



Review

Family-centred care at end of life in critical care: A retrospective descriptive study



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ABSTRACT

Background: A family-centred approach to care can aid family coping at the end of life in critical care. Yet little is known about how families' preferences for involvement in care planning and decision-making, are assessed and supported.

Aim: To explore how family involvement and assessment of their needs at the end of life are facilitated and supported in critical care

Methods: A descriptive study utilising a retrospective audit of the medical records of 50 patients who received end-of-life care in one critical care unit.

Findings: Next-of-kin were documented in 96% of records, with the spouse/partner fulfilling the role in 46% of cases. A Goals of Care Summary was completed in 74.0% of cases with 62.2% of patients for treatment limitation, 10.8% for supportive/palliative care, and 21.6% identified as terminal. In 75.7% of cases there was evidence of next-of-kin/family consultation and formal family meetings were held in 90.0% of cases. There was also evidence of supporting family involvement and needs before and after death. 22.0% received bereavement support and in 34.0% cultural/religious practices were facilitated after patient death.

Discussion: Clinicians rely on family members to inform care planning and decision-making. Hence, a family-centred approach to care is essential in critical care practice.

Conclusion: Opportunities for next-of-kin or extended family to be involved in patient care planning and decision making are key to ensuring family members to be as involved as they wish, kept informed and receive bereavement support. Addressing patients' and families' cultural/religious needs and other needs that extend beyond the clinical setting are essential to a family-centred approach to care at the end of life.

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Summary of Relevance

Issue

A family-centred approach to care provision, facilitated by formal family meetings can provide family members with an opportunity to contribute to care planning and decision making, and to aide family understanding

What is Already Known

Family members have unique needs extending beyond the immediate clinical environment. Further research is necessary to explore referrals to other specialists, such as specialist palliative care, to enable collaboration in patient care and to guide end-of-life decision-making and care, extending to the family

What this Paper Adds

Despite an assumption about critical care nurses' role in supporting families at the bedside, more comprehensive documentation, that clearly details assessment of family needs and actions to support families before and after death is needed, and would be helpful in promoting recognition of family needs and to ensure continuity of care

1. Introduction

Critical care admissions account for 1.4% (or 161,000) of hospital admissions in Australia every year (Australian Institute of Health and Welfare, 2019) and as many as 15% of patients admitted to critical care will die (Trankle, 2014). The majority of deaths in critical care settings occur following a decision to withhold or withdraw life-sustaining treatment (Lesieur, Leloup, Gonzalez, & Mamzer, 2015). With this in mind, the provision of end-of-life care should be planned and coordinated, with patient needs as the first priority. Family needs should also be considered and addressed in addition to patient needs. Family-centred care is an approach to the planning, provision and evaluation of care that supports individualised care through partnership between clinicians, patients and family members (Mitchell et al., 2016). The benefits of a family-centred approach to care in critical care settings are well recognised (Pretorius, Heyns, Filmalter, & Botma, 2021). Supporting next-of-kin and family to contribute to care planning and decision-making (Ranse, Bloomer, Coombs, & Endacott, 2016), and encouraging family members to participate in the patient's experience by spending time at the patient's bedside (Wetzig & Mitchell, 2017) can aid coping and may improve their healthcare experience (Goldfarb, Bibas, Bartlett, Jones, & Khan, 2017).

2. Literature review

Numerous previous studies have highlighted that receiving information is a priority for families when a patient is admitted to hospital (Bloomer, Endacott, Ranse, & Coombs, 2017; Viridun, Luckett, Davidson, & Phillips, 2015; Wetzig & Mitchell, 2017), as is speaking with members of the patient's treating team (Bloomer, Lee, & O'Connor, 2010a; Viridun et al., 2015; Wetzig & Mitchell, 2017), to ask questions, to advocate for the critically ill person, and to ensure care is consistent with the person's culture, values and wishes (Brooks, Bloomer, & Manias, 2019).

