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Intensive care bereavement practices across New Zealand and Australian intensive care units: a qualitative content analysis

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Author contributions:

Maureen Coombs and Marion Mitchell designed the study and the data collection tool.

Maureen Coombs, Marion Mitchell and Krista Wetzig were involved in data recruitment and data collection.

Marion Mitchell and Krista Wetzig were involved in data management and all authors were involved in data analysis. All authors were involved in drafting and revising of the paper. All authors have approved the final version.

Abstract

Background: End of life and bereavement care is an important consideration in intensive care. This study describes the type of bereavement care provided in intensive care units across Australia and New Zealand.

Design: Inductive qualitative content analysis was conducted on free-text responses to a web-based survey exploring unit-based bereavement practice distributed to nurse managers in 229 intensive care units in New Zealand and Australia.

Results: 153 (67%) surveys were returned with 68 respondents making free-text responses. Respondents were mainly Australian (n=54, 85.3%), from the public sector (n=51, 75%) and holding Nurse Unit Managers/Charge Nurse roles (n=39, 52.9%). 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 staff (n= 15, 8%) and organisational challenges (n= 27, 14.4%). 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. Organisational challenges focussed on lack of funding, especially for provision of bereavement follow-up.

Conclusions: This is the first Australasian-wide survey, and one of the few international studies, describing bereavement practices within intensive care, an important aspect of nursing practice. However, with funding for new bereavement services and education for staff lacking, there are continued challenges in developing bereavement care. Given

knowledge about the impact of these area of care on bereaved family members, this requires review.

Relevance to clinical practice. Nurses remain committed to supporting bereaved families during and following death in intensive care. With limited resource to support bereavement care, intensive care nurses undertake a range of bereavement care practices at time of death, and after death through family bereavement follow-up.

Summary box: 'What does this paper contribute to the wider global clinical community?'

- Offering quality end of life care for families of deceased patients in intensive care can reduce abnormal grief reactions and reduce incidence of mental health issues in family members.
- A range of intensive care bereavement care services are offered across to families including use of memorial boxes, annual remembrance services, and bereavement follow-up services.
- In-service education for nurses at the bedside and formal educational courses for bereavement co-ordinators are important to support nurses caring for bereaved family members in intensive care.

Key Words:

Bereavement, Death, Dying, End of life care, Nursing role, Family, Intensive Care

Introduction

Experiencing bereavement in intensive care can be sudden and traumatic for families of critically ill patients (Anderson *et al.* 2008, Siegal *et al.* 2008). In acknowledging this burden

on family members and the rapid and intense psychological adjustments required to be made by families in intensive care, there has been increased attention on initiatives to support those whose family member dies in intensive care (Lautrette *et al.* 2007). Over the past decade there has been wide reporting of bereavement care practices in intensive care (Curtis 2014), with most focussing on care of the critically ill patient and their family prior to death. An exception to this is the bereavement follow-up service that offers support to bereaved families after a death in intensive care. However, with the literature mainly reporting on how individual units provide bereavement care, little is known about the detail of intensive care bereavement practices and bereavement support provision at a national level.

This paper reports on qualitative findings from analysis of free text responses from an Australasian descriptive survey. The cross sectional survey was undertaken to identify provision of family bereavement support across Australia and New Zealand. On analysing all returned surveys, there was a large quantity of qualitative data describing aspects of bereavement practice outside of the forced choice questions in the survey. This data gave an in-depth account of bereavement care that merited publication. In this paper, bereavement care provided at time of death on the intensive care unit (ICU) and support given to families after a patient death through provision of bereavement follow-up services are described, and the challenges in providing this care across Australasian ICUs are explored.

Background

Disruption in cognitive, emotional, physical and social functioning is a normal reaction to bereavement and has been widely acknowledged (Bonnano & Kaltman 2001). This is usually temporary, and recovery from grief will occur for the majority of the population

(Genevro *et al.* 2004). However where death is traumatic, when unresolved issues exist from earlier losses in life, or when under-developed coping mechanisms exist, a more complicated, chronic grief reaction can be evidenced (Prigerson & Jacobs 2001). This is often associated with the bereaved experiencing mental health symptoms including depression, anxiety and post traumatic distress disorder, as well as physiological ill health, for example, high risk of cardiovascular events for the bereaved (Buckley *et al.* 2011).

