intensive Care Units in the United States. Am J Crit Care 2016; 25(2):110-7. doi: 10.4037/ajcc2016981.
41. Mitchell M, Coombs M, Wetzig K. The provision of family-centred intensive care bereavement support in Australia and New Zealand: Results of a cross sectional explorative descriptive survey. Aust Crit Care 2017;30(3):139-144. doi: 10.1016/j.aucc.2016.07.005.
42. Santiago C, Lee C, Placentino R, Deveau C, Villeneuve J, Diston MT, Smith O. A pilot study o f an interprofessional, multicomponent bereavement follow-up program in the intensive care unit. Can J Crit Care Nurs 2017; 28(3):18-24.
43. 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):233-240. doi: 10.1111/scs.12454.
44. Kentish-Barnes N, McAdam JL, Kouki S, Cohen-Solal Z, Chaize M, Galon M, Souppart V, Puntillo KA, Azoulay E. Research participation for bereaved family members: Experience and insights from a qualitative study. Crit Care Med 2015; 43(9):1839-45. doi: 10.1097/CCM.0000000000001092.
45. Kentish-Barnes N, Cohen-Solal Z, Souppart V, Galon M, Champigneulle B, Thirion M, Gilbert M, Lesieur O, Renault A, Garrouste-Orgeas M, Argaud L, Venot M, Demoule A, Guisset O, Vinatier I, Troché G, Massot J, Jaber S, Bornstain C, Gaday V, Robert R, Rigaud JP, Cinotti R, Adda M, Thomas F, Azoulay E. "It Was the Only Thing I Could Hold Onto, But…": Receiving a Letter of Condolence After Loss of a Loved One in the ICU: A Qualitative Study of Bereaved Relatives' Experience. Crit Care Med 2017; 45(12):1965-1971. doi: 10.1097/CCM.0000000000002687.

46. 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 Support Care 2015;13(3):451-63. doi: 10.1017/S1478951513001211.
47. Barnato AE, Schenker Y, Tiver G, Dew MA, Arnold RM, Nunez ER, Reynolds CF 3rd. 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
48. Kentish-Barnes N, Chevret S, Champigneulle B, Thirion M, Souppart V, Gilbert M, Lesieur O, Renault A, Garrouste-Orgeas M, Argaud L, Venot M, Demoule A, Guisset O, Vinatier I, Troché G, Massot J, Jaber S, Bornstain C, Gaday V, Robert R, Rigaud JP, Cinotti R, Adda M, Thomas F, Calvet L, Galon M, Cohen-Solal Z, Cariou A, Azoulay E; Famirea Study Group. 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):473-484. doi: 10.1007/s00134-016-4669-9.
49. Department of Health (UK). End of Life Care Strategy Promoting high quality care for all adults at the end of life. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf; 2008 {Accessed 25 May 2018].
50. Commonwealth of Australia. National Palliative Care Strategy 2010: Supporting Australians to Live Well at the End of Life. http://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/$File/NationalPalliativeCareStrategy.pdf; 2010 [Accessed 15 April 2018].
51. Jackson I. Bereavement follow-up service in intensive care. Intensive Crit Care Nurs 1992; 8(3):163-8.
52. Granger, E., George, C., Shelly, P. The management of bereavement on intensive care units. Intensive Care Med 1995; 21(5):429-36.
53. White DB, Angus DC, Shields A-M, Buddadhumaruk P, Pidro C, Paner C, Chaitin E, Chang CH, Pike F, Weissfeld L, Kahn JM, Darby JM, Kowinsky A, Martin S, Arnold RM; PARTNER Investigators. A randomised trial of family-support intervention in intensive care units. N Engl J Med 2018; 378(25):2365-2375. doi: 10.1056/NEJMoa1802637.
54. Holm MS, Fålun N, Gjengedal E, Norekvål TM. Music during after-death care: a focus group study. Nurs Crit Care 2012; 17(6):302-8. doi: 10.1111/j.1478-5153.2012.00525.x.
