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Research paper

# The provision of family-centred intensive care bereavement support in Australia and New Zealand: Results of a cross sectional explorative descriptive survey

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ABSTRACT

*Background:* Caring for the bereaved is an intrinsic part of intensive care practice with family bereavement support an important aspect of the nursing role at end of life. However, reporting on provision of intensive care family bereavement support at a national level has not been well reported since an Australian paper published ten years ago.
*Objectives:* The objective was to investigate provision of family bereavement support in intensive care units (ICU) across New Zealand (NZ) and Australia.
*Method:* A cross-sectional exploratory descriptive web-based survey was used. All ICUs [public/private, neonatal/pediatrics/adults] were included. The survey was distributed to one nursing leader from each identified ICU ($n = 229$; 188 in Australia, 41 in NZ). Internal validity of the survey was established through piloting. Descriptive statistics were used to analyse the data. Ethical approval was received by the ethics committees of two universities.
*Results:* One-hundred and fifty-three (67%) responses were received from across New Zealand and Australia with 69.3% of respondents from the public sector. Whilst respondents reported common bereavement practices to include debriefing for staff after a traumatic death (87.9%), there was greater variation in sending a sympathy card to families (NZ 54.2%, Australia 20.8%). Fifty percent of responding New Zealand units had a bereavement follow-up service compared to 28.3% of Australian unit respondents. Of those with follow-up services, 92.3% of New Zealand units undertook follow-up calls to families compared to 76.5% of Australian units. Bereavement follow-up services were mainly managed by social workers in Australia and nursing staff in New Zealand.
*Conclusions:* This is the first Australia and New Zealand-wide survey on ICU bereavement support services. Whilst key components of family bereavement support remain consistent over the past decade, there were fewer bereavement follow-up services in responding Australian ICUs in 2015. As a quality improvement initiative, support for this area of family care remains important with rigorous evaluation essential.


## 1. Introduction

Death is a normal part of life and the majority of bereaved persons experience uncomplicated grief with limited signs of impairment six months after their loss.[1] It is well established that death and supporting the bereaved is an intrinsic part of intensive care nursing practice[2] which is especially important given that complex bereavement has been well documented in bereaved intensive care family members.[3,4] Indeed, the nature of some ICU deaths and lack of family understanding about the death[5] may place bereaved ICU families at higher risk of experiencing complex grief. In one North American study, 34% of intensive care family members met criteria for at least one mental health illness and 5% had com-

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plicated grief disorder within one year of their relative's death in intensive care.[6] This evidence of increased long term bereavement impact on family health is associated with an increased uptake of health services and increased risk of death in the bereaved.[7,8]

Whilst social networks are effective sources of support for most people during their bereavement, those at risk of developing complex grief reactions may benefit from formal bereavement support services.[9] Indeed, this is recognised in several best practice guidelines that inform hospital-wide bereavement programs.[10,11] Over the past 30 years, intensive care units (ICU) have worked to support grieving families both at the time of death and afterwards, gradually developing an evidence base to inform this area of practice. Unit-based quality initiatives have been introduced to support families in the time leading up to end of life care[12] and also support offered to bereaved families through ICU bereavement follow-up services, offered by dedicated ICU staff, have emerged to support families after death in ICU.

Bereavement care in ICU has developed over the years based on individual unit knowledge of what works in practice to support families, and informed more recently by national guidelines for staff providing end of life care, for example, the National Health Service End of Life Care Programme 2014.[13] Bereavement care in ICU can be broadly classified into bereavement support for families that occurs prior to/at time of death on the ICU, and bereavement support that occurs after a death, or at follow-up with a bereaved family. However, work in this area to date demonstrates different approaches in supporting families after death in the ICU setting.[14–16] The majority of studies in this area are mainly limited to single site case reporting, although there are two exceptions to this. One is an Australian survey, undertaken a decade ago on the provision of family bereavement care.[17] Responses from 99 adult Australian ICUs were received (84.6% response rate) with the majority of units ($n = 85$, 86%) indicating that components of bereavement care, such as viewing of the deceased and communication with family members sometime after the bereavement, were offered. Less than one third of units surveyed ($n = 26$) provided additional follow-up services in the form of telephone calls to bereaved families or sympathy cards. No formal evaluation of these services had, at the time, been undertaken.