Although many deaths occur in hospitals (Trankle 2014), experiencing death and dying in the intensive care cannot be considered a normal environment. It is therefore unsurprising that approximately 10% of family members bereaved in intensive care, will exhibit signs of complicated chronic grief within two years of their loss (Villar *et al.* 2012). Whilst literature on support for those with complicated grief has explored use of psychotherapeutic (Shear *et al.* 2014) and pharmacological agents (Simon 2013), it is important that unit-based bereavement care practices are delivered in a way that supports current understanding of what promotes 'normal' patterns of grieving. Such practices are generally aligned to noted best practice (National Health Service 2011) and include: offering the family opportunity to view the deceased; use of bereavement packs for family members; sending out sympathy cards to bereaved family members; and bereavement follow-up.

Whilst most of these practices are well established, the intensive care bereavement follow-up service is less well recognised in the literature. In follow-up, family members are contacted after the death in intensive care and either a supportive phone call or a visit back to the intensive care is offered (Lebus *et al.* 2014). At this time, family members can speak with a nurse, or other members of the clinical team. Case reports have been published that describe the establishment of such services (Barber 2008) with families reporting benefits of this service (Fridh 2014).

With a third of people who have complicated grief needing support from mental health outpatient and/or mental health services (Piper *et al.* 2001), bereavement care is an area of importance across health care settings; and this includes intensive care. However, with few studies detailing the provision of bereavement care across ICUs (Valks *et al.* 2005, McAdam and Erikson 2016), little is known about what bereavement care is routinely offered by intensive care, how this care is offered, and what challenges exist. The aim of this content analysis was to qualitatively describe the type of bereavement care provided in ICUs across Australia and New Zealand, and the challenges experienced.

Methods

Study design

This study was a qualitative content analysis of free text responses to three free text questions in a survey on bereavement follow-up services across New Zealand and Australia. This web-based cross sectional descriptive survey was designed to identify the types of bereavement care practices offered, and the characteristics of bereavement follow-up services established in the public and private sector and across all adult, paediatric and neonatal intensive care specialities. The quantitative methods and results are reported elsewhere (Mitchell *et al.* in press).

Sample and Setting

ICU nursing managers (or their delegate) of all adult, paediatric, and neonatal ICUs in Australia and New Zealand were eligible for inclusion. A list of suitable units was developed from details supplied by the Australian and New Zealand Intensive Care Society, manual

internet searches for publically available ICU contact lists and established professional networks and contacts known to the researchers. Resultant from these sources, ICU nurse managers in Australia (n=188) and ICUs in New Zealand (n=41) were identified. This provided a total sample of 229 ICUs.

Survey Development

Results from a narrative literature review were integrated with a previously used survey instrument (Valks *et al.* 2005) and used to develop the final survey tool. The survey collected data around four domains: unit demographics, model of bereavement services; workforce model; service evaluation. Additional data were collected on bereavement care practices through use of three open questions that gave an option of giving additional free text information. For example, when asking about 'what elements of bereavement care are routinely offered?' pre-set options were listed including viewing of the deceased, distribution of information to family members etc. and then an option of 'other' with space given for details. There were also two open-ended free-text questions placed at the end of the survey, following the closed questions that stated: 'Do you have any further comments about bereavement care of services in ICU' and "Please give details of any other elements of bereavement follow-up care not explored in this survey'.

The survey tool (paper and on-line version) was pilot tested with twelve intensive care nurse volunteers and six experienced researchers from across one hospital and one academic site in New Zealand and Australia to assess content validity and face validity (Grey 2014).

Recruitment

Invitations to the survey were sent to the contact work emails of the ICU nurse manager in each identified unit. The email contained information about the study and a link to the 34-item ICU Bereavement Services survey, powered by SurveyMonkey®. A returned survey from respondents indicated consent. Two reminders were sent to all respondents.