55. Curtis JR, Nielsen EL, Treece PD, Downey L, Dotolo D, Shannon SE, Back AL, Rubenfeld GD, Engelberg RA. Effect of a Quality-Improvement Intervention on End-of- Life Care in the Intensive Care Unit: A Randomized Trial. Am J Respir Crit Care Med 2011; 183(3):348-55. doi: 10.1164/rccm.201006-1004OC.
56. Germain A, Mayland CR, Jack BA. The potential therapeutic value for bereaved relatives participating in research: An exploratory study. Palliat Support Care 2016; 14(5):479-87. doi: 10.1017/S1478951515001194.
57. Miyashita M, Aoyama M, Yoshida S, Yamada Y, Abe M, Yanagilhara K, Shirado A, Shutoh M, Okamoto Y, Hamano J, Miyamoto A, Nakahata M. The distress and benefit to bereaved family members of participating in a post-bereavement survey. Jpn J Clin Oncol 2018; 48(2):135-143. doi: 10.1093/jjco/hyx177.
58. Skinner-Cook A, Bosley G. The experience of participating in bereavement research: Stressful or therapeutic? Death Stud 1995; 19(2):157-70. DOI: 10.1080/07481189508252722.
59. Sque M. Walker W. Long-Sutehall T. Research with bereaved families: A framework for ethical decision-making. Nurs Ethics 2014; 21(8):946-55. doi: 10.1177/0969733014521097.
60. Jackson I. A study of bereavement in an intensive therapy unit. Nurs Crit Care 1998; 3(3):141-50.

61. Morris SE, Block SD. Adding Value to Palliative Care Services: The development of an institutional bereavement program. J Palliat Med 2015; 18(11):915-22.
62. Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, Adrie C, Barnoud D, Bleichner G, Bruel C, Choukroun G, Curtis JR, Fieux F, Galliot R, Garrouste-Orgeas M, Georges H, Goldgran-Toledano D, Jourdain M, Loubert G, Reignier J, Saidi F, Souweine B, Vincent F, Barnes NK, Pochard F, Schlemmer B, Azoulay E. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med 2007; 356(5):469-78. DOI:10.1056/NEJMoa063446.
63. Kentish-Barnes N, Seegers V, Legriel S, Cariou A, Jaber S, Lefrant JY, Floccard B, Renault A, Vinatier I, Mathonnet A, Reuter D, Guisset O, Cracco C, Seguin A, Durand-Gasselin J, Éon B, Thirion M, Rigaud JP, Philippon-Jouve B, Argaud L, Chouquer R, Adda M, Papazian L, Dedrie C, Georges H, Lebas E, Rolin N, Bollaert PE, Lecuyer L, Viquesnel G, Léone M, Chalumeau-Lemoine L, Cohen-Solal Z, Garrouste-Orgeas M, Tamion F, Falissard B, Chevret S, Azoulay E. CAESAR: a new tool to assess relatives' experience of dying and death in the ICU. Intensive Care Med 2016; 42(6):995-1002. doi: 10.1007/s00134-016-4260-4.
64. Yeager S, Doust C, Epting S, Iannantuono B, Indian C, Lenhart B, Manche D, Morris M, Newton B, Ortman L, Young K, Thomas K. Embrace Hope: an end-of-life intervention to support neurological critical care patients and their families. Crit Care Nurse 2010; 30(1):47-58; quiz 59. doi: 10.4037/ccn2010235.
65. Platt J. The planning, organising and delivery of a memorial service in critical care. Nurs Crit Care 2004; 9(5):222-9.
66. Voisey S, Davies J, Parry-Jones J, Stallard S. Five years experience of critical care bereavement follow-up. Crit Care 2007;11(Suppl 2):494.
67. Gerritsen RT, Hartog CS, Randall Curtis J. (2017) New developments in the provision of family-centered care in the intensive care unit. Intensive Care Med 2017; 43(4):550-553. doi: 10.1007/s00134-017-4684-5.
68. The Point of Care Foundation. EBCD: Experience-based co-design toolkit. https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/; 2018 [Accessed 20 September 2018]