

Family bereavement support in adult intensive care

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Background

- ▶ A substantial number of critically ill patients die in intensive care units (ICUs).
- ▶ In England, Wales and Northern Ireland, the ICU mortality rate for **2017–18 was 13.8%, which equated to 23,441 deaths** (ICNARC, 2018).
- ▶ End of Life care in ICU includes pre- and post-death support for the grieving and bereaved family.



Bereavement support



Background

Impact of ICU bereavement to experiencing families:

- ▶ Symptoms of psychiatric illness requiring professional help (Downar et al. 2014)
- ▶ Post-traumatic stress (Azoulay et al. 2005; Anderson et al. 2008)
- ▶ Complicated grief (Anderson et al. 2008; Siegel et al. 2008; Kentish-Barnes et al. 2015)
- ▶ Prolonged grief disorder (Rodriguez Villar et al. 2012)
- ▶ Social distress (Downar et al. 2018)

Aim of this presentation

To present the process and outcomes of a published systematic literature review related to family bereavement support in adult intensive care.

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*; 50: 177-187.

Review questions

- ▶ What is the state of ICU bereavement support globally?
- ▶ What bereavement support interventions are available for ICU decedents' families and what is their effectiveness?

Design

Systematic review

- ▶ We followed the Cochrane and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Narrative synthesis

- ▶ Heterogeneous studies;
- ▶ Developed a preliminary synthesis of study findings (Popay et al. 2006).

Protocol -> PROSPERO

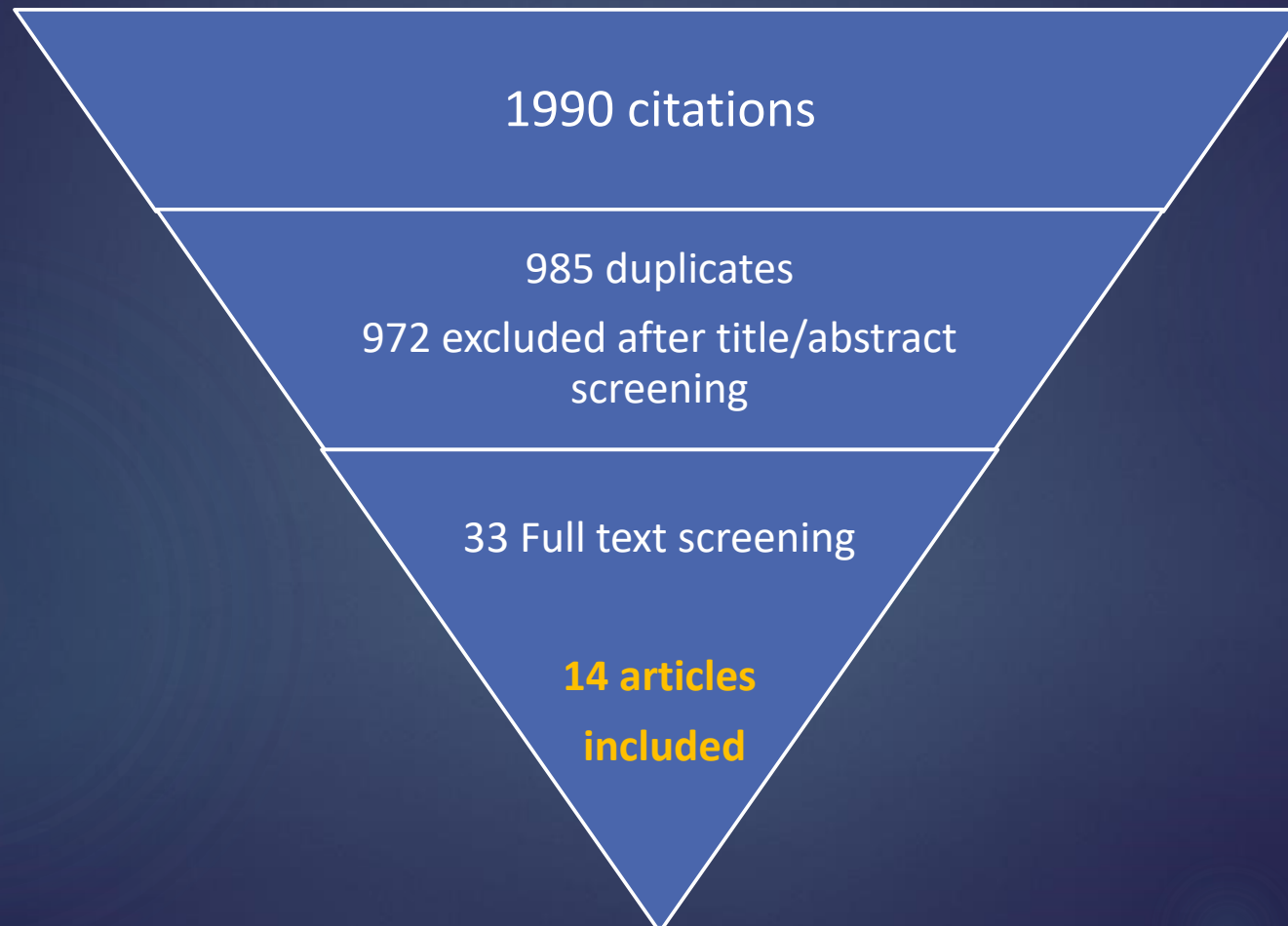
Database searches

Five databases were searched from the date they had available data to April 2018 (last database search 9/4/2018):

1. Medline
 2. CINAHL Plus
 3. PsycINFO (Ovid)
 4. Web of Science (Core collection)
 5. EMBASE
- ▶ A combination of keywords and Medical Subject Headings (MeSH) were used, initially on Medline and applied to subsequent database searches.