Data analysis

Qualitative data analysis was undertaken on responses to the free text survey questions. The analytical approach adopted was qualitative inductive content analysis and was selected in order to report on common issues raised in the data, rather than enabling a more detailed and nuanced account of data to be developed (Vaismoradi *et al* 2013). The analytic model used the processes of open coding, creating categories and abstraction (Elo & Kyngäs 2008). All open text responses were initially exported into a Word document. The responses were then read and re-read by three researchers (MC, SJ, KW) both as the Word version and in the context of the original respondent's replies. After this data immersion, the qualitative data underwent independent content analysis by MC and KW where data were grouped around central, recurrent ideas (Elo & Kyngäs 2008). The preliminary coding schema was discussed with a second researcher (SJ) and revised before all data within each code was re-examined. Codes were then sorted into categories based on the relationships and linking across the different codes.

Simple counts were also used to illustrate the proportion of comments that addressed specific categories (Elo & Kyngäs, 2008) with acknowledgement that more frequently raised issues were perceived by respondents as important aspects of practice. Direct quotes have been used to illustrate important findings within the data.

Ethics

Ethical approval for this study was given by two Human Ethics Committees. One of these was located in a New Zealand University; the other was in an Australian University.

Results

Respondent demographics

From the original 153 survey responses received from across New Zealand and Australia, 68 respondents made replies to the free text questions. As the majority of the sample was based in Australia, it is not surprising that the majority of respondents were from Australia (n=54, 79.4%) with 75% of respondents from the public sector (Table 1). Those who returned free text responses were mainly Nurse Unit Managers/Charge Nurses (n=39, 57.4%). Responses came from a variety of other post holders including Clinical Nurse Specialists (n=8, 11.8%), Nurse Educators (n=4, 5.9%) and social workers (n=4, 5.9%). Of the total sample, 50 (73.5%) respondents held postgraduate qualifications. Forty-six (67.6%) of respondents had in excess of 21 years' experience and 36 (52.9%) respondents had in excess of 21 years' experience in ICU.

INSERT TABLE 1

From the 68 respondents, there were 124 free text comments. From the content analysis, 187 individual codes were identified within the three categories: bereavement care practices (n= 145, 77.5%), educational provision to support staff in bereavement care (n= 15, 8%) and organisational challenges in delivering bereavement care (n= 27, 14.4%). These categories are now explored in more depth.

Bereavement care practices

Whilst acknowledging that there were some differences in the data (for example, greater involvement of social workers in psychological support of the bereaved family in some units), what was most noticeable was the similarity of the bereavement care practices offered across the sample. There was a clear reported process at end of life that emphasised care and attention to detail, respect for the dying, and that the body was seen by the family without invasive lines and machinery:

“When a patient dies we allow relatives as much time, we then encourage them to go to the waiting room for refreshments if they desire, whilst we wash and clean the patient and prepare the room. We remove everything that looks clinical from the room. We wash the patient and if we have their personal clothes, we will put them on. We have a lovely bedding set which we put on the bed and a nice pillow case. We try very hard to find fresh flowers to put in the room also. The families can come in and with all the tubes etc. removed the patient looks more like their loved on. Lighting is dimmed we hope that the last memories of their loved one are a little more pleasant than the previous picture of ET [endotracheal tube] lines and beeping machines.”

The noisy environment of ICU was sometimes seen as a challenge to the provision of respectful end of life care with respondents indicating that use of a side room was preferably, with other strategies considered. One respondent wrote that the use of “*some sort of flag to others, for example, a lily to pin to [the] patient’s curtain as a reminder*” is a strategy that may afford thoughtfulness, respect and privacy for the bereaved family.

Leading up to, and after the death of a patient, reference was made to many acts of memorialisation including the development of 'memory boxes' that included hand and footprints, locks of hair, and photos. These acts of memory making were especially made reference to when a child died. Support given to grieving and bereaved parents also included: bathing and sleeping with the child with specific facilities being available for this (quiet suite). On-going support for bereaved families extended over varying periods of time, from several days after the death, and extending to years; this is evidenced in exemplar comments in Box 1. Even where a practice appeared to be standard across some units, for example, the sending out of a card to bereaved families, different approaches were taken. In some units, the card was open for all nursing staff to sign, and in some, the card was sent out by the bereavement co-coordinator in the intensive care. In some units, bereavement cards were also sent to patients' families well known to the ICU staff and who had died on the wards.