A recently published United States study surveyed nurse leaders in 2013 using contact details from their professional critical care association's database.[18] Of the 237 respondents (response rate 24%), 37.6% ($n = 89$) offered bereavement follow-up services. These were reported to be informal in nature and provided by direct care nurses with inadequate resources cited as the greatest barrier to effective implementation.[18]

With such little empirical work in the area, this highlights lack of knowledge about the current scope and models of follow-up services for bereaved families in intensive care. The authors of the current study sought to add to the body of knowledge by examining family bereavement support across Australia and New Zealand. This exploratory work could thereby provide a platform for more robust evaluation and impact studies in this area within Australia and New Zealand. We describe the results from a cross-sectional survey undertaken in 2015 to map current provision of family bereavement support in ICUs across Australasia.

## 2. Methods

A cross sectional survey was undertaken to describe the provision of family bereavement support across Australia and New Zealand. The objectives of the study were to:

- Describe the nature of family bereavement support offered in ICUs.
- Quantify the number of ICUs offering bereavement follow-up.
- Identify the characteristics (e.g. referral processes) of the bereavement follow-up services and the resource (e.g. team members) required to operate these services.
- Describe impact evaluation data collected to date.

A web-based survey was developed and distributed to ICU nursing leaders in the public and private sector and across all adult, pediatric and neonatal ICU specialities. The survey was developed by the authors and internal validity established prior to survey deployment.

### 2.1. Sample

Senior nurses of all adult, pediatric, and neonatal ICUs in Australia and New Zealand were eligible for inclusion. A non-exhaustive list of ICUs was provided by the Australian and New Zealand Intensive Care Society and additional ICUs were sought through a manual internet search for publically available ICU contacts. Professional networks and contacts known to the researchers were also used to develop a comprehensive contact list. Telephone calls were made to many units to confirm contact details prior to survey distribution. One senior nurse leader per unit was contacted and invited to participate. This method of phone contact coupled with written contact has previously been successfully utilised by the researchers with a high response rate.[17] One hundred and eighty-eight Australian ICUs and 41 ICUs in New Zealand were identified as potential participant sites and eligible to participate; this provided a total sample of 229 senior nurses.

### 2.2. Survey development

Survey items were drawn from results of a narrative literature review, integrated with a survey instrument previously used by one of the research team in an Australian-wide audit of bereavement services.[17] The instrument items collected data around four domains: unit demographics, model of bereavement services; workforce model; service evaluation (Appendix A, Supplementary data). In the survey, additional information was collected on routine bereavement practices in the unit.

All aspects and components of the survey were pilot tested with ten nurse volunteers (five from the local ICUs of the first and second author) and with four experienced researchers (two from each of the first and second author's respective academic bases). This process allowed experts to evaluate whether the survey assessed the most important elements of ICU bereavement follow-up services thus ensuring content validity, while also assessing face validity[19] of the individual items. Key areas refined following this included clarification of level of ICU and some minor question re-ordering for ease of understanding. The survey tool, together with the practicalities and technology of survey completion online was then further pilot tested with clinicians and academics ($n = 4$) across Australia and New Zealand.

### 2.3. Recruitment

Work emails of the nursing leaders were used to distribute invitations to the survey. The contact email contained brief information about the study (including details re: confidentiality) and a link to the 34-item ICU Bereavement Services survey, powered by SurveyMonkey®. The initial information stated that a returned survey indicated consent. Two reminders were sent to all participants 10 days and 20 days after the initial email had been distributed. Surveys were anonymous; however participants were invited to provide contact details if they wished to receive a summary of results or be involved in future research initiatives.