Inclusion criteria	Exclusion criteria
Studies reporting status of bereavement support in ICUs	Bereavement support in coronary care units (CCUs)
Views and experiences reported by family members only	Abstracts
Primary , pilot and feasibility studies	Unpublished theses
Peer reviewed studies	Grey literature
English language	
Published the last 5 years (2014-2018)	

Databases' search outcome



Data extraction

- ▶ We developed, pilot tested and used a data extraction form;
- ▶ We extracted 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.

Appraisal of studies

- ▶ We used the AXIS appraisal tool for surveys (Downes et al. 2016) and the Critical Appraisal Skills Programme (CASP) tools for qualitative studies and randomised control trials (CASP 2018).

Results

Quality assessment of papers

- ▶ **8 surveys**: mixed quality (weaknesses included sample size justification, non-responders, funding/conflict of interest disclosure);
- ▶ **4 qualitative studies**: very good quality (common weakness was a failure to report the relationship between researcher and participant);
- ▶ **2 randomised control studies**: high quality.
- ▶ **Five papers** reported on the **status of ICU bereavement support**.
- ▶ **Nine papers** reported on **ICU bereavement support interventions and their impact**.



Results: Status of ICU bereavement support

	Australia Mitchell et al. 2017 153 Australian & New Zealand ICUs	New Zealand	Denmark Egerod et al. 2018 46 ICUs	UK Berry et al. 2017 113 ICUs	US McAdam & Erikson 2016 237 ICUs
Allowing families to view the deceased in ICU	Yes	Yes	Yes	-	-
Phone call to the family	76.5%	92.3%	26%	-	36%
A meeting with medical staff as routine	39.4%	61.5%	24%	-	-
A brochure on either hospital or community bereavement services	HBS 64.8% CBS 45.6%	HBS 66.7% CBS 58.3%	-	HBS & CBS 76%	CBS 48%
Condolence letter / sympathy card	20.8%	54.2%	28%	-	62.9%

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Results: Status of ICU bereavement support

- ▶ Coombs et al. 2017 (New Zealand & Australia) analysed free text responses from a questionnaire in relation to bereavement support distributed to 229 ICUs (A = 188, NZ = 41). The researchers identified two major challenges:
 - ▶ Lack of funding
 - ▶ Embedding bereavement care into the ICU culture
- ▶ Studies from UK and US identified training in bereavement support as problematic (Berry et al. 2017; McAdam & Erikson 2016).

Results: Interventions and impact

Storytelling (Schenker et al. 2015; Barnato et al. 2017, US)

- ▶ Case series; All subjects endorsed acceptability; 5/6 reported that it was helpful to talk about their experience; Distress scores were not higher than prior the intervention.
- ▶ Pilot trial; At 6 months, 9/13 (69%) control participants and 16/17 (94%) storytelling subjects reported feeling “better” or “much better”. Symptom burden was lower in the storytelling group.

ECG Memento© card (Beiermann et al. 2017, US)

- ▶ Survey; Family members were highly satisfied; 86% responded positively to the ECG Memento©.

Results: Interventions and impact

Condolence letter (Kentish-Barnes et al. 2017a; Kentish-Barnes et al. 2017b, France)

- ▶ Multicentre, RCT; No relatives complained about receiving a condolence letter. Higher levels of anxiety, depression and post traumatic stress disorder in intervention group.
- ▶ Qualitative study; a feeling of support, humanization of the medical system, an opportunity for reflection and to describe their loved one, continuity and closure, doubts and ambivalence, re-experience of the trauma, absence of further support.

Participation in bereavement research (Kentish-Barnes et al. 2015, France)

- ▶ Qualitative study; 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.

Results: Interventions and impact

Follow-up meeting (Kock et al. 2014, Sweden)

- ▶ Survey; 36/46 (78%) were satisfied or very satisfied, 31/46 (67%) thought that it should take place 2–6 weeks after death, 42/46 (91%) valued as important the presence of physician.

Diary (Johansson et al. 2018, Sweden)

- ▶ Qualitative study; The diary was experienced as a bridge that connected the past with the future.

Bereavement program: bereavement brochure, sympathy card, telephone follow-up, invitation to hospital memorial service (Santiago et al. 2017, Canada)

- ▶ Survey; General satisfaction with the intervention.

Limitations of the review

- ▶ Selection of keywords;
- ▶ Only publications in English language;
- ▶ Inclusion of pilot studies;
- ▶ Only few countries are represented in the review.



Conclusions

- ▶ Bereavement support in ICUs requires further exploration with experiencing families and staff;
- ▶ There is a need to understand the scope, nature and impact of support to ensure that we provide evidence-informed bereavement care practice;
- ▶ Bereaved family members have to be involved in developing and evaluating bereavement support interventions.

Findings are supported by papers published in the recent
Special Issue on Bereavement Care
Nursing in Critical Care (Vol 24, Issue 4)





Thank you