It was clear that many different teams played an important part in care of the dying and bereaved families in intensive care. There was evidence of palliative care, pastoral care, and social work teams acting as bereavement coordinators across the sample. This did raise some concern: *"Some can push this responsibility [bereavement care] on to the social worker, but nursing staff are at the forefront and what we do has an immense impact on family who are experiencing their loss"*. Interestingly in one unit where bereavement care was social worker led, the survey reply led to this realisation: *"it has alerted me to the fact that afterhours I'm not sure all nurses would have the information to hand if required regarding bereavement information."*

Other services were detailed as providing bereavement care including specific support services, for example, charities supporting parents following the death of a child and organ donor care services. Community support services, counselling services and General Practitioner services were also utilised, with some units providing specific written information

about services locally provided. The provision of local support detail, together with attendance at bereavement follow-up services, was noted to be more of a problem for tertiary centres where the bereaved family's home base was often in a different area of the country.

Given that this study was undertaken in an Australasian setting, we were interested to see reference to meeting cultural needs. Specific challenges were raised when supporting larger indigenous families/whānau: *"How best to manage the volume of family arriving for end of life processes balanced against the needs of other families and the clinical requirements of the unit."* Whilst not strongly present in the data, there was also reference made to use of Aboriginal Liaison Officers (Australia) and Whānau Ora services (New Zealand).

INSERT BOX 1

Support for staff at this time was also raised. Several respondents expressed concern about lack of use or uptake of de-briefing: *"debriefing not always effective i.e. debriefing misses the target staff or done too late"*, with some centres offering alternative support services, for example, employee assistance programmes. Many respondents gave details about special interest groups who undertook quality improvement and practice development work in end of life care and bereavement.

Some interesting and specific challenges in bereavement care were also highlighted. One comment raised the issue of bereavement care practices when families were dissatisfied: *"when families have been unhappy with care, do you send a card?"* A further challenge raised in managing death and dying for smaller community units, was where people knew each other well and, in indigenous populations in Australia, there may be *"two cousins dying in nearby beds"*.

Educational provision to support staff in bereavement care

There were similar approaches detailed across all respondents regarding educational provision. It was an area clearly seen as important: *“In this environment where staff are so extensively trained to care for patients/family when they are alive, they should also have excellent skills in caring for when they are dying and dead (and [their] families).”* Educational provision was identified as being locally provided through in-service programmes for all nursing staff and, in some units, social workers and medical staff (Box 2). Staff with a specialist interest in bereavement care, for example, bereavement coordinators, were supported by attendance on formal bereavement courses for bereavement coordinators. In addition, several bereavement resources were used to develop staff awareness in this area, for example, charitable trust publications (New Zealand Skylight). Interestingly, whilst reference was made to post-registration education provision, less positive comments were raised about pre-registration education in this area (see Box 2).

INSERT BOX 2

Organisational challenges in delivering bereavement care

For respondents, the importance of bereavement care was clear with specific services areas seen to add patient, family and organisational benefit: *“Bereavement follow-up I can recommend it to those who don’t do it. I think this is one of the best quality assurances we do... it means so much to those on the receiving end – it’s great.”*; *“an important area perceived to reduce the amount of complaints and defuse misunderstandings.”* However, especially with regards to development of bereavement follow-up services, organisational challenges were raised that focussed on lack of funding: *“What is needed is designated time and money for bereavement services”; ‘A service that is required however currently not funded (follow-up).”*

There were many examples of respondents expressing support for bereavement care, of wanting to improve this area, but being constrained by funding (Box 3). There were some

key suggestions given on how to raise the profile of bereavement care including engaging Executive sponsorship, developing be-spoke bereavement portfolio for senior team members: perhaps most interesting for us was the high numbers of respondents expressing interest in the outcomes of survey, and of hearing about bereavement practices in other units.

