



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.

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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 practice² which is especially important given

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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 death⁵ 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 complicated 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 care¹² 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, paediatric 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, paediatric, 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 validity¹⁹ 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 infor-

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