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### 2.4. Data analysis

Returned survey data were exported into Microsoft Excel and transferred into Statistical Package for Social Sciences (Version 19) for analysis. As the purpose of this study was to describe the population and service specification, the key analysis emphasis was descriptive statistics. There were a number of open-ended items where participants could write responses in their own words. Those reported in this paper were comprehensively summarised to provide a qualitative description of respondents' written comments.[20]

### 2.5. Ethics and research governance

Ethical approval for this study was given by Victoria University, Wellington, New Zealand and Griffith University, Australia. All data were securely stored on password protected computers. Analysis was undertaken by the research team using de-identified data.

## 3. Results

One hundred and fifty-three (67%) responses were received from 153 units across New Zealand and Australia with 69.3% of respondents from the public sector (Table 1). Australian responses were mainly from adult only units (63.3%) with mixed adult and pediatric units more representative in the New Zealand responses (52%).

Survey respondents were mainly Nurse Unit Managers (Australia $n = 79$, 64.2%; New Zealand $n = 19$, 79.2%). Responses from Australia came from a variety of other positions including Clinical Nurse Consultants ($n = 7$), Nurse Educators ($n = 7$) and Social Workers ($n = 11$). Of the total sample, 81 (56.3%) respondents held post graduate qualifications. This sample was experienced health care practitioners with 104 (71.7%) respondents having in excess of 21 years in their profession. Fifty-six (44.4%) Australian respondents and 18 (72%) New Zealand respondents had in excess of 21 years' experience in ICU.

The survey explored what routine bereavement care was undertaken in the ICUs (Table 2). Most ICUs ($n = 144$, 96.6%) routinely offered viewing of the deceased in the ICU. Similarly, debriefing for staff after traumatic deaths was identified as a regular practice. The practice of giving information to families about community bereavement services and the practice of sending a sympathy card to families were less frequently reported. The latter was noticeably different across Australia and New Zealand (20.8% Australia; 54.2% New Zealand). Eleven survey respondents (7.2%) indicated that their unit offered all of the following: [i] viewing of the deceased in ICU; [ii] viewing of the deceased in the hospital mortuary; [iii] debriefing of staff after unexpected or difficult traumatic patient death; [iv] distribution of information to family members on hospital bereavement services; [v] distribution of information to family members on community bereavement services; [vi] sending of a sympathy card to bereaved families. Forty-one (26.8%) offered at least five of these components.

The proportion of respondents from the ICUs in the two countries with bereavement follow-up services varied with less than a third of the responding Australian unit leaders indicating they had family support follow-up services ($n = 34$; 28.3%) with 50% of the New Zealand respondents ($n = 12$) indicating availability of this service (Table 2). A variety of health care professionals from across the health disciplines were involved in these follow-up bereavements services (Table 3). The services represented in this study were generally well established across Australia and New Zealand ($n = 21$, 52.5% established for >10 years). Whilst most units offered follow-up telephone calls to bereaved families with opportunity to re-visit the ICU, there were differences in practices noted across the two countries about meeting with medical staff and use of formal counselling services (Table 3).

Different staffing and management models were in place to deliver bereavement follow-up services. Thirteen of 31 Australian units had bereavement follow-up services managed by Allied Health staff (social workers) where in the responding New Zealand units, bereavement follow-up services were mainly managed by nursing staff ($n = 7$ of 12 units). Whilst ICU leader respondents from both countries indicated that staff providing these services were permanent within the team ($n = 21$, 72.4%) and that most staff had received additional training to support them in these roles ($n = 31$, 70.5%), this was more evident in the New Zealand units represented in the survey (Australian respondents $n = 20$, 62.5%, NZ respondents $n = 11$, 91.7%).

Based on open text responses, the majority of follow-up calls in responding Australia units were made to families by social workers ($n = 13$) with only three services' follow-up calls made by nurses. Most of these calls were made within one week of the bereavement ($n = 12$) with the aim of assessing how families were coping and giving them verbal support. In contrast, in the New Zealand units the majority of calls were made by 'bereavement' nurses ($n = 5$) with senior nurses making call in two other units. The majority of New Zealand ICU staff made these calls within a 4–6 week timeframe of the bereavement ($n = 8$) similarly with the aim of assessing family coping and offering support.