INSERT BOX 3

Discussion

As described in the findings, there were bereavement practises described as standard across many of the units, including the attendance on the dying patient, the removal of technology to make the dying person look as 'normal' as possible, the washing and preparation of the body, and the adaptation of the ICU environment with reduced lighting, and clean bedding. Seen in this way, such activities could be perceived as ICU death-related rituals used to help bereaved family members, and we would also suggest, to help staff acknowledge the transition of the patient from being alive to being deceased. In focussing on holistic care and communication at this time, these practices broadly align with what we currently understand to be best practice at end of life (National Institute for Healthcare Excellence 2011) and support for those who are grieving (University of Nottingham 2010).

There were many examples of how staff engaged with memorialisations during bereavement care, through use of photographs, handprints and locks of hair that were used to produce lasting memories of the deceased and also the use of memorial services. The creation of such meaning-making legacies has been explored in the literature (Rutenberg 2008, Platt 2004) and are noted ways to address grief and loss. In this study, the examples cited were mainly located within the paediatric and neonatal field, and this is similarly reflected in the

literature (Harvey *et al.* 2008). It is recognised that the loss of a child can lead to different experiences and needs compared to the loss of an adult. As an example, parents of a dying child often prefer to participate in the care of their child (Hyson *et al.* 2003). The circumstances and impact of a child's death can also be different to the death of an adult, resulting in bereaved parents having increased risk of complicated grief (Simon 2013). Whilst there are differences in bereavement experiences across the age span, it remains worth considering whether any bereavement practises undertaken with children such as memorialisations, could be more widely utilised in the adult intensive care setting.

Findings indicate broad agreement on bereavement practices prior to, at the point of death, and after death. The approaches described across the sample takes a 'one size fits all' approach, although use of bereavement follow-up was modified dependent on staffing and/or time availability. Grief theory indicates that the acute period of grief gradually leads to an acceptance for the majority of people. Even though intensive care families are more likely to develop complicated grief (Anderson, *op. cit.*), given limited resources, it is reasonable to consider whether a more 'individually tailored' bereavement care approach needs to be considered.

Education and development of bereavement and communication skills was seen as important by respondents. With communication known to improve bereaved family member's satisfaction with care (Lautrette *et al.*, 2007) it is clearly important that staff are supported to become effective communicators literally, in matters of life and death. Education can also help address issues of under-confidence and under-developed knowledge about end of life care, as recently reported (Gaffney 2015). Given that all staff engaged in direct care need to be prepared for delivering bereavement care, it is understandable that a 'train-the-trainer' approach was reported by respondents in the free text data. This is appropriate, as this

approach is known to be resource efficient, effective in improving health care knowledge and skills and have positive impact on outcomes (Pearce *et al.* 2012).

A key issue in the data was the on-going organisational challenge in providing end-of-life and bereavement care. With bereavement care perceived to be an important aspect of care provision, the use of dedicated clinical champions and the need for greater infrastructure/resource was evident in the responses. Whilst such approaches are consistent with latest policy guidance (National Health Service England 2015, Queensland Health 2015), respondents still highlighted the ongoing challenges experienced, and the solutions developed, to drive this important area of practice forward.

Limitations

This paper provides detail as to bereavement practices in Australasian ICUs. Free text respondents are broadly representative of respondents to the survey overall. However, due to limitations of sample identification methods and use of self-report survey, they may not be reflect the wider intensive care population. No assurance can be given with regards to generalizability outside of these areas.

Survey research, often utilises open or free text questions for respondents to elaborate on previous answers or to give additional information. This is a strategy that can enhance recruitment and ensure all relevant issues can be raised (McColl *et al.* 2001). However analysis of this data can be seen as a limitation. We acknowledge the potential response bias in respondents who are motivated to make open text replies. However, we strongly agree with Boynton and Greenhalgh (2004) who argue that it is unethical to ask open questions and not be prepared to analyse responses. We therefore undertook further

analysis on the expansion and extension type of open questions (O'Cathain & Thomas 2004) used and have made clear our analytic strategy in undertaking this.

Implications for future research

There is no clear evidence-based process of care for bereavement families in ICU. Further study is required to identify the impact on families of each component of bereavement care, as is currently being explored by Kentish-Barnes et al. (2016). Furthermore, in developing a structured and systematic pathway for families who are bereaved in intensive care, greater evidence needs to be developed to inform understanding about whether all families benefit from all bereavement care practices, or whether a more nuanced approach needs to occur.