Despite promotion of a family-centred approach to care in critical care settings, family-centred care does not always occur (Pretorius et al., 2021). When a patient is critically ill, the resuscitative nature of care in critical care settings can mean that clinicians are focused on life-saving care, rather than addressing the needs of family (King, Botti, McKenzie, Barrett, & Bloomer, 2021). In addition, previous studies have suggested that family presence or involvement in team meetings and ward rounds is clinician-dependent and remains a complex process (Furqan & Za-

karia, 2017). Clinicians' actual or perceived poor communication skills (Brooks et al., 2019), inadequate time to build rapport with family members and uncertainty about family dynamics and who to liaise with (Bloomer et al., 2017) may impede a family-centred approach to care.

Despite clear evidence that family members' perceptions of engagement and feeling involved in the care of their family member are some of the most essential needs of family members in the critical care setting (Wetzig & Mitchell, 2017), little is known about how this occurs or how family involvement and needs are assessed and supported at the end of life.

2.1. Aim

The aim of this study was to explore how family involvement and assessment of their needs at the end of life are facilitated and supported in critical care.

2.2. Participants

This study was undertaken in a tertiary, 26 bed adult intensive care unit at the largest public health service in Victoria, Australia, providing specialised care for cardiothoracic, renal neuroscience, obstetric and surgical patients (Monash Health, 2021). The health service provides care for one quarter of Melbourne's population (Monash Health, 2021). The sample included 50 patients, aged 18 years or over, who died in the intensive care unit in 2018. A sample of 50 was considered sufficient to demonstrate practices and patterns associated with family involvement in end-of-life care.

2.3. Ethics

This study is part of a larger study. Following ethical approval from the health service (19-0000121L-51299, 12th March, 2019) and Deakin University (2019-117, 22nd March, 2019), a descriptive study was conducted utilising a retrospective medical record audit. A waiver of consent was granted for this study to allow collection of data that was routinely available in the medical record, without contacting next-of-kin of the deceased. This study conforms to the National Statement on Ethical Conduct in Human Research (NHMRC, 2018).

3. Methods

In Australian hospital settings, including critical care, the usual practice is for all members of the care team, including clinicians and support personnel to document their care in the medical record. No existing tools were identified that capture data about family involvement and assessment of needs at the end of life in critical care from medical records. Therefore, a data collection tool, containing variables that captured family involvement and support in the intensive care unit was developed by the team of researchers from medical and nursing backgrounds, and with intensive care and palliative care expertise. Guided by the Comprehensive Care Standard (Australian Commission on Safety and Quality in Health Care, 2017) and descriptors of family-centred care interventions in adult intensive care units identified by Mitchell et al. (2016), multiple potential variables were identified and included in the draft data collection tool. The draft data collection tool was then independently piloted by two researchers, with a sample of four deceased patient medical records, not included in the final sample, to enable refinement. Variables for which information was not consistently recorded in medical records were excluded, resulting in the final version of the data collection tool. Data were initially entered directly into a Microsoft

Excel spreadsheet. A coding sheet and data dictionary were developed to detail the range of possible responses for each variable and their numerical codes, to guide the research assistant (KN) in data collection and enable data transfer to Statistical Package for the Social Sciences Version 26 (IBM Corporation, Released 2019) for analysis. Open text fields were included for data that could not be coded and for written excerpts that provided additional explanation.

Data collection took place from June to October, 2019, with all data collection undertaken by a research assistant (KN) who had no working relationship with the unit. After the first ten cases, a second researcher (MJB) undertook an independent review of the data to assess accuracy of data collection against the coding sheet. At completion of data collection, 20 randomly selected cases were reviewed for accuracy, with minor discrepancies resolved by negotiation and discussion. For some variables, text data were collected to aid understanding, with entries extracted for reporting to best represent the breadth of clinician entries related to the variable.

3.1. Analysis

Descriptive statistics were used to analyse quantitative data. Textual data from patient medical records were analysed using an inductive method of qualitative content analysis recommended for examining textual data such as that extracted from medical records (Grbich, 2013) to address the overall aim of the study. Qualitative findings were then used to further explain quantitative findings.

