



## Research paper

# Certainty and uncertainty about end of life care nursing practices in New Zealand Intensive Care Units: A mixed methods study



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## ABSTRACT

**Background:** With end-of-life (EOL) central to the nursing role in intensive care, few studies have been undertaken to explore EOL care in the context of New Zealand (NZ) intensive care nursing.

**Objective:** To investigate NZ intensive care nurses' experiences of, and attitudes towards EOL care.

**Design:** Sequential mixed methods study using cross sectional survey with follow-on focus groups.

**Methods:** NZ intensive care nurses ( $N=465$ ) across four large tertiary intensive care units (ICUs) were contacted to complete a 43-item web-based survey. A follow-on focus group was conducted in each of the sites to explore specific aspects of the survey findings.

**Results:** 203 fully completed surveys were returned (response rate 44%) from the four ICUs. Over half of nurses surveyed (55%,  $n=111$ ) disagreed that withholding and withdrawing life support treatment were ethically the same. 78% ( $n=159$ ) of nurses stated that withholding treatment was ethically more acceptable than withdrawing it. Whilst nurses generally supported reducing inspired oxygen to air for ventilated patients at EOL (71%,  $n=139$ ) this was also an area that demonstrated one of the highest levels of uncertainty (21%,  $n=41$ ). Just under a quarter of respondents were also uncertain about the use of continued nutritional support, continued passive limb exercises and use of deep sedation during EOL. The 18 nurses who participated in follow-on focus groups detailed the supportive, culturally sensitive, collaborative environment that EOL was conducted in. However diverse opinions and understandings were held on the use of passive limb and use of fluids at EOL.

**Conclusions:** Whilst results from this NZ study broadly align with European studies, uncertainty about specific areas of EOL practices highlight that further guidance for nurses is required.

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## 1. Introduction

Over the past two decades, the central position that end of life (EOL) holds within intensive care has become clear.<sup>1</sup> The tension between the delivery of life sustaining therapies in an environment with high mortality rates has been well-explored,<sup>2</sup> and the

processes used to manage EOL have been described.<sup>3</sup> During this sensitive time, the demands placed on family members have been identified<sup>4</sup> and interventions developed to support those grieving.<sup>5</sup>

As part of the developing evidence base in this area, we also know of the discrete roles that doctors and nurses undertake in delivering EOL care within the intensive care unit (ICU) setting. With medical staff taking accountability for overall medical treatment decisions, nursing staff work with families and clinical teams to influence and support EOL clinical decision-making<sup>3</sup> and then negotiating how the clinical decisions are delivered at the bedside.<sup>6</sup>

EOL care is therefore an intrinsic part of intensive care nursing practice. However, there is limited nursing work published about

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EOL in ICU from a New Zealand (NZ) perspective. Empirical work to date has explored EOL service development<sup>7</sup> and ethical decision making by intensive care nurses in this setting.<sup>8</sup> With a lack of NZ-based research to inform EOL care in ICU, assumptions are made that existing international knowledge in this area is transferable. However specific professional<sup>9</sup> and cultural<sup>10</sup> differences have highlighted unique factors that may impact on EOL in NZ. Furthermore understanding nurses' attitudes and beliefs about EOL care, especially if these are at variance with those held by others, can highlight areas that may challenge and cause tension within the team when delivering EOL practice in ICU. There is need to undertake review of the attitudes and beliefs towards EOL care held by ICU nurses in the NZ context.

## 2. Methods

This sequential two phased mixed methods study used a cross-sectional survey with follow-on focus groups to identify NZ ICU nurses experiences of, and attitudes towards EOL care.

In Phase I a cross-sectional descriptive survey was undertaken with a sample of registered nurses in four large tertiary ICUs in NZ. This survey replicated European work that explored attitudes and beliefs towards EOL care of European ICU nurses ( $n = 164$ ) across 22 countries.<sup>11</sup> Permission was given by the original authors for use of the survey. The survey instrument was piloted on 14 ICU nurses from a non-tertiary ICU in NZ to determine cultural relevance to NZ. Minor amendments were made to clarify clinical phrases commonly used.