Conclusion and relevance to clinical practice

Delivery of responsive clinical practice requires us to be cognisant of problems experienced by patient and families, and have awareness as to how these can be addressed. In ICU, meeting the needs of bereaved families is an important component of bedside care.

Undertaking this Australasian survey and reporting on bereavement care practices at this level, has shared collective learning, prompted reflection on current practices and on the challenges experienced.

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Conflict of Interests

The authors declare no conflicts of interests

References

- Anderson WG, Arnold RM, Angus DC, & Bryce CL (2008) Posttraumatic Stress and Complicated Grief in Family Members of Patients in the Intensive Care Unit. *Journal of General Internal Medicine* **23** 11, 1871–6. DOI: 10.1007/s11606-008-0770-2.
- Barber K (2008) Bereavement follow-up support service for families that had a loved in the Intensive Care Service. *CACCN* **19** 2, 35.
- Bonanno GA, & Kaltman S (2001) The varieties of grief experience. *Clin Psychol Rev.* **21** 5, 705-34.
- Boynton PM & Greenhalgh T (2004) Selecting, designing, and developing your questionnaire. *BMJ* **328** 1312-5.
- Buckley T, Mihailidou AS, Bartrop R, McKinley S, Ward C, Morel-Kopp MC, et al. (2011) Haemodynamic changes during early bereavement: potential contribution to increased cardiovascular risk. *Heart Lung Circ.* **20** 2, 91–98 <http://dx.doi.org/10.1016/j.hlc.2010.10.073>.
- Curtis JR (2014) Palliative care in critical illness: Challenges for research and practice. *Palliative Medicine* **29** 4, 291-292 doi: 10.1177/0269216315573901.
- Elo S & Kyngäs SH (2008) The qualitative content analysis process. *Journal of Advanced Nursing* **62** 1, 107–115 doi: 10.1111/j.1365-2648.2007.04569.x.
- Fridh I (2014) Caring for the dying patient in the ICU -The past the present and the future, *Intensive and Critical Care Nursing* **30** 6, 306 - 311.
- Gaffney MK (2015) Critical Care Nurses' Perceptions of Their Knowledge and Self-Efficacy About Providing End of- Life Care. PhD Dissertation. Walden University Scholar Works. Walden University, USA.
- Genevro JL, Marshall T, Miller T, & Centre for Advancement of Health (2004) Report on Bereavement and Grief Research. *Death Studies* **28** 6, 491-575.
- Gray DE (2014) *Doing research in the real world*. 3rd edition. Sage, London.

Harvey S, Snowdon S, & Elbourne D (2008) Effectiveness of bereavement interventions in neonatal intensive care: A review of the evidence. *Seminars in Fetal and Neonatal Medicine* **13** 5, 341–356.

Hynson JL, Gillis J, Collins JJ, Irving H, Trethewie SJ (2003) The dying child: how is care different? *Medical Journal of Australia* 179: S20–S22

Kentish-Barnes N, Chevret S, & Azoulay E (2016) Impact of the condolence letter on the experience of bereaved families after a death in intensive care: study protocol for a randomised controlled trial. *Trials* 17:102. DOI 10.1186/s13063-016-1212-9.

Lautrette A, Darmon M, Megarbane B, Joly LM, Chevret S, et al. (2007). A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU. *New England Journal of Medicine* **356** 469-478 DOI: 10.1056/NEJMoa063446

Lebus C, Parker RA, Morrison K, Fraser D, & Fuld J. (2014) Families' concern after bereavement in Hospital: what we can learn? *Journal Palliative Care Medicine* **17** 6, 712-17.

McAdam JL, & Erikson A. (2016) Bereavement services offered in adult Intensive Care Units in the United States. *American Journal of Critical Care* **25** 2, 110-117.

McColl E, Jacoby A., Thomas L, Soutter J, Bamford C, et al. (2001) Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients. *Health Technol Assess* **5** 31, 1-256.

Mitchell M, Coombs M, & Wetzig, K. (2016) The provision of intensive care bereavement follow-up services in Australia and New Zealand: Results of a cross sectional descriptive survey. *Australia Critical Care*. In press.