4. Results

Deceased patients' median age was 67.5 (IQR 25) years; just over half (52.0%, n=26) were male, the majority (74.0%, n=37) were admitted to hospital from home. The median length of stay in hospital was 5.0 (IQR 11) days. 44.0% (n=22) identified as Christian, 46.0% (n=23) were born overseas and 12.0% (n=6) indicated a language other than English as their preferred language, yet a professional interpreter was used for only 6.0% (n=3) cases. Next-of-kin was documented in the medical record in 96.0% (n=48) of cases, and the next-of-kin was most commonly the spouse/partner (46.0%, n=23), followed by a relative other than the spouse (44.0%, n=22) and in 4.0% (n=2) of cases, there was no next-of-kin. None of the deceased patients in this sample had an Advance Care Plan or had appointed a Medical Power of Attorney (Table 1).

A Goals of Care Summary, which is typically completed within the first 24 hours of admission and used to record treatment/resuscitation limitations according to four levels of limitation (Fig. 1), was completed in 74.0% (n=37) cases.

According to the data which represents the last recorded treatment level prior to death, in 62.2% (n=23) of cases some limitation of medical treatment was indicated, 21.6% (n=8) identified as terminal, and another 10.8% (n=4) for supportive/palliative care. In just over three-quarters (75.7%, n=28) of cases there was evidence of next-of-kin or other family consultation to determine the limitation of treatment. The median length of time from last completion of the Goals of Care summary to death was 1 day (range 0–26) (Table 2).

4.1. Family support and participation before death

Aside from the Goals of Care Summary, in almost all cases (92.0%, n=46) there was other written evidence in the patient's medical record to indicate death was anticipated, with formal family meetings held in 90.0% (n=45) of cases. Whilst not explicitly stated, evidence of family involvement in decision-making regarding treatment in 84.0% (n=42) of cases suggests formal family meetings were used to confirm the plan of care, such as deter-

Table 1
Demographic and hospital admission characteristics (N=50)

	Years	(IQR)
Age at admission (years)		
Range	37-86	
Median (IQR)	67.5	25
Length of stay in hospital (days)	Days	
Range	0-79	
Median (IQR)	5.0	11
Sex - Male	n	(%)
	26	52.0
Admission source		
Home	37	74.0
Other Hospital or Residential Care Facility	13	26.0
Ethnicity		
Non-Indigenous Australian	27	54.0
European	13	26.0
Asian	8	16.0
Other	2	4.0
Preferred language		
English	44	88.0
Other including Greek, Khmer, Tamil and Dari	6	12.0
Professional Interpreter Used	3	6.0
Religion		
Christian	22	44.0
No religion	21	42.0
Buddhist	3	6.0
Not documented	2	4.0
Next-of-kin documented	48	96.0
Relationship of next-of-kin		
Spouse/Partner	23	46.0
Relative other than spouse	22	44.0
No Next-of-Kin	2	4.0
Other or not specified	3	6.0
Prior expressed wishes		
Advance Care Plan	0	0.0
Medical Power of Attorney	0	0.0

Table 2
Goals of care summary (N=50).

	n	%
Summary completed	37	74.0
Treatment level specified (n=37)		
No limitation of treatment	2	5.4
Limitation of Medical Treatment	23	62.2
Supportive/Palliative	4	10.8
Terminal	8	21.6
Evidence of next-of-kin and/or family consultation (n=37)	28	75.7
Days from last completion to death	Days	(IQR)
Range	0-26	
Median (IQR)	1.0	2.5

mining treatment limitations and planning for end-of-life care. In 14.0% (n=7) of cases, there was also evidence of family conflict or disagreement in relation to patient care and decision-making.

In Case 4, not all family members were in agreement about resuscitation:

“One sister wanting patient to be for CPR [cardiopulmonary resuscitation]” (Case 4, 51M).

In another case, one family member did not want to accept the diagnosis:

“One family member wanting further scan however extensive discussions with medical team and patient's Next-of-Kin who all agreed patient is brain dead and no further scan required” (Case 6, 74M).