In preparation for data collection, the study was presented to staff in each of the four study sites during staff meetings. An email invitation with survey information and survey link (through Survey Monkey) was sent out by nurse managers to all ICU nurses ( $N = 465$ ). Consent was understood as implicit by completion of the survey with all responses anonymised and confidential. Two reminders were sent out at three weekly intervals. Survey data were analysed using Statistical Package for Social Scientists (SPSS, version 21). Statistical examination replicated analysis in the European study.<sup>11</sup> Data were coded numerically and subjected to descriptive and inferential statistical analysis. Chi square tests (with Yates Continuity Correction for 2 by 2 tables) were used to measure the association between categorical variables; with Phi or Cramer's V, as appropriate, used to calculate effect size. Association between ordinal variables was assessed using Spearman's Rho.

Results from Phase I were reviewed by MC and PF and areas of similarity and difference in experiences and attitudes towards EOL between European and NZ ICU nurses were identified. Based on this, a focus group guide was developed and used in Phase 2.

In Phase 2, follow-on focus groups were undertaken using a developed focus group guide to explore: EOL in ICU, use of fluids, nutritional support and passive limb exercises during EOL care. Participants were drawn from participants in Phase I. Consent was gained prior to focus group commencement. Focus groups were digitally recorded, transcribed and then underwent directed content analysis<sup>12</sup> by RT and MC.

## 3. Results

### 3.1. Phase I – survey demographics

From the pool of 465 nurses in four NZ ICUs, 220 surveys were returned, giving a response rate of 47.3%. However, only 203 respondents completed the survey tool fully. The demographics of the respondents are shown in Table 1.

**Table 1**  
Demographics of respondents ( $n = 220$ ).

Characteristics	Category	$n$ (%)
Gender	Female	194 (88.2)
	Male	26 (11.8)
Age group (years)	<30	41 (18.6)
	30–39	74 (33.6)
	40–49	68 (30.9)
	>49	37 (16.8)
Ethnicity	NZ/Pakeha	96 (43.6)
	European	78 (35.5)
	Asian	19 (8.6)
	Indian	16 (7.3)
	Māori/Pacific Islander	6 (2.8)
	Other	5 (2.3)
Religious background	Atheist/agnostic	82 (37.3)
	Protestant	67 (30.5)
	Catholic	53 (24.1)
	Buddhist	4 (1.8)
	Other	14 (6.4)
Intensive care unit	A	48 (21.8)
	B	40 (18.2)
	C	45 (20.5)
	D	87 (39.5)
Main practice role	Clinical practice	193 (87.7)
	Education	8 (3.6)
	Management	7 (3.2)
	Research	7 (3.2)
	Other	5 (2.3)
Years of experience in nursing	0–5	29 (13.2)
	6–10	51 (23.2)
	11–15	44 (20.0)
	16–20	26 (11.8)
	≥21	70 (31.8)
Years of experience in ICU nursing	<1	15 (6.8)
	1–4	53 (24.1)
	5–9	49 (22.3)
	10–14	45 (20.5)
	15–19	26 (11.8)
	≥20	32 (14.5)

### 3.2. Survey results: beliefs and attitudes about EOL care

Over half of nurses surveyed (55%,  $n = 111$ ) disagreed that withholding and withdrawing life support treatment were ethically the same. Although the majority (93%,  $n = 189$ ) agreed that withholding OR withdrawing life support treatment was ethical, 78% ( $n = 159$ ) of nurses felt that withholding life supporting treatment was more ethically acceptable than withdrawing it. Based on their experiences, most respondents (88%,  $n = 179$ ) disagreed that decisions to withdraw life support were taken too early, and although a third (33%,  $n = 68$ ) felt that decisions were made too late, two-thirds (68%,  $n = 139$ ) felt that the timing was just right.

A large proportion of the sample (45%,  $n = 98$ ) indicated that their religious beliefs were not at all important with regard to influencing their views about EOL care. When those who declared themselves agnostic or atheist were compared to others, a Chi square test (with Yates Continuity Correction) indicated a significant association between religious belief and the influence of religious view on EOL care [ $\chi^2$  (1,  $n = 220$ ) = 25.42,  $p < 0.001$ ,  $\phi = 0.35$ ].

When making decisions to withhold or withdraw life support, the expected quality of life as perceived by the patient and by their family were reported as the most important factors, with most nurses (96%,  $n = 194$  and 90%,  $n = 183$ ; respectively) in agreement. The expected quality of life from the medical and nursing teams' perspectives was considered to be much less important (63%,  $n = 128$  and 44%,  $n = 90$ ; respectively). Most respondents indicated that the patient's (68%,  $n = 138$ ) and family's

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