National Health Service (2011) *National End of Life Programme. 2011. Guidance for staff responsible for care after death.* www.endoflifecareforadults.nhs.uk

National Health Service (2015) Transforming end of life NHS England (Revised December 2015) The route to success 'how to' guide care in acute hospitals. National Health Service, London.

National Institute for Healthcare Excellence (2011) *End of life care for adults. NICE quality standard [QS13].* National Institute for Healthcare Excellence, London.

O'Cathain A, & Thomas KJ (2004) "Any other comments?" Open questions on questionnaires – a bane or a bonus to research? *BMC Medical Research Methodology* **4** 25
doi:10.1186/1471-2288-4-25

Pearce J, Mann MK, Jones C, van Buschbach S, Olf M, Bisson JI. The most effective way of delivering a train-the-trainers program: a systematic review. *J Contin Educ Health Prof.* 2012;32(3):215–26

Piper WE, Hassan FA, Ogrodniczuk JS, & Weideman R (2001) Prevalence of loss and complicated grief among psychiatric outpatients. *Psychiatric Services* **52** 8, 1069-1074.

Platt J (2004) The planning, organising and delivery of a memorial service in critical care. *Nursing in Critical Care* **9** 5, 222-228.

Prigerson HG, & Jacobs SC (2001) Traumatic Grief as a Distinct Disorder: A Rationale, Consensus Criteria and a Preliminary Empirical Test. In: Stroebe, M.S., Hansson, R.O., Stroebe W, & Schut H. (Eds.), *Handbook of bereavement research: Consequences, coping, and care.* (pp. 588-613). American Psychological Association: Washington, DC.

Queensland Health (2015) Statewide strategy for end-of-life care 2015. State of Queensland (Queensland Health), Australia.

Rutenberg M (2008). Casting the spirit: a handmade legacy. *Art Therapy: Journal of the American Art Therapy Association* **25** 3, 108-114.

Shear MK, Wang Y, Skritskaya N, Duan N, Mauro C, et al. (2014) Treatment of complicated grief in elderly persons: a randomized clinical trial. *JAMA Psychiatry* **1** 11, 1287–1295.

Siegel MD, Hayes E, Vanderwerker LC, Loseth DB, & Prigerson HG (2008). Psychiatric illness in the next-of-kin of patients who die in the intensive care unit. *Critical Care Medicine* **36** 1722–1728.

Simon NM (2013) Treating complicated grief. *J Am Med Assoc* **310** 4, 416–423
<http://dx.doi.org/10.1001/jama.2013.8614.54>

Trankle SA (2014) Is a good death possible in Australian critical and acute settings?: Physician experiences with end-of-life care. *BMC Palliat Care* **13**. 41.2.

University of Nottingham (2010) *Bereavement care services: a synthesis of the literature. Final Report of review commissioned by DH to support implementation of the End of Life Care Strategy*. Department of Health: London.

Valks K, Mitchell M, Inglis-Simons C, & Limpus A (2005) Dealing with death: an audit of family bereavement programs in Australian intensive care units. *Australian Critical Care* **18** 146-151.

Vaismoradi M, Turunen H, Bondas T. (2013) Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing and Health Sciences* **15** 398–405

Villar SR, Casado MS, Prigerson HG, García SM, Villar MR, et al. (2012) Prolonged grief disorder in the next of kin of adult patients who die during or after admission to intensive care. *Chest J* **141** 6, 1635 – 1636.

Table 1: Open text questions - demographics of respondents (n= 68)

Country	Australia	54 (79.4%)
	New Zealand	14 (20.6%)
Type of hospital	Public	51 (75%)
	Private	16 (23.5%)
	Combined Public & Private	1 (1.5%)
Level of unit	Level 1	10 (14.7%)
	Level 2	28 (41.2%)
	Level 3	30 (44.1%)
Type of patient is admitted	Adults only	37 (54.4%)
	Paediatric only	3 (4.4%)
	Mixed Adults and Paediatrics	23 (33.8%)
	Neonates	4 (5.9%)
	Missing data	1 (1.5%)
Years qualified	0-4 years	0 (0.0%)
	5-9 years	4 (5.9%)
	10-15 years	5 (7.4%)
	16-20 years	9 (13.2%)
	In excess of 21 years	46 (67.6%)
	Missing data	4 (5.9%)
Years of experience in Intensive Care	0-4 years	0 (0.0%)
	5-9 years	9 (13.2%)
	10-15 years	10 (14.7%)
	16-20 year	13 (19.1%)
	Greater than 21 years	36 (52.9%)