Where return visits to the ICU were offered to bereaved family members, these were mainly offered by social workers in the Australian units ($n = 5$) and occurred based on individual family need ($n = 7$) or from within one to two days of the death of the family member ($n = 1$) to six weeks post bereavement ($n = 2$) or annually as part of an ICU memorial service ($n = 1$). In responding New Zealand units, follow-up visits were often facilitated by the nursing and medical staff in the ICU around six weeks after bereavement. One ICU had developed a special place, that is, a quilt where families could place a shell in remembrance of their baby, whilst others were cognisant that some families could be distressed by re-visiting the ICU and therefore meetings were held in what they termed "Patient Advocacy" rooms.

In the Australian units, formal counselling of bereaved family members following a death in ICU was often undertaken by the social worker ($n = 15$) but some units also included community based services ($n = 4$) and pastoral care officers ($n = 2$). Similarly in the New Zealand ICUs, counselling was often undertaken in the local community by the General Practitioner, spiritual and cultural support and local counselling services.

Seventeen of the 44 units had undertaken some form of evaluation of their service, although this was reported as being mainly through verbal feedback from staff and relatives ($n = 9$). Although there was minimal formal evaluation work reported, free text comments identified practice improvements had been instituted as a result of feedback including: improving communication between ICU and community services, and better visitor facilities for grieving families.

## 4. Discussion

Caring for and supporting the bereaved is a fundamental part of intensive care practice.[2] With approximately 160,000 admissions to Australian and New Zealand ICUs in 2012–2013, with a reported six percent ICU mortality rate (ANZICS Core data 2012–2013), this equates to over 9500 bereaved families during this time period. Given current understanding that bereaved ICU family members can encounter complex bereavement after their loss[3,4] and understanding of the significant adverse physical and emotional outcomes experienced by the bereaved,[21] it is important that early assessment and supportive measures be in place. With lack

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**Table 1**
Demographic characteristics of ICUs.

| Characteristic | Options | Australia *N* = 128 (%) | New Zealand *N* = 25 (%) | Combined *N* = 153 (%) |
|---|---|---|---|---|
| Country | N/A | 128(83.7) | 25(16.3) | 153(100) |
| Hospital type | Public | 84(65.6) | 22(88.0) | 106(69.3) |
| | Private | 39(30.5) | 3(12.0) | 42(27.5) |
| | Combined | 5(3.9) | 0(0.0) | 5(3.3) |
| Unit level | Level I[a] | 18(14.1) | 7(28.0) | 25(16.3) |
| | Level II[b] | 52(40.6) | 8(32.0) | 60(39.2) |
| | Level III[c] | 58(45.3) | 10(40.0) | 68(44.4) |
| | | Australia *N* = 127 (%) | New Zealand *N* = 25 (%) | Combined *N* = 152 (%) |
| Type of unit | Adults only | 81(63.3) | 7(28.0) | 88(57.5) |
| | Pediatrics only | 6(4.7) | 2(8.0) | 8(5.2) |
| | Mixed | 30(23.4) | 13(52.0) | 43(28.1) |
| | Neonates | 10(7.8) | 3(12.0) | 13(8.5) |
| | | Australia *N* = 104 (%) | New Zealand *N* = 21 (%) | Combined *N* = 125 (%) |
| Speciality units identified in addition to type of unit | Cardiac | 43(41.3) | 9(42.9) | 52(41.6) |
| | Neurological | 34(32.7) | 7(33.3) | 41(32.8) |
| | Other | 27(26.0) | 5(23.8) | 32(25.6) |

[a] Level I = ICU capable of providing immediate resuscitation and short term cardio-respiratory support.
[b] Level II = ICU capable of providing a high standard of general intensive care, including complex multi-system life support, may refer patients for specialty support.
[c] Level III = ICU capable of providing comprehensive critical care including complex multi-system life support for an indefinite period.