Disagreement about the disclosure of information to family members, and differences between patients' and next-of-kins' expressed wishes were also cause for conflict:

“Family fear that they will be asked to decide if support should be turned off or not, they don't want to make this decision. Multiple family meetings held, family cancelling interpreters due to not wanting mother to know patient's prognosis, family see terminating life support as killing patient as per religious leader” (Case 22, 76M)

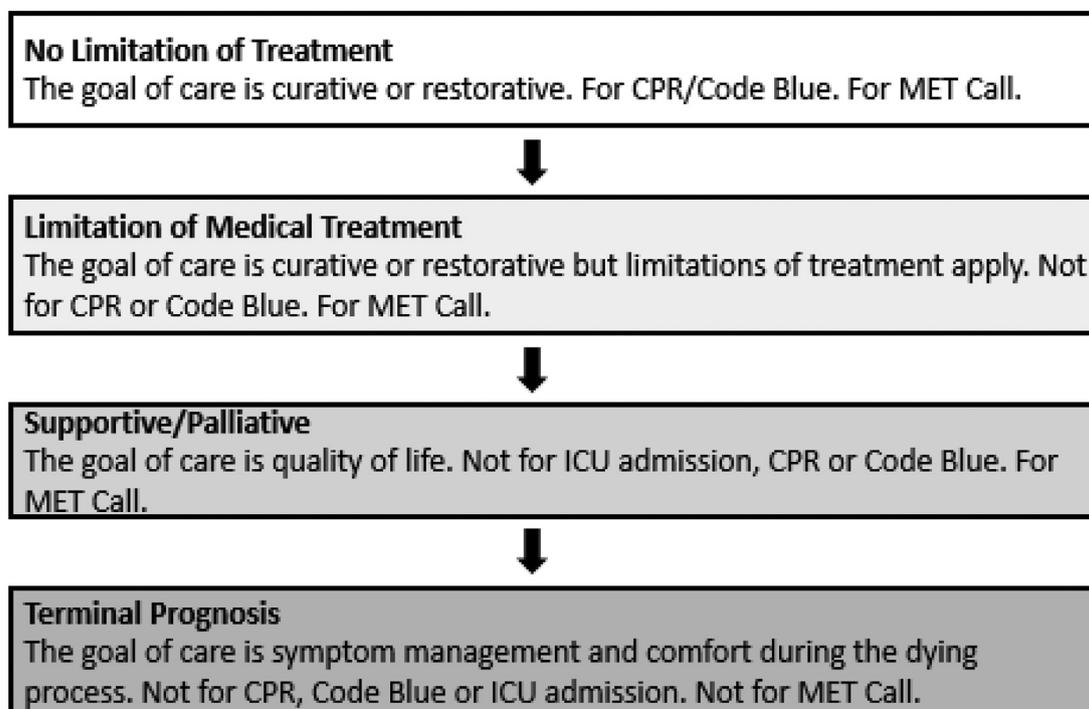


Fig. 1. Goals of care.

Table 3
Family support and participation (N=50).

Before death	n	%
Evidence that death was anticipated	46	92.0
Evidence of formal family meeting	45	90.0
Evidence of family involvement in decision-making	42	84.0
Evidence of family disagreement in decision-making	7	14.0
Evidence of social worker involvement	34	68.0
Evidence of palliative care involvement	3	6.0
Evidence of pastoral care involvement	5	10.0
Evidence of assessment of family needs and wishes	30	60.0
Dying Care Pathway initiated	11	22.0
Next-of-Kin notified by phone of impending death	10	20.0
After death		
Time of death		
Between 0801 and 2000hrs	27	54.0
Between 2001 and 0800hrs	16	32.0
Time of death not recorded	7	14.0
Family present at death	36	72.0
Bereavement support provided	11	22.0
Evidence of facilitation of cultural/religious practices after patient death	17	34.0

“Patient wanted palliative management, wife insisting on active management, patient intubated therefore medical team continued as per wife’s wishes. Further family meeting both medical team and family came to agree on withdrawal” (Case 30, 74M)