PROCESSES OF BEREAVEMENT CARE

'The bereavement card is sent by nursing staff on behalf of the unit. Within two weeks of death. A one year anniversary card is also sent. We also send bereavements cards to PCIU [paediatric intensive care unit] patients (frequent flyers or long term patients) who die on the wards or at home.'

'Handwritten sympathy card sent by RN [Registered Nurse] who has designated Bereavement team time within 7 days'.

'4-6 weeks after a death a card is sent by the bereavement coordinator. It is open for signing by all staff and 1 year after death, sent by the bereavement coordinator and open for signing by all staff.'

'All family meetings are documented and a copy given to families both prior to the pending death and if family return for a follow-up meeting after the death. This appears from feedback to be extremely useful as families' state they receive so much information which is difficult to retain.'

'It has long been the practice of the intensivists that work here that they will give their contact details to the bereaved people and meet with them multiple times to assist the family understand cause of death.'

MEMORIALISATION

'We routinely prepare memory packs – hand and foot prints, hair locks and a poem for parents. Arrange photography services for appropriate patients, provide information of other memory making opportunities, for example, finger print jewellery, provide books for siblings.'

'Every year we invite staff and relatives to attend a service in memory of the deceased that particular year.'

OTHER TEAMS INVOLVED

'We have a strict bereavement policy... It is social work in this hospital and many other hospitals who is responsible for the bereavement follow-up; We have regular contact in the

following days, at 6 weeks make contact again and offer a post mortem meeting with the medical team, then first birthday, first anniversary, and first Christmas as a minimum’.

‘Pastoral services team are involved with the family as soon as possible who provide ongoing support and information regarding community services. They also follow up with a card, sent to NOK [next of kin].’

Box 1: Example responses of bereavement care practices

'Further training in the area of bereavement for ICU nurses and staff would be appropriate. This is an element of undergraduate nursing that is not well covered. Also when looking to senior staff for advice in years gone by, I have found that nurses are good at explaining what to do 'clinically' but the emotional /counselling side of things is let down to 'doing what you feel is right' rather than having helpful direct prompts on what to do with/for the patient and family.'

'I am the senior social worker in ICU and run end of life courses with nurse educators for staff. Also run in-services on bereavement for staff.'

'As educator, I undertake education of PICU staff on end of life care and give feedback to nursing and medical staff.'

Box 2: Example responses of educational provision

EMBEDDING BEREAVEMENT CARE INTO THE CULTURE

'It can always be improved. Most staff who care for paed [paediatric] patients in our unit are very passionate about bereavement care.'

'There are many portfolios in force in the ICU. I think it would be good to incorporate some form of offered bereavement follow up into an existing or new portfolio under the guidance of CNCs.'

'We are exploring this area through an Executive Advisory Committee around end of life care. In particular reviewing how we support ward staff and family members when a patient required transfer from ICU to the ward with limitations to treatment.'

RESOURCE CONSTRAINTS

'The bereavement card used to be send by one of our permanent night staff within the first 2 weeks depending on how busy the unit was. Since she left last year though, nobody has taken on the responsibility.'

'We have had a bereavement service in the ICU [Intensive Care Unit] for a number of years. However, the service declined and our follow-up calls to families lessened. It was decided as a team to put our service on hold. It is now under review again.'

'We are hoping to establish a bereavement service within the next 12 months.'

'We do offer it, with counselling support if needed – but we are not directly funded for this.'

'No funding or time available – service could be a lot better with support from the organisation.'

'Cost. This is done within unit resources and time. If rostered time when another nurse covers while RN makes calls.'

ORGANISATIONAL OPPORTUNITIES

'Think a valuable and important service to whānau/significant others and staff, especially

when most of our deaths occur in the first 5 days'

'Still underutilised in our unit. A work in progress.'

Box 3: Example responses of organisational challenges