**Table 2**
Bereavement care offered *N* = 149.

| Characteristic | Options | Australia *N* = 125 (%) | New Zealand *N* = 24 (%) | Combined *N* = 149 (%) |
|---|---|---|---|---|
| Elements of bereavement care offered | Viewing of deceased in ICU | 121(96.8) | 23(95.8) | 144(96.6) |
| | Viewing of deceased in morgue | 69(55.2) | 15(62.5) | 84(56.4) |
| | Debriefing of staff after difficult or traumatic death | 112(89.6) | 19(79.2) | 131(87.9) |
| | Distribution of information to family members on hospital bereavement services | 81(64.8) | 16(66.7) | 97(65.1) |
| | Distribution of information to family members on community bereavement services | 57(45.6) | 14(58.3) | 71(47.7) |
| | Sending a sympathy card | 26(20.8) | 13(54.2) | 39(26.2) |
| | | Australia *N* = 120 (%) | New Zealand *N* = 24 (%) | Combined *N* = 144 (%) |
| Does ICU offer a bereavement follow-up service | Yes | 34(28.3) | 12(50.0) | 46(31.9) |
| | No | 89(74.2) | 12(50.0) | 101(70.1) |

of clarity on best practice guidelines or bereavement support models to inform practice, this study builds knowledge by identifying the range of bereavement support care practices and bereavement follow-up services in ICUs across New Zealand and Australia. In replicating a bereavement services' study undertaken ten years ago, this study provides information about the progress in, and evaluation of, these services over the past decade.[17]

Elements of bereavement care feature in both Australia and New Zealand ICUs with the nurse leaders in the responding ICUs indicating that the majority of the bereavement care services were located within ICU [viewing the deceased; de-briefing of staff]. Interestingly, sending of sympathy cards and providing brochures occurs more frequently in ICUs in the United States[18] than reported by respondents to the current survey. However, referral to external bereavement care services in the community occurs rarely across our sample of Australia and New Zealand ICUs with similar poor utilisation of community support reported in the United States. Given that the practice of giving information to families about community bereavement services is recommended to support families in the grieving process and to assist early detection of symptoms of complicated grief and mitigate risk of mental health issues,[22–24] this is an area requiring development.

However, from the responses received from this survey, it would appear that very little has changed in respect to the provision of intensive care bereavement services in Australia. Ten years ago, 30% of ICUs responding to a survey indicated provision of bereavement follow-up,[17] whereas in 2015, 27% of respondents indicated provision in this area. Importantly, there was a lower response rate in the current study (67% versus 84.6% in 2005) which may have impacted upon the Australian results. Internationally, bereavement services in United States' ICUs are reported at a similar level (38%).[18] Results from this current study, indicate that responding New Zealand ICUs were better represented with this service (50%) than those in the responding Australian ICUs and the United States. Beyond these countries ICU bereavement follow-up services have not been reported in the literature.

Bereavement service evaluation across all reported studies[17,18] is inadequate to inform both current practice and practice change. Complex and multifaceted interventions such as the elements reported in this bereavement survey need to be evaluated from both an outcome[25,26] and process perspective to inform clinicians and policy-makers of the benefits (or otherwise) of the intervention.[27] This is currently not occurring.

### 4.1. Strengths and limitations

Although the response rate was less than optimal at 67% it is much higher than that reported elsewhere.[16] The inclusion of all levels and specialty ICUs in the current study provided a comprehensive documenting of bereavement services across the two

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**Table 3**
Bereavement service follow-up.