Rates of specialist palliative care and pastoral care involvement were low (6.0%, n=3; and 10.0%, n=5) yet social workers were involved in 68.0% (n=34) of cases (Table 3). In written entries in the medical record, there was evidence of assessment of family needs and wishes in 60.0% (n=34) of cases, with entries demonstrating the predominant role of social workers in assessing and facilitating family needs and wishes. Entries demonstrated that not all families expressed or indicated specific needs or wishes, or requested any additional support:

“Nursing staff assessed if family required social work or pastoral care support, family declined” (Case 15, 78M)

Other cases suggest a range of diverse needs. For some, family requests were for more time to comprehend and prepare for patient death:

“Family needing long time to process possible death, given time rather than extubating” (Case 22, 76M)

“Family given time to come to terms with outcome prior to making decision about organ donation and withdrawal of care” (Case 38, 78M)

Other entries indicated families requested additional time before death:

“Family requesting continue current treatment until family can attend” (Case 36, 56M)

“Family needing to speak with family in UK, postponed withdrawal of treatment until family ready” (Case 28, 72M)

“Family requesting more time to allow family from overseas to arrive. Requested supporting docs for visa approval” (Case 35, 52M)

Several cases demonstrated that, where children were involved, the needs of the children were specifically identified and addressed:

“Social work assisting to support wife re telling young children about patient” (Case 14, 41F)

“Patient was mother of very young children, dad given support for how to break bad news [to children]” (Case 46, 37F)

“Social work assisted with informing grandchildren re pt dying” (Case 16, 56F)

In some cases, entries in the medical record detail practical supports provided for family members, including emergency accommodation for family and support for financial matters:

“Nursing staff noted social work required for accommodation supports whilst patient in hospital” (Case 17, 63M)

“Social work referred family onto finance [support] to help work out payment of medical bills given patient is from overseas” (Case 40, 58F)

For others, the focus of support was on addressing families’ needs after patient death:

“Social work assessed needs of wife who will require HLC [high-level residential care] if patient dies” (Case 18, 80M)

“Family stated they will need some grievance support, information offered by social worker” (Case 44, 69F)

Whilst family members were present at death in 72% of cases, there were no data to explain this finding. Time of death may have influenced this, with 54% of deaths occurring during the day. There was evidence of bereavement support being provided in 22% of cases (Table 3).

4.2. Family support and participation after death

After death, bereavement support was provided in 22.0% (n=11) of cases. Bereavement support was provided by the social worker in all but one case, but data were not provided to detail what bereavement support entailed. In 34.0% (n=17) of cases there was evidence of facilitation of cultural or religious practices after patient death (Table 3). Examples included attending to religious customs such as:

“...last rites read by Orthodox priest” (Case 26, 77F) and

“...monk present and praying at bedside” (Case 48, 69M).

In other cases, clinicians documented facilitating time for family to perform other religious symbolic rituals, such as:

“...priest came for last rites, rose quartz put in pts [patient’s] hand by daughter and music played” (Case 32, 51F) and

“...family had birthday and end-of-life celebration before extubating as it was the patient’s birthday” (Case 35, 52M).

5. Discussion

Importantly, none of the deceased patients in this sample had documentary evidence, such as an Advance Care Plan, to indicate their prior expressed wishes. In the absence of prior expressed wishes, clinicians often relied on next-of-kin and other family members to guide care planning and decision-making. Of note, these findings demonstrated variation in the relationship of the person identified as next-of-kin, with the patient’s spouse/partner named as next-of-kin in less than half of the cases. Previous research indicates that the perceived responsibilities associated with the next-of-kin role, such as contributing to decision-making can lead to stress and distress (Digby & Bloomer, 2014) and therefore may influence who is nominated for or accepts this role. Factors such as family dynamics, the desire to avoid family conflict (Mendoza & Burns, 2015; Periyakoil, Neri, & Kraemer, 2016) and poor health literacy (Periyakoil et al., 2016) may also influence who is appointed as next-of-kin for a critically ill patient. In more recent times, the COVID-19 pandemic has meant that the role, responsibility and privileges afforded to next-of-kin have been significantly limited and resulted in significant distress, not just for families, but also for clinicians caring for patients who die (Hart, Turn-

bull, Oppenheim, & Courtright, 2020). Guidance has been provided to facilitate next-of-kin presence at the bedside for patients dying from COVID-19 in Australia (Bloomer & Bouchoucha, 2021), but as these findings highlight, next-of-kin or family needs extend beyond visitation.

