



Research paper

Family centred care before and during life-sustaining treatment withdrawal in intensive care: A survey of information provided to families by Australasian critical care nurses



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ABSTRACT

Background: A core component of family-centred nursing care during the provision of end-of-life care in intensive care settings is information sharing with families. Yet little is known about information provided in these circumstances.

Objective: To identify information most frequently given by critical care nurses to families in preparation for and during withdrawal of life-sustaining treatment.

Design: An online cross-sectional survey.

Methods: During May 2015, critical care nurses in Australia and New Zealand were invited to complete the Preparing Families for Treatment Withdrawal questionnaire. Data analysis included descriptive statistics to identify areas of information most and least frequently shared with families. Cross tabulations with demographic data were used to explore any associations in the data.

Results: From the responses of 159 critical care nurses, information related to the emotional care and support of the family was most frequently provided to families in preparation for and during withdrawal of life-sustaining treatment. Variation was noted in the frequency of provision of information across body systems and their associated physical changes during the dying process. Significant associations ($p < 0.05$) were identified between the variables gender, nursing experience and critical care experiences and some of the information items most and least frequently provided.

Conclusions: The provision of information during end-of-life care reflects a family-centred care approach by critical care nurses with information pertaining to emotional care and support of the family paramount. The findings of this study provide a useful framework for the development of interventions to improve practice and support nurses in communicating with families at this time.

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1. Introduction

The majority of patient deaths in intensive care occur following a decision to withhold or withdraw life-sustaining treatment.^{1,2}

With 86% of patient deaths in intensive care expected, the provision of end-of-life care can be planned and facilitated in these circumstances.² Family-centred care is a model of care where the family can contribute to and participate in the planning and delivery of care in partnership with health care providers.³ Family-centred care should be at the core of critical care nurses' practice during the provision of end-of-life care,^{4,5} with research indicating nursing practice consistent with this approach.^{6,7} The proximity and constancy of the critical care nurse at the bedside, resultant

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from the high nurse-patient ratios, places critical care nurses in a unique position to facilitate positive patient- and family-centred end-of-life care experiences.^{8,9}

An important component of family-centred care is the provision of information to and communication with the family. Key to the provision of a quality end-of-life care experience, and indeed to improving outcomes for bereaved family members is helping families understand events occurring prior to, and during withdrawal of life-sustaining treatment.^{10,11} Previous research has identified that provision of information to families is a core and frequently undertaken component of nursing work during end-of-life care.⁸ The actual content of messages imparted by critical care nurses to families at this time has received limited attention except through acknowledgement of the role of critical care nurses in answering questions posed by families and explaining what was happening to the patient.^{7,12,13}

One study that has undertaken a more detailed and nuanced exploration of the type of information nurses give to families at this time was undertaken by researchers in the United States and focused on preparing families for death of their relative following withdrawal of mechanical ventilation.¹⁴ Content analysis of the responses of 31 critical care nurses identified 43 descriptors of different types of information conveyed to families. The majority of descriptors (67.5%, $n=29$) were related to physical sensations and symptoms although study authors acknowledged that the format of the questionnaire may have contributed to this finding due to prompts specifically provided for the physical domain.¹⁴

Given the opportunity for nurses to positively impact end-of-life care practice and the importance of a family centred care approach for critically ill patients and their families at this time, further research is needed to identify the content of information communicated by critical care nurses to families prior to and during withdrawal of life-sustaining treatment. This research can inform the development of educational content and interventions to be implemented in practice to assist critical care nurses sharing information with families.

2. Method

2.1. Study aim

To identify information most frequently given by critical care nurses to families in preparation for and during withdrawal of life sustaining treatment.

2.2. Design

An online cross-sectional survey was used in this study.

2.3. Preparing families for treatment withdrawal questionnaire

The survey instrument used in this study was developed from previous research undertaken by Kirchhoff, Conrath and Anumandla.¹⁴ Kirchhoff et al. originally designed the questionnaire to explore the content of messages given to families by critical care nurses in preparation for withdrawal of life-sustaining treatment and expected death of the patient. The study was informed by self-regulation theory (SRT) based on the premise that providing a person with information regarding a potentially stressful event will assist them in coping with the experience.¹⁴ The four concrete-objective domains of SRT (1. Physical sensations and symptoms, 2. Temporal characteristics, 3. Environmental features and 4. Causes of sensations, symptoms and experiences) provided a framework for the questionnaire, under which participants could record a narrative response of the information that they provide to families in preparation for treatment withdrawal.¹⁴ Each SRT domain heading

was accompanied by a definition to enhance clarity for the participant. In addition, eight sub-headings (respiratory, skin, neurologic, musculoskeletal, sense organs, gastrointestinal, genitourinary and others) were provided with the physical sensation and symptoms domain to capture all possible information provided to families within these categories. Kirchhoff et al. circulated their questionnaire to a sample of critical care nurses and from the 31 responses, content analysis identified 43 descriptors of information provided to families to prepare them for treatment withdrawal.¹⁴

Permission was given to use and re-develop the questionnaire (KT Kirchhoff, personal communication, 18 November 2014). For this study, the original headings comprising the SRT domains were retained and descriptors identified by Kirchhoff et al.¹⁴ were placed on a 1–5 rating scale (Never, Rarely, Sometimes, Often, Always). The two descriptor responses ‘not addressed’ pertaining to the gastrointestinal and genitourinary physical domains from Kirchhoff et al. were not included in the revised survey instrument. These responses were deemed unnecessary as this information would be captured in a ‘never’ response by a participant. The instrument was reviewed for face validity by a reference group, comprised of individuals meeting the inclusion criteria for participation. In response to the comments of this reference group, the descriptor ‘eye closed’ within the sense organ sub-heading was removed from the revised instrument. The final revised instrument consisted of 40 descriptors of information potentially provided to families to prepare them for treatment withdrawal.

The online questionnaire also included a series of questions to obtain demographic information from the respondent including age, gender, years of nursing experience, years of critical care experience, highest qualification in nursing, current workplace and location (Australia or New Zealand).

2.4. Setting and participants

Australian and New Zealand critical care nurses who had provided end-of-life care in an intensive care unit within the last 12 months were the target population for this study. All members of the Australian College of Critical Care Nurses who had registered their willingness to be contacted for research purposes ($n=952$) and critical care nurses working in two Intensive Care Units in New Zealand ($n=209$) were the population sampled for this study.

An email invitation to participate in the study was circulated to potential participants in May 2015. The invitation contained a link to the questionnaire available online using the platform Survey Monkey (<http://www.surveymonkey.com>). A reminder email was circulated two weeks later as a method of encouraging participation. The survey remained available online for a period of five weeks.

2.5. Data analysis

Data analysis was undertaken using SPSS version 21. Descriptive statistics were calculated for each demographic variable to ascertain the potential representativeness of the sample to the broader critical care nurse population in Australia and New Zealand.

The frequency of participant response to each item on the survey was calculated. Mean and standard deviation were also calculated to identify the most and least frequent information given to families based on mean score. Cross tabulations, using the Monte Carlo method (with default confidence level of 99% and number of samples 10,000), were calculated to explore associations within the data. Specifically, if each of the ten information items most and least frequently provided to families were associated with select demographic variables (country of practice, gender, nursing experience and critical care experience).

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