| Elements | | Australia $N = 32$ (%) | New Zealand $N = 11$ (%) | Combined $N = 43$ (%) |
|---|---|---|---|---|
| Follow-up conducted by: | Donate life staff | 13(40.6) | 4(36.4) | 17(39.5) |
| | Psychologist/counsellor | 4(12.5) | 2(18.2) | 6(14.0) |
| | Physiotherapist/OT | 0(0.0) | 0(0.0) | 0(0.0) |
| | Social worker | 24(75.0) | 5(45.5) | 29(67.4) |
| | Other | 15(46.9)[a] | 9(81.8)[b] | 24(55.8) |
| | | Australia $N = 34$(%) | New Zealand $N = 13$(%) | Combined $N = 47$(%) |
| Is a telephone follow-up call offered to families? | Yes | 26(76.5) | 12(92.3) | 38(80.9) |
| | No | 8(23.5) | 1(7.7) | 9(19.1) |
| | | Australia $N = 33$(%) | New Zealand $N = 12$(%) | Combined $N = 45$(%) |
| Is a visit to the ICU offered? | Yes | 15(45.5) | 9(75.0) | 24(53.3) |
| | No | 18(54.5) | 3(25.0) | 21(46.7) |
| | | Australia $N = 32$(%) | New Zealand $N = 13$(%) | Combined $N = 45$(%) |
| Is formal counselling offered? | Yes | 24(75.0) | 5(38.5) | 29(64.4) |
| | No | 8(25.0) | 8(61.5) | 16(35.6) |
| | | Australia $N = 33$(%) | New Zealand $N = 13$(%) | Combined $N = 46$(%) |
| Is a meeting with medical staff offered? | Yes— routinely | 13(39.4) | 8(61.5) | 21(45.7) |
| | Yes—on request | 16(48.5) | 5(38.5) | 21(45.7) |
| | No | 4(12.1) | 0(0.0) | 4(8.7) |
| | | Australia $N = 33$(%) | New Zealand $N = 13$(%) | Combined $N = 46$(%) |
| Other support | Yes | 15(45.5)[c] | 7(53.8)[c] | 22(47.8) |
| | No | 18(54.5) | 6(46.2) | 24(52.2) |
| | | Australia $N = 28$(%) | New Zealand $N = 12$(%) | Combined $N = 40$(%) |
| How many years has the service been established? | 1 | 1(3.6) | 1(8.3) | 2(5.0) |
| | 2 | 2(7.1) | 0(0.0) | 2(5.0) |
| | 3–4 | 0(0.0) | 0(0.0) | 0(0.0) |
| | 5–9 | 5(17.9) | 2(16.7) | 7(17.5) |
| | 10–19 | 7(25.0) | 6(50.0) | 13(32.5) |
| | 20–29 | 4(14.3) | 3(25.0) | 7(17.5) |
| | ≥30 | 1(3.6) | 0(0.0) | 1(2.5) |
| | Unknown | 8(28.6) | 0(0.0) | 8(20.0) |

[a] Includes: consultant $n = 7$, pastoral care $n = 5$.
[b] Includes: nurse $n = 3$, social worker $n = 2$, consultant $n = 1$.
[c] Use of support groups and referral to other services ($n = 8$) (respondents could choose which items they would respond to resulting in variable $N$ values).

countries. However, a limitation of this study includes the potential for responder bias where participants may have provided responses that they deemed more acceptable. In addition, a survey innately has limitations but provides a pragmatic data collection method which enabled us to meet the aims of the project.

### *4.2. Implications for future research*

Researchers are looking beyond the walls of the ICU when they examine the effect of a critical illness on patients and family[4,28,29] as the impact of critical illness (and death) is not contained within the ICU. In a case of bereavement within the ICU, the family has to adapt to a dramatically different personal circumstance; providing meaningful support to these families is imperative. Further research is required to help understand about relevant support for families with targeted interventions that provide community support options to the bereaved. Both process and outcome evaluation is important to adequately assess the worth and feasibility of interventions.

## 5. Conclusion

This is the first Australia and New Zealand wide survey on ICU family bereavement support services. Whilst the key components of bereavement support remain consistent over the past decade, there were fewer bereavement follow-up services in responding Australia ICUs in 2015. As a quality improvement initiative, support for this area of family care remains important.

## Author contributions

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

All authors 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.

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## Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.aucc.2016.07.005.

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