The Goals of Care Summary, which was used to record treatment/resuscitation limitations, was expected to be completed as a matter of routine within 24 hours of admission but could be amended multiple times in response to the patient’s condition. For this sample, the median length of stay was five days and the median time from last completion of the Goals of Care Summary to death was one day, therefore suggesting a revision of the Goals of Care Summary in response to patient deterioration in the day before death. Importantly, the Goals of Care Summary also indicated next-of-kin or family consultation in just over three-quarters of cases. This suggests that anticipation of death may also have been used as a trigger for arranging formal family meetings. Formal family meetings are essential to optimal care planning, decision-making and family support (Hudson, Quinn, O’Hanlon, & Aranda, 2008), and families often need more than one meeting to understand the patient’s condition and prognosis and to reach consensus on the plan of care (Bloomer et al., 2010a; Bloomer, Tiruvoipati, Tsiripillis, & Botha, 2010b). Evidence of family disagreement highlights the importance of formal family meetings in providing an opportunity for family members to seek information and clarification and resolve disagreements within the family unit. This is important because family members’ perceptions that hospital clinicians are not available to provide information and offer emotional support impacts family preparedness (Moon, McDermott, & Kissane, 2018). Even when family members understand the dying person’s prognosis (Tang et al., 2021), they may not be prepared for patient deterioration and death (Tang et al., 2021; Workman & Mann, 2007).

There was evidence of assessment of family needs and wishes in 60% of cases. Yet interestingly, palliative care personnel were involved in very few cases. Why specialist palliative care personnel were involved in some cases, but not more is not known, suggesting further research is necessary to explore and understand the interplay between specialties and how this influences referral practices. One possible factor contributing to this is the perspective that the provision of palliative care is embedded in the role of critical care clinicians (Buckley et al., 2009). In contrast, social workers were involved in more than two-thirds of cases; a finding supported by previous research demonstrating that social workers were integral to supporting optimal family-centred care (Jonas, Scanlon, Schmidt, & Bogetz, 2020) and addressing emotional, social and existential concerns at the end of life (Farabelli et al., 2020). These findings also highlight the diversity of support offered by social workers, in addition to the support offered at the bedside by critical care nurses (Bloomer et al., 2017; Ranse et al., 2016). Conversely, given that understanding and addressing the spiritual care needs and preferences of patients and their families is a priority (Selman et al., 2017), it is surprising that rates of pastoral care involvement were low in this audit. This may be associated with the fact that 42% of the patients in this cohort did not identify with a religion, and therefore perhaps family declined support from pastoral care.

Whilst nurses do provide immediate bereavement support to families, demonstrated through their family-centred approach to care and advocacy (Raymond, Lee, & Bloomer, 2017), evidence of bereavement support was low; it is possible that bereavement support was offered and declined, and therefore not documented in the medical record. One way to overcome inconsistency could be to develop a minimum dataset or pathway to guide end-of-life care, or more specifically, family care in critical care. This approach has been used to guide handover and ensure critical information is

not omitted (Spooner, Aitken, Corley, & Chaboyer, 2018). But this approach should be used with caution, with the risk of an end-of-life dataset placing the emphasis on paperwork, and leading to prescriptive, less thoughtful care and an absolution from patient and family-centred decision-making (Sleeman et al., 2015).

These findings highlight that some aspects of family involvement in end-of-life care were readily demonstrated in the medical records included in this study, but others were inconsistently recorded or notably absent. These findings demonstrate practices to support family involvement at the end-of-life are inconsistent. In order to guide end-of-life care practices in Australia, a national position statement on adult end-of-life care was endorsed by the Australian College of Critical Care Nurses (Bloomer, Ranse, Butler, & Brooks, 2022). The position statement provides 28 practice recommendations for end-of-life care, which include recommendations for family-centred care, optimal communication and decision-making with the patient and family, and care of the family after patient death (Bloomer et al., in press). Whilst not designed to be prescriptive, these recommendations could be used to guide improvements to current practice so that optimal patient care is provided, family members are afforded a greater opportunity to be involved in communication, care planning and decision-making, as determined by them, and to be offered the social and emotional supports they need. These actions can promote a shift away from the view that the patient is separate from the family, to one where the patient and family are seen as one social unit, where family are a natural part of the care team (Mitchell et al., 2016).

5.1. Limitations

This work is retrospective and limited by what is documented in the patient medical record. It is possible that other actions to support family involvement and needs at the end of life occurred but were not documented, or that when support was offered but declined, this was not recorded in the medical record. This study was conducted in one health service, hence practices and actions designed to support family may differ across settings, thus impacting the generalisability of these findings. Whilst content analysis was used to analyse written entries in the medical record, it must be acknowledged that the richness of the data were limited by the brevity of clinician's notes. As with all audits, the quality of the data were limited to what is recorded in the medical record, and may not be an accurate reflection of actual practice.

5.2. Strengths

A strength of this research is the way in which rigour was assured throughout the development of the data collection tool, data collection and analysis. Each of the steps involved at least two researchers to ensure transparency in tool development and accuracy in data collection and interpretation. In addition, the inclusion of consecutive deceased patients, according to date of death, limited the risk of selection bias and ensured that the evidence drawn from the sample is most likely indicative of practice at the time.

6. Conclusion

These findings demonstrate how a family-centred approach to care is embedded into critical care practice particularly at the end of life. Formal family meetings are routinely used, and provide an important opportunity to optimise care planning, decision-making and consideration of involvement of additional personnel or speciality teams who may be able to contribute to end-of-life care for the patient, and/or care for the family. Interestingly, rates of involvement of specialist palliative care and pastoral care were

low in this study, suggesting missed opportunities for maximising next-of-kin and family support at the end of life, and after patient death. Future research to understand critical care referral practices would be helpful to aid understanding and inform future practice.

Nonetheless, as an extension of patient care, these data clearly demonstrate how family needs are assessed and accommodated and the ways in which family involvement is facilitated. In the absence of knowing the patient's prior expressed wishes, providing opportunities for next-of-kin and extended family to be involved in care planning and decision-making are key to ensuring family feel supported to be involved as they wish. When death is anticipated, actions to understand and address family needs, including cultural and religious needs and those that extend beyond the clinical setting are also essential to a family-centred approach to care at the end of life.

It is evident that social workers played a lead role in supporting family involvement and needs in ways that are uniquely different to that of clinicians. In contrast, evidence of critical care nurses' role and actions to support families were largely absent. Social workers may document such actions as a matter of routine, but unlike the routine documentation of clinical data such as vital signs, nurses may not routinely document their family's needs or their actions to support families at the end of life. Critical care nurses should ensure their actions to support families and demonstrate a family-centred approach to care are documented.

These findings can be used to inform recommendations for practice, education and further research to demonstrate the importance of family involvement and addressing family needs at the end of life in critical care, and the importance of documenting actions taken in support of families.

Authorship contribution statement

MJB – the conception and design of the study, data collection, analysis and interpretation, drafting and final approval of the manuscript;

PP – contribution to design of the study, data analysis and interpretation, review and final approval of the manuscript;

FR – contribution to design of the study, data analysis and interpretation, review and final approval of the manuscript;

AMH – the contribution to the conception and design of the study, data analysis and interpretation, drafting and final approval of the manuscript.

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Ethical Statement

This study involved human research and received ethical approval as a scientific research study from the health service (19-0000121L-51299, 12th March, 2019) and Deakin University (2019-117, 22nd March, 2019).

Conflict of interest

The authors declare that there are no conflicts of interest.

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